Case 7—When the Palliative Care Team Got Fired

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The patient, BK, was a 17-year-old African American male with Stage IV metastatic colon cancer. He was diagnosed five years ago, and had a partial bowel resection at that time and was given a course of chemotherapy. Since colon cancer is very rare in pediatric patients, BK's oncologist typically treated adult patients. One year following completion of chemotherapy, his scans were clear and his oncologist discussed the importance of regular follow up testing. BK's parents were overjoyed by the good news that their son had been "cured," and although they greatly admired and respected this physician, they believed that God had healed their son.

BK felt fine for several years. He was a quiet teenager who generally preferred the company of his family and who spent Wednesday nights and Sundays involved with his church and their youth group. He did not follow up with his oncologist. His parents did not remind him of the conversation with the oncologist, and because BK appeared healthy and they believed him to be cured, they did not heed the doctor's advice. When he turned 16, BK began to experience symptoms, but he kept them to himself. A favorite family story was about how miraculously BK had been healed, and he did not wish to ruin its promise by tempting fate with further testing. Bowel habits are a private matter, so it was easy for BK to conceal the fact that he was often constipated, had dark, tarry stools, and frequently experienced abdominal pain and bloating.

One morning, BK was in so much pain that it was impossible to conceal his discomfort from his mother. She took him to the Emergency Department of the hospital where he had been treated previously. He was diagnosed with a significant bowel obstruction. Surgery for the obstruction revealed metastases to his lungs, liver and abdomen, and he was again started on chemotherapy post-operatively. He was unable to tolerate anything by mouth and had a feeding tube placed. Already tall and thin at this point, BK appeared severely cachectic and dehydrated.

BK's mother stayed at his bedside nearly 24/7, and his father and other family members came and went frequently. BK's mother was very reserved, and although she was pleasant to the nurses and other health care providers who came to her

L. A. Roscoe and D. P. Schenck, *Communication and Bioethics at the End of Life*,
https://doi.org/10.1007/978-3-319-70920-8_7

son's room, it was clear that she preferred privacy. She had a strong Christian religious faith and tremendous trust in the adult oncology physician who had been treating her son since his initial diagnosis. Over time, one of the chaplains befriended BK's mother, and they prayed together. The chaplain also discovered that BK's mother loved scripture, particularly Bible verses that spoke of miraculous cures and the healing power of faith. The chaplain became close to BK as well, who seemed to appreciate having someone in the hospital able to communicate with his mother and offer her some comfort. BK himself appeared to need comfort too; the muscles in his neck would tense up when he thought no one was looking. He deferred to his mother, however, when he was asked about pain levels, leaving her to claim that he did not want any narcotics or any pain medication that would interfere with his ability to communicate with his family and with God. BK acknowledged having pain but would then decline any adjustment that would increase his pain medication and decrease his level of alertness.

BK's mother shared with the chaplain that her son had been fighting cancer for the past five years and was not ready to "give up." She said she had given him permission to "go home to God" if God called him. She added she felt relieved that BK was continuing to receive chemotherapy because that honored his desire to fight his disease and to live. She expressed the belief that since BK had been "cured" of his cancer before, it was likely that would be the case again. She also said she did not want to prolong her son's suffering, and that she was certain God's plan would prevail.

The hospitalist assigned to the case became concerned about inadequate pain control and requested a palliative care consult, but he neglected to tell BK or his mother and they were completely unprepared. They were frightened and upset to have a new doctor come on board unannounced, especially one who was pressing for more pain medication. The palliative care physician was an expert in pediatric palliative care, but he soon became aware that any mention of BK's prognosis, changes to his medication, or any discussion about stopping the current round of chemotherapy was most unwelcome. He asked BK's mother about her discomfort with having her son's pain medication increased, and she replied, "We certainly don't want our son to be a drug addict!" The doctor explained, "Addiction is not really a concern given your son's advanced disease, fears about addiction are not a realistic concern at this point." BK's mother looked up from the Bible on her lap and said to the physician in a quiet but firm voice, "Please leave now. And don't come back."

The social worker assigned to the palliative care team visited with BK during a rare morning when his mother was not there. She talked to him about advance directives, and he said he would like to have one. They worked on it together, and BK recorded his wishes for continued aggressive care. The social worker asked him about his pain level and what he understood about his disease. BK said, "I hurt a lot a lot of the time. I know I'm close to dying and I'm okay with that, but I can't talk about either of those things because that would cause my mom pain and I couldn't stand that." On the way out of BK's room, the social worker spoke to two nurses who had been taking care of him. Both said they were upset about BK's increasing levels of pain and discomfort, as well as by his mother's unwillingness to allow her son to have any relief. The social worker left BK's room and called for an ethics committee consult. By now BK had been on the in-patient oncology unit for 2½ months, and he was clearly declining.

The ethics consult reflected the high levels of moral distress experienced by the nurses who were required to provide aggressive care for BK rather than the pain control and symptom management they felt was more appropriate given his terminal prognosis and deteriorating condition. All team members felt they were doing harm by continuing to provide the aggressive treatment demanded by BK's mother. Even though BK's advance directive confirmed his wishes to continue aggressive treatment, the nurses on the unit doubted that was a true expression of his treatment preferences. The nursing staff also felt that poor care coordination had resulted in BK's mother receiving conflicting information about her son's condition. The trusted family oncologist said they should "stay the course;" the hospitalist and palliative care team members, as well as the nurses, believed further aggressive treatment to be futile and unnecessarily burdensome, but had been politely "excused" from BK's room any time they attempted to have a conversation about changing the goals of care. The nurses caring for BK felt that he did not have a voice in his care since he continually deferred to his mother, even when asked about his pain levels. The nurses also believed that the oncologist BK's mother trusted implicitly had given her unrealistic expectations about her son's prognosis, and that her belief in miracles was making it impossible for her to make decisions in her son's best interests and that realistically reflected his prognosis and need for better pain management. Although he was not legally an adult, BK was a young man who had dealt with serious illness for the past several years, and the health care professionals caring for him felt he should have at least some influence over his care. The oncologist agreed BK should participate in treatment decision-making, and he pointed to the advance directive as evidence of his agreement with the plan of care.

The ethics committee recommended that BK and his family consider discontinuing aggressive treatment and adopting a palliative plan of care. The committee felt that continued chemotherapy was futile and was adding to BK's distress. They also recommended that dialysis, ventilator support and cardiopulmonary resuscitation would be inappropriate, should events occur for which these procedures would otherwise be indicated. The palliative care social worker visited with BK and his mother and told them what the ethics committee had recommended. In her quietly commanding way, BK's mother said, as she had to many others, "please leave, and tell everyone else who has been colluding behind my back to make these recommendations that they are no longer allowed to care for my son." Only the adult oncologist who had "cured" BK in the past would be allowed to come into his room. The palliative care team, and even the chaplain who had previously enjoyed a warm relationship with BK and his mother, were banned from further contact.

BK was discharged to home for a few days during Christmas, but he returned to the hospital shortly after when his condition again deteriorated. Soon after readmission he developed fevers and hypotension. He was transferred from the oncology unit to the Pediatric Intensive Care Unit (PICU) where he developed septic shock. He was put on a ventilator and was moved back to the oncology unit when his condition stabilized. As before, BK's mother refused to allow her son's pain medication to be increased to levels even her trusted oncologist felt were warranted. BK died three weeks later, approximately 3 months before his 18th birthday. His death was painful and private. His family kept the door closed and clearly indicated that they were handling BK's situation with God; no one else was invited.

Discussion Questions

1. Under what circumstances can a patient and/or family member effectively bar medical professionals from doing their jobs and providing appropriate patient care?
2. What role should seriously ill children have in specifying, or agreeing to, plans of care, especially as they approach the legal age of adulthood?

A Bioethicist Responds

By any measure, this is an extraordinarily unfortunate case. Colon cancer is rare in pediatric patients. Overall, colon and rectal cancer in the U.S. ranks fourth behind cancers of the breast, lung and prostate, and as such it accounts for only 8% of the total of all cancers. The average age at time of diagnosis is in the mid to late 60s for all races, and both sexes; it is most frequently found among persons aged 65–74 (24.0% of all those diagnosed). Specific data reveal the highest incidence to occur among Black males, where 59.2 new cases are reported per 100,000 persons, age-adjusted, by race/ethnicity and sex. The disease is so rarely seen in persons under 20, regardless of age, race or sex, that the figure for colon and rectal cancer for all persons, of all races and both sexes under the age of 20 represents only .01% of the entire total of these cancers for all persons, all races and ages, and both sexes (Howlader et al. 2016). In fact, during the time period when BK became ill, and up through the time of his death, there were no cases of colon or rectal cancer reported to the SEER Registry for persons in his age group. BK was most unlucky, indeed.

Cancer presents a challenge to a patient of any age, particularly one as young as BK, but it was not as though he did not also have a few things in his favor: One year post-treatment his scans showed no evidence of disease; his parents believed him to have been healed by God, which must have been very supportive to him at the time; and, for several years he apparently enjoyed the life of a normal, quiet teenager. One could even imagine BK growing into his own person during these years, as would most teens at this stage of their lives, especially if he, too, believed fervently in the healing granted to him by God. Nonetheless, the subsequent onset of symptoms, coupled with his embarrassment over bowel issues and the desire to protect the favorite family story of his miracle cure from cancer, all provided for the crucial turning point in this case, the point at which BK realized he had lost control over his life and the recognition that someone else was in control. Perhaps BK might only have been subconsciously aware of the shift in locus of control at that point, but it is hard to image he could have remained oblivious to it for very long.

The medical facts of this case, together with the increasing pain levels and discomfort acknowledged by BK and those caring for him, leave little doubt as to the suffering created by this disease; it was his mother who demonstrated an attitude of singular nonchalance, if not to say callous indifference, to his pain and discomfort, leaving her to stand in stark contrast to virtually everyone else. Thus, by the time BK had been on the in-patient oncology unit for 2½ months and was clearly declining, and a chaplain, a hospitalist and the palliative care team with its own social worker had all been marshaled to help, a number of professionals were prepared to advocate for BK's welfare, to ensure his good. Unfortunately, their collective view of what was in his best interest was not at all consonant with that of his mother.

There are several ethical issues to be addressed here. The one that may be most troublesome has to do with the unresolvable friction among the multiple players involved in BK's care: his mother, the chaplain, the hospitalist, the palliative care team, the social worker from pediatric palliative care, the nurses, and the outside oncologist trusted by his mother. It seems fairly clear in reading the case narrative that BK's mother rather quickly developed an "us-vs-them" perspective, where she felt compelled to protect her son from unwanted intrusions into what she was convinced would be God's plan for a cure and where she feared BK would become too sedated or addicted to narcotics. Perhaps this conflict should more accurately be described as "me-vs-the rest of you," inasmuch as BK's mother presumed to speak wholly for her son regarding any medications or treatment whatsoever. She maintained this stance to the moment of his death, finally sidelining her heretofore trusted oncologist who had eventually recommended increasing pain medications during BK's final hospitalization. Situations such as these are absolute nightmares for everyone involved: families, physicians, nurses, chaplains, social workers, therapists of all types, aides and, most of all (unless they may be totally incapacitated), the patients themselves. It is difficult to say what, if anything, might have been done differently in order to provide for a better outcome for BK, to have eased his dying process. This albeit loving mother ultimately refused to communicate whatsoever with the highly skilled, experienced and very compassionate professionals caring for her son. Moreover, she was the legitimate surrogate for her minor child who thus held his autonomous rights in her own hands.

This is not a unique story, yet research on the subject of successful communication between families of pediatric patients and physicians and/or nurses is relatively limited. An interesting study by Durall, Zurakowski and Wolfe about advance-care discussions (ACDs) for children with life-threatening conditions revealed that clinicians perceived the most common barriers to be unrealistic parental expectations, differences between clinician and patient/parent understanding of diagnosis, and lack of parent readiness to have the discussion (2012). Less than one-third of clinicians believed that ACDs typically happened at the right time during the course of the patient's illness, and more than 90% of them responded that discussions of overall goals of care should occur either at time of diagnosis or during a time of stability. Nonetheless, the majority of both physicians and nurses reported that these types of discussions happen much later in the patient's illness.

Clearly, a host of factors may figure in the overall issue of communication between parties in a health care setting, perhaps none more significantly than cultural and religious ones. In view of the increasingly multicultural nature of society in the United States, and in view of the increasingly difficult task facing healthcare providers who must try to offer appropriate care for persons with different life experiences, beliefs, value systems, religions, languages and notions of healthcare, Wiener and her colleagues set out to explore and review how culture and religion inform and shape pediatric palliative care (Weiner et al. 2013). They found seven distinct themes: the role of culture in decision making, faith and the involvement of clergy, communication (spoken and unspoken language), communicating to children about death (truth telling), the meaning of pain and suffering, the meaning of death and dying, and location of end-of-life care.

One of the domains identified by Weiner and her group is that of the meaning of illness, dying and death, and they note that such meaning is clearly not static across cultures. Himelstein and his colleagues offered a recommendation that would seem applicable to various cultures: they argued for including a spiritual assessment in the pediatric palliative care plan, an assessment developed from a review of issues such as the child's hopes, dreams, meaning of life, views on prayer and ritual, and beliefs regarding death (Himelstein et al. 2004). It would at least seem to be applicable to various cultures provided the person or persons conducting the spiritual assessment had in-depth knowledge of the patient's culture, were fluent in her/his language, were skilled in conducting such assessments, and were trained in pertinent issues related to cultural competency.[1] In the case of BK, there appeared on the surface to be no serious impediments to the satisfaction of these requirements, and thus to the effective completion of a spiritual assessment. However, there was no way to use whatever spiritual assessment might have been available as part of an implemented care plan because of BK's mother's lack of receptiveness.

There was no meaningful care plan for BK at all. Those responsible for his care in the hospital could not all be expected to function together smoothly as a unified team given the resistance put up by his mother. BK's mother was determined to remain in rigid control of her son, his room, his caregivers and the entire environment in which he had to experience the final chapter of his life. In so doing, she was not only in total control of BK and everything surrounding him, but she effectively usurped the autonomy of this young man despite the fact that he was of capacity and had reached an age where he was capable of speaking for himself, certainly with regard to how he was feeling and as to whether or not he would like more or less pain relief. The result is that BK suffered unconscionably and unnecessarily on more than one level: physically, spiritually and mentally.

One more issue might bear consideration here. Blinderman presents a detailed ethical analysis of the case of a 65-year-old woman dying of cancer and complaining of severe pain, but whose family surrogates wished to minimize her sedation and confusion and increase her alertness and ability to communicate with them (2012). While the patient in this case was a mature adult who lapsed in and out of capacity, and while BK was a minor, family surrogates represented both patients. The argument Blinderman crafts in developing an answer to the question of whether surrogates have a right to refuse pain medication for incapacitated patients is a very compelling one. A full review of how he constructs that argument cannot be undertaken here; suffice it say that he establishes the position that "suffering is bad and that we have an obligation to prevent it or reduce it when it exists" (2012, 302). He also points out that a legal basis for the right to pain relief in the U.S. can be found in the Supreme Court case of Vacco v. Quill (1997); and, in extrapolating a bit from the New Jersey Supreme Court's *In re Conroy* decision (1983), he points out that the best interest standard simply asks: What would a reasonable person in the patient's circumstances consider to be the balance between the benefits and burdens of a particular treatment? Blinderman goes on to state: "If a given treatment (e.g., morphine) is believed to decrease the burdens of life (e.g., terminal cancer pain) and is of benefit (e.g., decreases pain severity) a reasonable person in such circumstances would not refuse such a treatment, even if the treatment were associated with some degree of sedation. Surrogates who attempt to refuse strong opioids that are effective in relieving pain are not acting in the best interests of the patient and are, therefore, not meeting the minimum standard for surrogate decision making" (303).

Happily, in Blinderman's actual case, a resolution was achieved through multiple conversations with the patient's family, and he concluded his article with a statement of his position that "end-of-life medical decisions, including the palliation of pain and other symptoms, should be made together with the patient, or when the patient lacks capacity, with the patient's legally appointed surrogate decision maker or family, to ensure that the patient's specific goals and values are upheld (303)." In the end, Blinderman suggested a very balanced approach that is designed to protect both the unique values and goals of patients and their expressed wishes or best interests, as well as their health care providers' moral obligation to treat pain and suffering, particularly when it concerns vulnerable incapacitated and terminally ill patients (303). He also made it clear that once a treatment plan has been established for an incapacitated patient, and should that plan require opioids, the surrogate or family member should not alter the plan, the sole exception to which should be when the patient had given prior instructions to the surrogate or family member to refuse pain medications on her behalf should she become unable to do so on her own.

Now, it might be argued that Blinderman's piece has little to offer with regard to BK's situation. Blinderman's patient was a mature adult who became incapacitated, and as he reports, the palliative care team was finally able to resolve the issues there; BK was a minor whose surrogate ends up categorically refusing to communicate with anyone. What seems instructive nonetheless is Blinderman's final sentence: "Hospital ethics committees, together with pain palliative care specialists, should draft policies supporting the physician's obligations to treat pain and other symptoms in incapacitated, terminally ill patients over family objections (304)."

This suggestion by Blinderman might well appeal to many physicians and bioethicists, yet hospital administrators (and especially their risk managers) are far more likely to be chary of it. But let us suppose for a moment, just for the sake of argument, that the institution in which the case of BK occurred had such a policy in place. Could such a policy have been used to support the palliative care physician's appeal to wrest control of care from the mother in order to treat BK's pain and discomfort? An interesting question, but even posing it assumes that everyone in this unfortunate case, including the institution itself, erred in not forcing the issue in some way. And to suggest that would be most unfair. One has to consider that BK himself insisted on following his mother's lead even though he also admitted to being in great pain and would have preferred more pain relief; and, it is quite understandable how things develop over time in these situations and how those involved may become reluctant to risk law suits when it may not be clear that charges of "child abuse" (i.e., on the part of BK's mother) could be firmly established. Nonetheless, if a balanced view is to be attempted here, it would not be unfair to say that this is a case where the obligation to treat pain and discomfort in a dying, extremely vulnerable patient was not observed.

A Health Communication Scholar Responds

BK is the central figure of concern is this case, and perhaps the one that evades the closest scrutiny. We know he has been sick for a third of his life with a life-threatening illness that is very rare in teenagers and young adults. It is difficult to be a seriously ill child, and being sick with an "adult" disease is even more distressing. Age is the number one risk factor for colorectal cancer; more than 90% of people diagnosed with the disease are 50 or older and the average age at diagnosis is in the mid to late 60s.[2] In general, teenagers are not likely to get colon cancer. But some genetic conditions and inherited mutations do predispose younger people, including teens and younger children, to developing colorectal cancer.

People with Familial Adenomatous Polyposis Syndrome (FAP), a genetic disorder, have a nearly certain chance of having colorectal cancer, usually diagnosed by age 45, if screening and treatment are not undertaken. This syndrome causes the body to create thousands of adenomatous polyps in the colon, starting in adolescence. One of 10,000 babies will be born with FAP. If a person of a first-degree relative has been diagnosed with FAP, or if there is a family history of the syndrome, colon cancer screening should start between the ages of 10 and 12, with an annual flexible sigmoidoscopy to follow. Bowel surgery to remove the colon (colectomy) is the foremost treatment modality for FAP. People with Hereditary Nonpolyposis Colorectal Cancer Syndrome (HNPCC), also known as Lynch syndrome, also have a nearly 80% of developing colon cancer, and increased risks of developing uterine, stomach, bile duct and urinary tract cancers. People with HNPCC may also have aggressive tumors, which can grow and spread faster than average. People with HNPCC should begin screening by the time they are 20 to 25. People with a first-degree relative who has been diagnosed with colon cancer should begin screening 10 years prior to the age at which the family member was diagnosed (or at 20–25 years old, whichever comes first). A colonoscopy every one to two years may follow the initial screening. We do not know anything about BK's genetic disposition to colon cancer, or whether there was a family history of the disease. We only know that he contracted it at a very young age.[3] The oncologist who treated BK was an expert in colorectal cancer in adult patients, and no doubt he did the best he could to treat BK effectively and compassionately with the tools and treatments he had available. We have no information, however, regarding his experience in treating pediatric oncology patients, or whether he thoroughly inquired about BK's family medical history.

There are many difficulties that occur when a hospitalized patient transfers between pediatric and adult hospital floors and services and health care professionals who normally treat children and those reserved for adult patients. The expected difficulties around coordination of care are exacerbated in such circumstances, and there is scarce research literature on best practices to guide policy changes (LoCasel-Crouch and Johnson 2005). In BK's case, his mother trusted the oncologist who treated BK upon his initial diagnosis and who was involved in his care five years later. Although likely highly qualified, this physician was not an expert in dealing with parents of seriously ill children, of managing pain in seriously ill children, or in coordinating the care that pediatric patients and their families might require (including Child Life Specialists, etc.). Eventually it appeared that all the right players were involved—palliative care, ethics, various other specialists and intensivists—but it is not sufficient just to have all the right people involved asynchronously. They must be on the same page in terms of the information given to the patient and family, and they must be committed to developing and implementing a plan of care that respects their various disciplinary contributions informed by the current state of medical science, the values and preferences of the patient and family, and the medical facts of the patient's condition. This is best achieved in a face-to-face meeting, which may be difficult to arrange (but should not be impossible).

BK's mother may not have had all the information she needed in order to make decisions that were in her son's best interest. First and foremost, she did not acknowledge or know what BK himself was experiencing, knew, or desired—the first key step in honoring a person's autonomy is knowing what they want for themselves. In BK's case, he seemed consistently to want what would cause his mother the least pain and distress, including spiritual distress. It is not difficult to imagine that a young man who has been seriously ill for much of his life would look to his parents for guidance, and he may well have lacked the emotional maturity to make or even to formulate independent ideas about what he valued and cared about. There also was a lack of communication between the palliative care team, the hospitalist, and the oncologist in terms of what they were telling BK and his mother and what they were sharing amongst themselves. It is quite possible that BK's mother really did believe her son had been cured earlier, and that she steadfastly believed another miraculous cure was likely or at least possible. Again, since we do not know BK's family health history, we can only guess at his parents' level of health literacy and ability to interpret and act upon the information she was given about BK's condition and prognosis (Berkman et al. 2011).

Physicians and other medical professionals are likely to roll their eyes at family members who insist that God will make the decisions and that a miracle is sure to happen. Just because BK's mother was a woman of strong faith who was hoping and praying for a miraculous cure for her son does not mean she did not believe nor understand the medical information she was given about his prognosis. Recent research has shown that parents of seriously ill children use both medical and spiritual resources when making decisions about their children's health care (Davidson 2016). For parents of seriously ill children, often every choice they could make appears bad. For example, consenting to surgery may be distressing and painful to their child and/or of uncertain benefit, but not consenting to surgery also brings anguish and uncertainty. Sometimes asking or hoping for a miracle is more a reflection of a need for more time, and a need for a spiritual sign, rather than a denial of the seriousness of their child's condition or prognosis. In BK's case, however, we do not know to what extent his mother understood and accepted her son's dire prognosis. Her unwillingness to bring him for follow up testing after his earlier remission might indicate either a deep denial or a serious misunderstanding of her son's chronic medical condition.

It might also be the case that BK's mother did not want additional medical information, and that may explain why she sent away the palliative care team who tried to challenge the plan of care. The Theory of Motivated Information Management (TMIM) posits that the likelihood we will seek information depends on our perceived need for it, our coping ability, and the way in which the information is conveyed (Afifi and Weiner 2004). It focuses on interpersonal sources of information, and it predicts that when the stakes are high, most people prefer face-to-face communication from highly trusted sources. It appears that BK's mother felt she had all the information she needed from her trusted sources, namely, her son's oncologist, and God.

The last issue to be addressed concerns the level of pain management that BK apparently needed but was not willing to access. Many patients prefer some level of discomfort along with the ability to interact with family and friends rather than complete pain control that renders them semi-conscious. For spiritually inclined families such as BK's, the ability to pray and interact with God is also an important value. The risk of becoming addicted to narcotic pain medication is real, but limited by several factors, and overall the risk is quite low. Fishbain and colleagues (2008) conducted a structured evidence-based review of all available studies on the development of abuse/addiction and aberrant drug-related behaviors in chronic pain patients with nonmalignant pain who were exposed to chronic opioid analgesic therapy. Their results revealed that for patients with no previous or current history of abuse or addiction, the risk of becoming addicted or of abusing opioids was less than 1.0%. In BK's case, it was extremely unlikely that he would become addicted before he died, but because his mother was not willing to concede that his life expectancy was foreshortened the risk of addiction was real to her. Perhaps a family history of addiction was another pertinent medical clue that this very private family chose not to share.

BK died in pain, after being subjected to months of life-prolonging medical treatment that did nothing to maximize his chances of recovery or comfort. His death was distressing to the medical professionals caring for him, and it is likely also distressing to those reading this case study. It is important to remember that even so-called "good" deaths involve some level of compromise and distress, and perhaps the most painful thing for BK would have been to witness the pain and suffering his death caused his parents and family.

Notes

[1] Cultural competency is a huge field. Even with delimiters set to healthcare, a literature search will yield over 2600 items; by comparison, relatively little research has been done in pediatric and hospice, or end-of-life care. The following may be useful in developing a general overview of this field:

Brunger, Fern. 2016. Guidelines for teaching cross-cultural clinical ethics: Critiquing ideology and confronting power in the service of a principles-based pedagogy. *Journal of Bioethical Inquiry* 13: 117–132.
Cheng, Tina A., Mickey A. Emmanuel, Daniel J. Levy, and Renee K. Jenkins. 2016. Child health disparities: What can a clinician do? *Pediatrics* 136: 961–968.
Houghson, Jo-anne, Robyn Woodward-Kron, Anna Parker, John Hajek, Agnese Bresin, Ute Knoch, Tuong Phan, and David Story. 2016. A review of approaches to improve participation of culturally and linguistically diverse populations in clinical trials. *Trials* 26: 263.
Purnell, Larry. 2016. Are we really measuring cultural competence? *Nursing Science Quarterly* 29: 124–127.

[2] *Detailed Guide: Colon and Rectum Cancer: What Are the Risk Factors for Colorectal Cancer?* American Cancer Society. 7 Mar. 2006. 23 Jun. 2006 [http://www.cancer.org/docroot/CRI/content/CRI_2_4_2X_What_are_the_risk_factors_for_colon_and_rectum_cancer.asp].

[3] There are some other rare genetic mutations that might cause colon cancer in young patients. Peutz-Jeghers syndrome is a very rare genetic syndrome that is characterized by polyps in the gastrointestinal tract and may be accompanied by freckles around the mouth, hands and feet. Peutz-Jeghers syndrome greatly increases the chances of developing colon cancer. It is caused by a defect in the STK1 gene and can be diagnosed through genetic testing. Juvenile polyposis is a condition that causes multiplication of the polyps in the gastrointestinal tract of young children. It will lead to colorectal cancer if untreated. Turcot syndrome is another very rare syndrome that can increase the risk of developing adenomatous polyps. There are two variations of Turcot—one that mimics FAP and one that mimics the mutations seen in HNPCC. Turcot syndrome may also increase the risk of developing brain cancer.

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