Prologue

Healthcare providers encounter ethical dilemmas all the time, even if those dilemmas do not make the evening news. This book is a testament to the myriad of these daily challenges. In some cases, dilemmas arise due to difficult decision-making in the face of uncertainty. Other dilemmas surface because, as often happens, reasonable people can disagree, or because someone – a practitioner or family member – has questioned or challenged the status quo. As a parent of a child with severe impairments, I am heartened by this inquiry and the authors’ desire to illuminate these ‘everyday’ challenges faced by healthcare providers. Not only might readers recognize themselves or their patients in the scenarios but they may also discover a wealth of creative approaches to address these dilemmas. Raising awareness of ethical issues in everyday clinical encounters can only serve to benefit the relationships between providers, patients and caregivers, and to improve outcomes for patients and their families.

However, the approach to compiling this book – inviting healthcare providers to recount and analyze their own ethical dilemmas – is not without some risk. For example, we might erroneously consider these self-identified dilemmas to be comprehensive or complete; or we might misunderstand a particular creative solution to be the right solution, or the only solution; or we might miss other ethical dilemmas that cannot be seen when launching this inquiry from the perspective of the healthcare provider or institution. Although we might be tempted to assume that a well-considered ethical analysis is inherently bias-free (or, rather, includes all known and relevant perspectives), we might
also consider that ethical questions raised by the family, or by the patient, might invite entirely different questions.

For example, an institution’s concerns about resource allocation may raise questions about ventilator use, while a parent’s concerns regarding resource allocation may raise questions about how to divide her time between her children (with and without impairments). A clinician may judge that a particular treatment is not worth the risk, while a parent wants to show her child she is doing everything she can to help them; in this case, their notions of beneficence are quite different. We might also consider a growing debate in the literature about use of the ‘best interests’ standard (e.g. Rhodes & Holzman 2014; Veatch 1995), which cannot be determined without a value judgment of what ‘best’ means, or even of what ‘interests’ mean. In other words, we ought to consider that an expression of interest in ethical inquiry must also be assumed to be an expression of bias. Perhaps this is unavoidable: the inquiry must be launched from somewhere.

Many of the scenarios described in this book are recognizable to me as the primary decision-maker in my young son’s years-long, intensive journey through pediatric medicine, neurology, neurosurgery, developmental services and therapy. Although I experienced them from the other side – the patient’s side – the scenes feel familiar. At the time, I could sometimes see that there was a dilemma of some kind going on, but I would not have known the specific concerns as identified by the healthcare provider. As a parent, I was contemplating issues of a different sort.

In this chapter, I will suggest some areas for ethical consideration that may not be immediately obvious to healthcare providers when self-identifying ethical issues. I will also be referencing personal anecdotes to illustrate these issues, and so must start with a brief background of our family.

**Family background**

My son Owen, my first child, was born in 1998. He had already had a complicated journey – he had hydrops fetalis, requiring chest and abdominal shunts (inserted in utero) to relieve accumulating fluid. His birth was preterm (at 32 wks) and he stayed in the neonatal intensive-care unit (NICU) for three months.

Owen did not develop typically. He missed milestone after milestone, never gaining functional control of his trunk, head or extremities. He required full assistance for all aspects of daily living: he was non-ambulatory, incontinent and deaf; he had virtually no functional use of his hands; he received a percutaneous gastrostomy tube (or g-tube) around 4 years of age and an intrathecal baclofen pump when he was 9 years of age (the pump malfunctioned and was later removed); and he had fully supportive assistive
equipment, including a stander, neck-and-head support and a custom wheelchair. His health was surprisingly robust, with the exception of frequent aspiration pneumonias. (His respiratory health improved significantly after he got his g-tube.)

Owen had a brother, Angus, who was 2 years younger. Angus was Owen’s chief companion and advocate, proudly holding his hand or pushing his wheelchair, shrugging off stares from other kids and criticizing adults for talking to Owen ‘like a baby’. My partner Michael was an active father and deeply accepting of who Owen was. I was in charge of Owen’s routines and therapies, and ensured he received exemplary care, services and treatment. Michael and I separated in 2007, but quickly established a friendly and consistent routine of sharing care of the boys, with Owen’s caregivers working with him wherever he happened to be.

Owen died in 2010, at the age of 12. His death took us all by surprise, as he had been in good general health for the previous year or two and did not appear frail. He died sometime in the night, while the household slept. His official cause of death was sudden unexpected death from epilepsy (SUDEP) (see Chapter 27), which according to the coroner was admittedly a diagnosis of elimination. (Owen had not had a seizure since he was an infant.)

We were not disappointed by the lack of diagnosis. Throughout his life, Owen’s constellation of symptoms was never diagnosed as anything other than cerebral palsy, yet there was no evidence of brain injury, congenital anomaly or other clues that might lead us to an underlying cause for his impairments. We were used to not knowing.

I think most of our healthcare providers would agree: I appeared to be a confident, capable decision-maker and caregiver. I was decisive, generally unsentimental, and open to being wrong if provided with facts. We were, in many ways, an ideal ‘patient family’ – we were engaged and cooperative, with few social, cultural or financial barriers to pursue treatments or therapies. My decisions were never questioned because I seemed so knowledgeable and reasonable.

In this context, my parental decision-making autonomy appeared to be complete. However, as illustrated by the following anecdotes, I was perhaps not as informed as I thought I was.

**Policy nudges**

When Owen was diagnosed with profound hearing loss

*Owen ‘failed’ his auditory evoked potentials while still in the NICU. His profound hearing loss was confirmed when he was around 2 years old. I remember how the audiologist sat us down*
to deliver the news. ‘I’m sorry’, she said, eyes downcast. She let us know that someone would be in touch soon, to discuss next steps. After all we’d been through with Owen, the audiologist’s apology seemed unnecessarily grim – we were pleased to have Owen home with us and generally healthy. We did not think of the diagnosis as a ‘problem’.

Two weeks later I received an excited call from the hearing clinic at the hospital. We were asked to come in for an information session, now that we were on the list. I paused before responding: ‘What list?’

The hospital clinic automatically placed children with profound hearing loss on the cochlear implant waiting list. They were keen to get new children assessed and ‘processed’ quickly. When we attended the information session, we found out why: the clinic had received funding to do a certain number of implants in a certain amount of time. The allotted time was coming to an end, and the surgeon wanted to move through the waiting list before the deadline. His presentation during the information session was focused on this funding.

Later, I asked our assigned social worker why Owen was placed on the cochlear implant list when it had never been discussed. She seemed surprised at the question, and reminded us that the cochlear implant is what the hospital provides as treatment for profound hearing loss. According to the hospital, the cochlear implant was simply ‘the next step’.

A parent’s perspective
After this experience, I became wary of process and protocol. I wondered how many other times I had been subtly guided toward ‘decisions’ without even noticing. What is most noteworthy here is that I only noticed the ‘nudge’ because I did not think Owen’s hearing loss was a problem. I had reason to second-guess the default assumption that I would want to pursue the cochlear implant. Other families who did pursue the cochlear implant may not have had reason to question this treatment, and possibly many were satisfied and would not have decided otherwise. However, the ethical problem remains: informed decision-making and patient autonomy are compromised when an in-built process assumes that a particular treatment will follow, which can easily be perceived (and adopted by the parent) as a decision.

It is plausible that healthcare providers may be unaware that these policy nudges are in place. It is also plausible that policies like these are developed to aid efficiency: could it be that at one point a patient had been overlooked, necessitating automatic referral to the waiting list for everyone after that?

Policies and procedures may have unintended consequences, and it is worthwhile to query the effects of ‘due process’ at all stages. Healthcare providers could investigate the
path of referral, both into and out of the clinic, to discover if there are hidden nudges or influences that may compromise parent or patient informed consent. Additionally, healthcare providers may inquire of parents and families as to how they arrived at their decisions, allowing providers to evaluate the integrity (and consequences) of institutional policy as it relates to shared decision-making.

**Broken communication**

*The DBS consultation*

Owen’s dystonia and spasticity were compounded problems – one made the other worse. He had already had an intrathecal baclofen pump, which had malfunctioned and had been removed. His spasticity, then, was untreated and his dystonia made his discomfort worse. His unpredictable movements also made carrying and caring for him difficult. His neurologist suggested we learn more about deep brain stimulation (DBS). We were referred to a neurosurgical specialist.

When we arrived, the specialist checked Owen over. She weighed him, moved his limbs, inquired about his movements, asked about his general health and medical history. When she was finished, she made her announcement: ‘Yes, he would be a good candidate’. The surgery might have a positive effect on his movements. She went on to tell us about the supporting data, research and statistics. Then she stopped and simply looked at us, waiting for a response.

Her ‘yes’ had come so quickly that Michael and I felt a little stunned. I also felt sad about the prospect of another surgery, particularly one I perceived to be risky. We began to discuss next steps when I realized how quickly I had gotten ahead of myself. I reminded myself that we were there to find out if DBS was a good option for Owen, not if Owen was going to be a good candidate for DBS – a subtle but important difference. The specialist, on the other hand, was doing an assessment. I was asking if we should, and she was answering if we can.

How quickly I heard the ‘yes’ to mean that she was recommending the surgery specifically for Owen!

*A parent’s perspective*

As healthcare produces more and more subspecialties, parents must learn to navigate an ever-growing myriad of appointments, facilities and approaches. In some ways, this is the easy part of having a child with complex needs; we become very skilled at managing busy schedules. Despite this efficiency, parents can remain fairly naïve or inexperienced at evaluating the merits of consultations, the quality of interactions and the intentions of the parties involved (to name just a few aspects worth assessing). Parents would do
well to ask themselves, What is the purpose of this meeting? Is it necessary for me or my child? What do I need to know? Am I expected to make a decision during the meeting? Am I prepared to make a decision?

At the appointment described above, the specialist and I were essentially talking past one another. She was answering a different question than the one I had in mind, yet neither of us realized it at first. We were using the same terms, referring to the same child and discussing the same procedure, yet we had different motivations, and therefore were seeking different answers.

Parents of a child like Owen often function as a link between specialists, risking a ‘broken telephone’ effect of miscommunication and misunderstanding. Had I not caught my own misassumptions, I may very well have told our neurologist that the neurosurgeon strongly recommended the surgery. Thus a ‘new’ truth would have been born, attached to words the neurosurgeon had never said.

Admittedly, this is tricky territory. This is more than a matter of parental understanding or comprehension, which may be rather easier to parse out. Instead, this may be a matter of differing motivations, resulting in a kind of information distortion. Although we might be assured that all parties are aligned to a single vision of supporting the child, parents may not be especially attuned to noticing when they are unconsciously trying to match what they hear to what they want. In these moments, it is essential that healthcare providers are rigorous in their attention to transparency about their own roles, interests and motivations. By doing so, the healthcare provider helps to support and preserve a parent’s ability to make informed decisions.

### Autonomy without guidance

**Owen’s struggles with feeding**

*By the time Owen was 4 years old, he was exceptionally thin. Feeding continued to be extremely difficult: he aspirated liquids and solids alike, could not chew effectively, and had razor-sharp teeth (due to acid wear from reflux) that cut through his lips and inner cheeks. If he was sick, it was almost impossible to get him to ingest antibiotics, pain relievers or any other medications; because of his reflux, he often vomited whatever food we could get into him. Yet, I was determined to persist in feeding him by mouth. Not once in our frequent feeding clinic appointments was a g-tube mentioned. Instead, after every swallow study, I was given careful instructions for thickening his liquids, pureeing his solids, timing his swallows, positioning his head and neck, and encouraging chewing. I was praised for ‘sticking with it’. On one (final) occasion, I was given instructions that, if followed, required that I feed Owen for over 6 hours every day! I confided in a friend (who was also a nurse) – she*
encouraged me to ask about getting a g-tube. I was resistant at first, insisting that because it was never suggested, he didn’t need it. Eventually I gave in. After an assessment (at my request), we arranged for the procedure to be done in the coming weeks. With the g-tube, Owen gained weight, his sleep improved and his aspiration pneumonias became much less frequent.

A parent’s perspective

Even though I appeared to be ‘doing fine’ with feeding, Owen was not fully thriving. He was underweight and sickly, he was not getting all of his medications orally, and we were exhausted from feeding difficulties. Furthermore, the doctor who recommended our feeding plan failed to notice how much time would be required to feed Owen according to his prescribed schedule. I believe that because I was a confident, determined parent, and because I didn’t complain, an appropriate alternative to feeding was never suggested. I interpreted the silence to mean that he didn’t need a g-tube, and therefore did not ask about it until I was desperate.

In this situation, it could never be suggested that I did not have full autonomy – it was indeed my choice to feed Owen orally, and my choice to request a g-tube. However, we might also see that I was in need of honest counsel (to see our reality) and supportive encouragement (to explore other options), neither of which I received from our feeding specialists.

By providing autonomy alone, without professional advice or guidance, healthcare providers may unintentionally be compromising the ability of parents to provide optimal care for their child. In my opinion, parents (particularly those with children with complex needs) need professional guidance and advice – sometimes, even when unsolicited – in order to make informed decisions. This may include ‘giving parents permission’ to consider alternatives that they might either not have known existed or at times were hesitant to voice aloud.

A parent’s perspective on everyday ethics

The anecdotes described above only skim the surface in considering ethics. In the three vignettes, a reader may agree that things did not seem quite right – but could we consider them to be ethical dilemmas per se? Did any one healthcare provider act poorly, or unethically?

In truth, my interpersonal exchanges with healthcare providers, in the context of caring for my son, were generally positive, respectful and at times even enjoyable. Indeed, I am grateful for the life-saving care we received and the compassion and consideration with which it was offered. My relationships with our healthcare providers were
friendly; I had no doubt that everyone on our various interdisciplinary medical teams could be trusted professionally and had my son’s best (healthcare) interests at heart; I encountered no bad actors, and no mal-intent.

I believe, however, that we were primarily successful in the healthcare environment because I engaged with it according to its own terms. My role as ‘expert parent’ was carefully constructed by me to ensure that I would be heard, understood and respected. I made efforts to appear calm and organized. This was rewarded with congratulations and appreciation – recognition of a job well done, with (I imagine) not a small sigh of relief that I continued to be an ‘easy’ parent to counsel. Although I inserted myself actively into every clinical discussion, I was not a source of resistance or friction — I did not argue, disagree, or make demands. Instead, I negotiated mutually acceptable terms in order to effect good outcomes for my son and my family, and this was positively received. The Family-Centred Care model was perhaps constructed with outcomes like ours in mind, where parents not only participate in decision-making, but formulate questions, educate themselves and ultimately (feel they) make satisfying, informed choices on their child’s behalf (Kuo et al. 2012).

If, then, I was the ideal parent-as-advocate, what should we make of the vignettes I have just presented? To be clear, these are just three of dozens of stories I might have told. The common thread I identify throughout is that, despite my own in-the-moment positive feelings of empowerment and autonomy, I was unaware of those mechanisms that made decisions on my behalf, or that nudged me in certain directions. In other words, I was invited to make decisions only at times that were deemed appropriate by the healthcare system (and the healthcare provider), and was denied visibility into what factors informed a healthcare provider’s recommendations. From a classic bioethics perspective, this easily challenges well-accepted principles of beneficence, justice and autonomy (Beauchamp & Childress 2012).

Many essays in this book present the contemplations of a healthcare provider in a clinical setting; the authors evaluate a challenging situation, consider what could occur next, and weigh options through an ethical lens or framework. In some cases, these contemplations are a direct result of parental ‘friction’, of the sort I mention above. It is interesting to note that many of these accounts are about families from vulnerable or disenfranchised populations. In these pages, we see dilemmas arising from encounters with families living in poverty, mothers with addiction issues, patients from different cultural backgrounds, and parents with varying levels of acceptance of evidence-based medicine. These cases certainly present personal ethical dilemmas for healthcare providers in terms of how best to manage a challenging situation, and most are handled with sensitivity and honest self-reflection. However, we should not disregard the fact that these clinician-identified ethical dilemmas are triggered by acts of ‘non-compliance’ by parents, notably ones who do not conform to cultural norms.
We should not accept as coincidence that the views of ‘ideal’ parents – parents who conduct themselves well – seem to be more readily accepted.¹

A close reading of these chapters may invite the question of whether we are addressing ethical dilemmas specifically (for example, ‘I am facing an ethical problem and don’t know what to do’) or if we are rather evaluating ethical frameworks and solutions to common challenges of living in a diverse society (for example, ‘What is an ethical response to this difficult situation?’). Does this distinction matter? Perhaps not, if we are primarily concerned with supporting problem-solving for the healthcare provider. I suggest, however, that addressing clinical challenges with ethical approaches is not enough; we should not absolve ourselves from the perhaps more daunting task of remedying – indeed, working to prevent – ethical problems in the wider healthcare system in which these challenges occur, and which compromise parents’ ability to care for their child.

Epilogue

When considering clinical encounters through an ethics lens, healthcare providers usually make an effort to include the family or parents’ perspective. This helps to provide a more robust ethical analysis, which will hopefully lead to optimal or improved decisions or outcomes. However, the healthcare providers’ interpretation of the parents’ perspective may not be the same as the parents’ perspective itself.

In this chapter, I have highlighted moments in which healthcare providers may find opportunities to support a parent’s informed decision-making and autonomy. The three issues I identified – policy nudges, broken communication and autonomy without guidance – are just the tip of the iceberg; further exploration of parent and family perspectives will surely yield more, as will close examination of ethics as enacted (or not) by the wider healthcare system.

The project of this book is to explore everyday clinical situations, cases and scenarios through an ethical lens or framework, to discover ways in which healthcare providers can improve relationships with parents, outcomes for their patients, and their own

¹ Despite my positive relationships with healthcare providers generally, I could easily have been the subject of one of the chapters in this book, as a parent whose decisions did not align with our healthcare providers’ recommendations. In Owen’s later years, I chose to withdraw him from many therapeutic programs and interventions, pursuing only those therapies that addressed specific medical problems. This was due in large part to my growing dissatisfaction with therapies aimed at normalizing Owen, rather than supporting him in his differences. I wrote about this extensively in No Ordinary Boy (Johannesen 2011). I believe I was not challenged on these decisions because, as mentioned earlier, I was considered an ideal parent. (Nonethless, some of these decisions on my part may have been interpreted differently by our healthcare providers.)
self-reflexive skills (to name just a few of the possible benefits). Certainly this is a laudable task. However, we must be careful to not allow ‘ethics’ to become merely a problem-solving tool, or a blunt instrument by which to earn trust from parents. I think parents can sense these efforts, which may lead to or reinforce skepticism and distrust. For ethics to be meaningful and substantive, it should rather be part of an overarching ethos of transparency and respect that infuses all interactions, processes and systems – even if there is no dilemma at hand.

References


