

Commentary

Reflecting on Parental Concerns in the Treatment of Pediatric Brain Tumors: Observations From A General Pediatrician

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Conflicts of Interest. The author reports no conflicts of interest.

Abstract. This issue of *Narrative Inquiry in Bioethics* explores the concerns and point of view of parents who have had to confront the devastating diagnosis of a pediatric brain tumor. This commentary, written by a general pediatrician, is a synthesis of several narrative themes which touch on a range of topics from relapse to long-term sequelae and other issues that effect a growing population of pediatric brain tumor patients. It offers a glimpse into the problems that need to be addressed by health professionals, educators and support teams who provide short and long term care to these patients and their families.

Key Words. Detached Medical Professionals, Long-term Sequelae, Pediatric Brain Tumors, Relapse

Introduction

This issue of *Narrative Inquiries in Bioethics* explores the concerns and point of view of parents who have had to confront the devastating diagnosis of a brain tumor in their child. Until the last few decades, the diagnosis of a pediatric brain tumor was a death sentence—there were few, if any, treatment options. The last forty years has seen an explosion in medical research that has helped delineate the biology of tumors and hone in on treatments. Along the way, a new field of doctors has emerged: pediatric neuro-oncologists, pediatric neuroradiologists, etc. and increasingly, there are new breed of patients: childhood survivors of pediatric brain tumors.

The stories in this journal were selected because they highlight a range of concerns expressed by parents who have been thrown into the fire and brimstone world of hospitals, doctors, and treatment protocols. Every family remembers the first time they hear those words: “Your child has a brain tumor” and in those few seconds that it takes to process that short sentence, the life of a family is turned upside down and will never be the same. These stories illustrate the journey from diagnosis to an array of outcomes, and they are difficult to read. The heartache in these tales reveals how this diagnosis touches every aspect of a family’s life: siblings, marriages, careers, and finances. My hope is that these words will provide an invaluable roadmap to families searching for

guidance and that these stories will also enlighten the physicians who are treating these desperately ill children.

The Facts

Each year there are nearly 3,750 new diagnoses of pediatric brain tumors in the United States (Lau & Teo, 2013). The majority of these children will be sent to tertiary care centers for diagnosis, surgery, and treatment. There will be scans, surgery (either a biopsy or an attempt at resection), a waiting period for pathology reports, consultation with a radiation oncologist, and meetings with the neuro-oncology team to discuss treatment options. Parents are inundated with medical jargon, survival data, and the harsh reality that treatment almost always involves collateral damage. The extent of long-term sequelae, a condition that is the consequence of a previous disease or injury, is hard to fathom at the time of diagnosis when parents' only concern is "Will my child survive?" The truth is that many of these children have survived: 26,000 and counting (Lau & Teo, 2013). But the collateral damage of these life-sparing treatments has left a generation of children with physical and cognitive impairment, which includes a range of learning difficulties and motor deficits (Packer, Gurney, Punyko, Donaldson, 2003). Parents, schools and the medical community are not prepared to handle the challenges of this growing population of long-term survivors.

In this collection of narratives, three children died at the time their stories were written and one child was experiencing a late relapse. One was a mere six months off treatment. Of the eight survivors, four have severe impairment.

Narrative Themes

The stories chosen for inclusion in this compilation each illustrate a topic that deserves a forum for discussion. But beyond the unique circumstances that surround these individual narratives, there are common threads that are important talking points.

Detached Medical Professionals

Many families expressed frustration that their doctors were detached and they expected more compassionate care. From the families' standpoint, life-and-death decisions are being made about how to treat their child who has been diagnosed with cancer. These parents are overwhelmed, terrified and in shock. For the doctors, these occasions are routine; it's hard to imagine but *all* of their patients have life-threatening diseases. In general, oncologists are not known for their "bedside manners." Physicians drawn to the field of oncology generally are interested in research and are well schooled in the hard-core basic sciences. Their training requires at least two years of laboratory research and only one year of full-time clinical work. Oncologists are trained to be level-headed, clear thinking, and can occasionally come across as dispassionate.

Several stories mentioned "doctor-ese": the language that doctors use to explain things. One family said the doctor described the mass in his daughter's head as "impressive" (Wecks). I imagine a child having an impressive accomplishment but never a tumor. Another doctor, when discussing treatment said "it shaved IQ points" (Riley). Doctors learn this language during their training (I did) and are not taught to modify their clinical vernacular before interacting with families. The profession needs a lexicon for patient/family interaction that should be taught during the training period. In a very short period of time, parents become conversant in the language of neuroscience. It's a steep learning curve. "In our first meeting with the head of neurosurgery, we were drowned in information. It was most certainly malignant, maybe AT/RT (Atypical Teratoid Rhabdoid Tumor) or PNET (Primitive Neuroectodermal Tumor). Meaningless then, but so familiar now" (Wecks). Parents, unless they have a background in neurosciences, should be spoon-fed information that is clear and direct during those initial meetings: "Your child has a brain tumor. It is probably malignant. We will be able to make a definitive diagnosis after a biopsy." That should be it. There will be plenty of time to get into the details about tumor type and treatment options when there

is a diagnosis. It may save a family the feeling that they are being “suffocated” (Riley).

One family felt that the doctors were treating the tumor and not their child. One wrote that they wished that their son was seen as “more than a vehicle for cancer” (Anonymous Two). Another complained that doctors often don’t listen or hear patients: “Just because a test doesn’t show what is wrong doesn’t mean that everything is right” (Anonymous Three). Reading these words made me realize that this compilation of stories should be required reading for all oncologists and surgeons who care for children with brain tumors. Health care professionals can learn something from these families; it’s important for doctors to remember how desperate and scared these people are every day. One father said of the his son’s treatment “All in all, it was a dehumanizing experience—and there were many times when we felt as if we were in jail, being punished for a crime we did not commit” (Abell).

In stark contrast to the many detached doctors cited in these narratives is the oncologist who was described by a parent as being too enmeshed with their family. In the end, the family chose not to proceed with a second opinion and risk jeopardizing the relationship with their beloved oncologist. Describing the oncologist, the author says: “(he) cared for him (the son) both personally and professionally as if he was his own child.” But when the child relapsed six years after originally diagnosed, the oncologist recommended against another surgery in favor of more radiation. The parent, through her research, had determined that another surgery was, in her words, “a no-brainer”. But she decided she could not “take the risk (of another surgery) without her oncologist’s support. The guilt in the aftermath of surgery with a bad outcome would have debilitated me emotionally.” This parent felt the doctor should have said: “Let’s take all the scans, reports, emails, conversations about this matter and send it to this other brilliant and knowledgeable Dr. X in Facility X to have a look at it” (Anonymous One). It takes a village of opinions to create optimal solutions for patients with hard-to-cure cancer. A corollary is that most of the best options for patients with rare cancers are drug trials and

there is no actual “standard of care”. This is a fact of life that all families ought to be aware of from the outset and that all oncologists should concede without hesitation.

Urgency of the diagnosis

When a child is diagnosed with a brain tumor there is no time to waste. No shopping around for a second opinion or trying to find ‘the best’ neurosurgeon to operate on your child’s brain. Most children are diagnosed after months of symptoms and then ‘BAM’: the situation is dire. A CT scan is obtained, the mass is seen, and the wheels are set in motion. That child and family are swiftly transferred to the nearest facility with a pediatric neurosurgeon. They are placed in the hands of a doctor they have never met and a biopsy or resection is scheduled ASAP. There is a feeling of utter helplessness and urgency; there is no time to think. Most families have no idea of the questions to ask. They just want to know if their child will survive. They are in a vulnerable position: they need to trust the doctors who have been assigned to save their child’s life but are often afraid to question that doctor’s judgment or request a second opinion. It’s hard to imagine that a person would challenge the doctor who is about to operate on his or her child’s brain. Additionally, you don’t want to be labeled a ‘problem parent’—which is what happened to one family who brought up the subject of sperm banking for their newly diagnosed 13 ½ year old son. “I knew that infertility concerns were usually pushed aside at diagnosis to make way for other priorities, namely the urgency of starting treatment” (Anonymous Two).

From my standpoint, there is never a problem parent. The problem is the brain tumor. Stabilizing the patient must be the first priority, but after that, another opinion should be encouraged. Once a diagnosis is made, the questions should be: “Who has the most experience with this particular type of tumor? Can a phone consultation be arranged? Is it even feasible to get treatment elsewhere?”

One family, sent home to spend their first and last Christmas with their newly diagnosed two-month-old infant, was not offered a surgical option

(after an initial biopsy). Following a meeting with the neuro-oncologist the next week, the family was sent to meet another neurosurgeon at a nearby children's hospital. The second opinion was surgical resection, which is what the family opted for. "She was discharged a month after we were told she was going to die, tumor free" (Wecks). These crucial early decisions need to be made using language that is accessible and without the veil of egos or turf wars. After all, a child's life is at stake.

Grief and Guilt

Grief and guilt accompany a pediatric brain tumor diagnosis and remain entwined with every aspect of decision-making and treatment. From the time of initial diagnosis and postoperative hospitalization, continuing during the course of intensive treatment and finally into the period of long-term follow-up, all families experience an immense sense of loss and the grief associated with it. Everyone seems to suffer: the child who was hit by a bolt of lightning called a brain tumor, siblings who are out-placed to other family members, dreams that are put aside, often forever. One father, speaking about his wife, said it so poignantly: "Her grief wasn't about the death of her son. It was about the death of her dreams" (Riley).

The issue of guilt starts at the time of diagnosis. Parents may have a nagging feeling that something is not right. An initial visit to the pediatrician may reassure them. Weeks or even months go by before a diagnosis is made. "It does make me question our parenting and ability to know what is best for our child's wellbeing. Add to that a doctor who made you feel very inadequate as a parent; it was hard to have the confidence to question the doctor" (Rocker). There is guilt and grief from this time forward. Did we choose the correct treatment option? Was it the right decision to postpone radiation, which would allow a young brain more time to develop? What about a second surgery? Should a complete resection be attempted (potentially doing more damage to the brain) if a scan shows residual tumor or do you hope that the chemotherapy will take care of any tumor that was left behind? Every

question implies that there is a right and wrong answer or at least an optimal decision for the best possible outcome.

Most treatment decisions are made based on studies or protocols that have looked at outcome data collected over the past forty years through the Children's Oncology Group (and its predecessors). The treatment of pediatric brain tumors is constantly evolving. The children being treated now benefit from the information gleaned from those who struggled before them. The guilt surrounding treatment options is part and parcel of this diagnosis; there is always a choice between several bad options. No one ever wants to be in this position. Ever.

There is universal guilt about the other children at home. "We sacrificed the good of one child to save another" (Riley). "I feel that we neglected her (a daughter three years older than their child with cancer) during that time" (Scheumann). "We feel certain that our constant focus on Sarah made his (her twin brother) path to drug addiction almost inevitable" (Carlson).

There is guilt if your child survives. "During those first few months after our diagnosis, we met three other families who had daughters with brain tumors. My daughter is the only one still alive" (Rocker). Doctors should be cognizant that these families find support and community with other brain tumor families. The death of other children reminds them how fragile their own child's existence is. "As they passed our pew, my wife clutched my arm and wept tears of sympathy, guilt and fear" (Abell).

Recurrence and Hospice

Relapse, regrowth, late recurrence, this is what is on every parent's mind. Follow-up for pediatric brain tumors starts as soon as treatment ends. Initially scans are scheduled three months apart. Then clinic visits become less frequent and the duration of time between scans is increased. But as the months and years pass, every headache, stumble, fever gets analyzed. Could this be a relapse? "In many ways we have returned to a somewhat normal life. Despite this, cancer still strangles us with fear" (Abell).

Four of the children in this series experienced relapse between one to eight years after their diagnosis. Those relapse stories are even more heart-breaking. It's bad enough to put your child through treatment the first time. The second go-around is that much more difficult and the options are frequently limited. Brain radiation is given either as whole brain treatment or focused treatment to the tumor bed. Either way, there is a maximum lifetime dose of radiation (Donahue, 1992). Chemotherapeutic agents may also have maximum lifetime dosages. Prognosis following relapse is very poor. Relapse is a time to review past treatment history and determine what options are out there. It's also a time to re-consider a second opinion and look into drug trials.

When the prognosis after a recurrence is extremely poor, hospice replaces hospitalization. There is a shift from trying to prolong life to make what time is left as comfortable as possible. Hospice care is usually offered at the end of failed treatments but one brave family opted against treatment at the time of their daughter's initial diagnosis and immediately sought support through hospice. I actually thought that this was a beautiful and heroic narrative. Despite pressure from doctors, the family stuck with their decision since this tumor type had 100% mortality. "We surprised the doctors by telling them that since Stella was going to die sometime in the coming months, we wanted to be connected immediately with a palliative care team" (Methven). This family had 16 months of support from a loving hospice team and they had no regrets.

Long Term Sequelae

More than half of the survivors in this sample of stories had significant long-term sequelae ranging from educational impairment to devastating, life-altering complications. Surgery, radiation and chemotherapy offer the only hope of survival but they come with a price tag. Most families could not have comprehended the degree of impairment that their child would suffer. Although doctors cite a litany of complications: seizures, hearing loss, visual impairment and growth failure, most parents are willing

to accept everything as long as their child survives the cancer. Basically there are no good options. It's human nature that we want to believe that our child will be the small percentage that breezes through this nightmare unscathed. Long-term disability happens to someone else. After reading the story of a child "still deteriorating, her seizures were uncontrollable and her quality of life was extremely poor" (Anonymous Four) thirteen years after cancer was treated or cured, I reflected on the decisions that were made that resulted in this devastating outcome. The treatment protocol in 1997 was high dose radiation to her brain although she was only four years old. That would never happen now but the fact is that there are children and families living with the side effects of those early treatment decisions. Parents and doctors make the "best" decision based on the most recent data and studies and then cross their fingers.

The list of long-term sequelae is long. A frequently mentioned problem of brain tumor survivors is fatigue. Everyday tasks like walking may be more difficult. Vision problems including strabismus can affect depth perception and may cause eye fatigue that interferes with homework and reading. Cognitive deficits require that there is an educational plan in places that addresses the issue of accommodation. One parent whose child had a 504 educational plan to accommodate his needs writes: "In March of his kindergarten year, Ben lashed out at his teachers and was suspended. He was given a home/hospital teacher for the remainder of the year" (Hilliard). It is hard to imagine that a child who was thought to be disease free could not be supported in a classroom setting. As more children become survivors, a greater support system must be in place to cater to their specific needs.

CONCLUSION

This issue of *Narrative Inquiries in Bioethics* addresses some of the important themes that are encountered by a growing population of pediatric brain tumor survivors. It offers a glimpse into the problems that need to be addressed by health professionals, educators, and support teams. Treatments will continue