

Working paper: *What Helped? What Didn't? Caring for Simon Vodosek through Cancer*

Mott Children's Hospital/U of Michigan Comprehensive Cancer Center • Memorial Sloan Kettering Cancer Center (MSKCC) • Primary Children's Medical Center (PCMC) • U of California San Francisco (UCSF)

| <b>Diagnosis</b>   |   |
|--|---|
| <b>Helpful +</b>   | <b>Detrimental -</b>  |
| <ul style="list-style-type: none"> <li>• Orthopedist saw Simon quickly when symptoms returned after he had been asymptomatic at initial consult several weeks earlier (suspicion of Legg Calve Perthes, later possible bone infection)</li> <li>• Diagnosing oncologist happened to be in Radiology while initial MRI was read, and he took an immediate and lasting interest in Simon's case</li> <li>• Pediatric oncologist friends helped us interpret results of medical tests</li> <li>• Anthroposophical doctor* outside diagnosing hospital who asked us: "Has Simon done what he came to do?" to help us weigh the option of treating, or not</li> </ul> <p>* M.D. with training in homeopathy, naturopathy, and Swiss/German anthroposophical medicine who had treated Simon's ear infections without antibiotics after allergies were discovered in infancy to amoxicillin and sulfa drugs</p> | <ul style="list-style-type: none"> <li>• Our first visit to the "playroom" (pediatric infusion room) took place the day after the final diagnosis via CT, without any preparation for what we would see in a room full of kids in cancer treatment (bald, pale, unhealthy)</li> <li>• Simon forced to undergo a conscious bone marrow draw because there was no space in OR (due to low staffing over the holidays) and sample had to be sent off that day to get him enrolled in the clinical study to begin treatment</li> <li>• "Holiday diagnosis" with final diagnosis on 12/26/01 and start of chemo on 12/28/01--every practitioner told us "it's not normally like this, just between the holidays"</li> <li>• Two weeks into treatment at our first clinic visit, the clinic coordinator asked, "Have you had a tour?" "No!" I barked, taking out all my frustration over the "unusual" treatment of a holiday diagnosis.</li> <li>• During diagnosis, the doctors' suspicion of cancer was not made clear to us until the diagnosis was finalized; leukemia was ruled out with a bone marrow aspirate; a bone biopsy was done to "rule out" infection; it seemed that the medical team fully expected Simon to come out with a cancer diagnosis, but they only told us they were looking to rule out leukemia, and we were falsely relieved when that test was negative</li> <li>• Each specialist (orthopedist, infectious disease doc, oncologist) interpreted Simon's presentation within their own specialty: Legg Calve Perthes, bone infection, arthritis, leukemia); it seemed they were not working together to hone in on what they might all be able to agree upon as most likely dx</li> </ul> |

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| <b>Treatment</b>  |  |
|---|--|
| <b>Helpful +</b>  | <b>Detrimental -</b>   |
| <ul style="list-style-type: none"> <li>• In-patient: decorate room with lights, our own pillow cases, conveniences</li> <li>• Ethernet in room to do computer work</li> <li>• Gift bags of good, useful stuff, like the Candlelighters bag at PCMC (hand sanitizer, thank-you notes, etc.)</li> <li>• Books read to patient by walk-about book readers (MSKCC)</li> <li>• Books given to kids by book cart (Mott); Art Cart to swap art on wall of inpatient room (Mott)</li> <li>• Active Child Life program, especially including art projects, as a combo of keeping busy and getting emotional support for all family members</li> <li>• "Choose one" treasure baskets, rather than random gifts</li> <li>• Infusion room/playroom where patients and families can interact and feel surrounded by company</li> <li>• Coffee/breakfast cart!!!</li> <li>• Nintendo, television, videos.</li> <li>• Food delivered to out-patient location for lunch (PCMC).</li> <li>• Elaborate sticker chart during stem cell transplant for every med taken, mouth cleaning, etc.</li> <li>• Doing chemo at home here in Utah (not offered this option in Michigan)</li> <li>• Substantial time in consultation with doctors to understand all treatment options and health issues</li> </ul> <p style="text-align: right;">(continues on next page)</p> | <ul style="list-style-type: none"> <li>• Gift bags full of dumb stuff (i.e., cheap plastic toys like Kids' Meal toys)</li> <li>• Bags full of valentines (clutter hospital room and home, places that are cluttered already with supplies, machines, paperwork, gifts from family/friends)</li> <li>• Cell-like exam/infusion rooms at PCMC</li> <li>• Insistence from doctors and nurses for Simon to cooperate with an exam or a medication, rather than attempts to work creatively around Simon's TV watching or specific preferences about oral medications, etc.</li> <li>• Radiation therapy in separate institution that treats adults more than kids--very unprepared for after-effects of radiation therapy to jaw, especially how to manage mucositis pain in throat.</li> <li>• Poor preparation for flow of radiation therapy--the techs seemed to think it was better not to tell us ahead of time what was going on. As a result, we thought we were done after the first segment, but there were many more to go. Simon always did better with enough time to adjust and comprehend what was going on, rather than being taken by surprise or unawares.</li> <li>• Unpleasant hospital food. Most of the food on Simon's trays remained untouched.</li> <li>• Cafeteria times that cater more to staff than parents.</li> <li>• Lack of Ethernet connection in hospital room</li> <li>• Nurses/docs that turned on light to do routine exams or monitor infusion pumps when we had the room darkened for sleep</li> </ul> <p style="text-align: right;">(continues on next page)</p> |

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| <b>Treatment (continued)</b>  |   |
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| <b>Helpful +</b>  | <b>Detrimental -</b>  |
| <ul style="list-style-type: none"> <li>• Email interaction with all of Simon's main doctors</li> <li>• Possibility to receive a call from on-call doctor quickly</li> <li>• Possibility to page doctor in certain situations</li> <li>• In-patient caregivers that respected night-time and TV-watching by not turning lights on in room and interrupting Simon unnecessarily</li> <li>• Friends to call on to run errands at any time</li> <li>• Microwave ovens, fridge and freezer to store food, basic food items like milk, cereal, juices on inpatient service</li> </ul> | <ul style="list-style-type: none"> <li>• Hospital room bathroom off-limits to parents. Had to leave room and call for someone to stay with Simon.</li> <li>• Often uncomfortable sleeping accommodations for parent in room. Seems an afterthought rather than an intended use. One of the best ways to comfort a sick child is to snuggle up. Maybe pediatric beds need to be wider to allow room for cuddling?</li> </ul> |

| <b>Surgery</b>  |   |
|---|---|
| <b>Helpful +</b>  | <b>Detrimental -</b>  |
| <ul style="list-style-type: none"> <li>• Accompanying Simon into OR until safely asleep under anesthesia</li> <li>• Meeting with surgeon ahead of time (that was our request--it would not otherwise have happened, and I couldn't imagine letting a person I'd never met cut Simon wide open and resect tumors)</li> <li>• Viewing the tumor after removal (also our request--not standard policy)</li> <li>• Receiving digital images of tumor and tumor bed after the surgery</li> <li>• Frequent updates from OR during course of 8-hour surgery</li> <li>• "Breakfast at bedtime" before any NPO morning (usually at home for this)</li> <li>• Propofol as med of choice to go to sleep</li> </ul> | <ul style="list-style-type: none"> <li>• Lack of attention to easing wake-up by using medications like Verset</li> <li>• Improvised recovery room at Sloan Kettering in pediatric day hospital for bone marrow draws—didn't even have a glass of water for Simon to sip or choices in flavors of tylenol</li> </ul> |

| <b>Clinical Trials/Travel for Treatment</b>  |   |
|--|---|
| <b>Helpful +</b>   | <b>Detrimental -</b>  |
| <ul style="list-style-type: none"> <li>• Detailed requests from new hospital for all records needed</li> <li>• Ronald McDonald House in Manhattan</li> <li>• Charitable flights from Southwest Air (very uncomplicated process, available once per calendar year, flew all four of us to Oakland, CA twice)</li> <li>• Oncologists at home hospital that keep up-to-date on all available trials and patient's eligibility</li> <li>• Trust and communication between doctors at multiple treating institutions</li> </ul> | <ul style="list-style-type: none"> <li>• Difficult to adjust to non-pediatric setting (MSKCC, UCSF) where scan techs work more with adults than kids and all equipment is adult oriented--had to advocate for measures to keep Simon entertained while lying still, rather than expecting hospital to know how to work with kids</li> <li>• Very difficult to keep medical record continuum with multiple hospitals involved, even when we hand carried radiology films and reports back to home hospital. E.g., a very scary incident when a new head CT was compared with most recent institutional CT (2 months old) rather than CT from outside institution performed two weeks prior. Initial report was that there had been substantial tumor growth in interval, when in fact there had been some decrease after salvage chemo</li> <li>• Inappropriate joke by doctor about jaw pain. Simon told a new doctor that he had a tingly pain in his jaw. She looked at him and said, "I think it's serious!" Then she laughed and said she was kidding. Later we learned the sensation came from a rapidly growing tumor in the mandible. Not funny.</li> <li>• Lack of trust among hospitals: MSKCC insisted on doing all scans and tests themselves, even if recent studies from another hospital were available.</li> <li>• Technology not standardized among hospitals. Difficulty exchanging digital records (scans, etc.); measurements not the same (serum LDH different at different places); blood draw methods (finger stick vs. draw from line); urine collection for catecholamine levels (24-hour vs. single sample)</li> <li>• Disappointing results from clinical trials, including the very difficult treatment-emergent onset of ITP</li> </ul> |

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| <b>End of Life</b>  |   |
|---|---|
| <b>Helpful +</b>  | <b>Detrimental -</b>  |
| <ul style="list-style-type: none"> <li>• Book to prepare for end-of-life: <i>Shelter from the Storm: Caring for a Child with a Life-Threatening Condition</i> by Joanne Hilden, et al (ISBN 0-7382-0534-6). Book to think about death (with a child): <i>The Death Book</i> by Pernilla Stafelt (ISBN 0-88899-482-6). Book on bereavement (kids and adults): <i>Tear Soup: A Recipe for Healing After Loss</i> by Pat Schweibert and Chuck DeKlyen (ISBN 0-9615197-6-2).</li> <li>• House call by oncologist during last few days of life offered great comfort and reassurance about what was going on with Simon as he suffered and slowly shut down</li> <li>• Pediatric palliative care/oncologist friend in another state who consulted regularly with us by phone</li> <li>• Meeting with home care company, PCMC staff, and both parents to set course for palliative care about 7 weeks before Simon died (our request)</li> <li>• Practical advice to manage end-of-life situations: get dark maroon sheets to have on hand in case bleeding becomes an issue (we were able to return our sheets unused, but felt less fearful of this eventuality)</li> <li>• Now receiving newsletters from bereavement programs at four hospitals (pediatric orientation much than general materials that relate to adults)</li> <li>• Getting support from PCMC and homecare for finding the right comfort measures (e.g., locating a non-stick dressing supply to put next to Simon's eyes so discharge would not adhere to pillow case). We would describe our concern, like the discharge, and the team would come up with a way to address it. Aggressive palliative care can be very low-tech.</li> <li>• Bereavement group specifically for parents who have lost a child who is a minor, and a group for siblings.</li> </ul> | <ul style="list-style-type: none"> <li>• Called PCMC early in July to get help from on-call doctor. Connected with new resident. Asked, "Are you familiar with the case of Simon Vodosek?" The doctors said, "No." It is not fair to have to explain that your child is now dying after nearly three years in treatment. The team should be well informed about end-of-life cases.</li> <li>• Primary doctor was out of town during two critical weeks of Simon's end-of-life care. Both times we needed to work hard to feel continuity of care.</li> <li>• Two months after Simon's death, I had a billing department in New York ask me, "How's he doing?" I had informed our treatment team there and requested that the information be shared with all pertinent hospital staff and functions. I think that should include making the billing office aware that the patient has died.</li> <li>• Bereavement group for Simon's sister at our hospital included children who were mourning the loss of a parent. We were unprepared for the fact that our 5-year-old daughter would encounter the idea of parent suicide as she worked to face her grief about losing her big brother.</li> <li>• Sudden switch to homecare and no longer having face-to-face contact with trusted medical team from hospital. We bridged this gap by requesting a house call by Simon's oncologist a few days before he died. More contact, at home, would be so wonderful.</li> </ul> |

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| <b>Throughout the process</b>   |  |
|---|--|
| <b>Helpful +</b>  | <b>Detrimental -</b>   |
| <ul style="list-style-type: none"> <li>• Living very close to top-quality cancer treatment hospital with excellent pediatric care (University of Michigan and PCMC--both under 10 minutes from our homes)</li> <li>• Email contact possible with doctors, social workers, nurses</li> <li>• Occasionally direct-paging the doctor</li> <li>• Hearing results as soon as available--we so appreciate those 8:00 pm phone calls from the doctor with news of what the tests show</li> <li>• Excellent rapport with medical team to allow frank discussion</li> <li>• Doctors who draw pictures of what's going on inside the body, how a medication works, etc.</li> <li>• Web site as tool to communicate about Simon to family and friends (<a href="http://www.simonsplace.org">www.simonsplace.org</a>)</li> <li>• ACOR* listserv for neuroblastoma families (467 subscribers, some M.D.s)</li> <li>• Food delivery and errand runners from family, friends, church, neighborhood</li> <li>• Excellent health insurance coverage with minimal burden on us to pay out of pocket (even if parts if it required diligence and fighting denied claims)</li> <li>• Help from family, especially grandparents.</li> <li>• Simon's amazing attitude and the delightful company he was.</li> </ul> <p>* ACOR is the Association of Online Cancer Resources, <a href="http://www.acor.org">www.acor.org</a></p> | <ul style="list-style-type: none"> <li>• Reliance on one primary oncologist for advice, help, treatment. When doctor is unavailable (vacation, conference, holiday), family scrambles to keep up on medical needs. Buddy-system (somewhat like our experience in Michigan with oncologist Mody and BMT doc Yanik) is helpful.</li> <li>• Unholistic view of Simon's needs (e.g., treatment for ITP and seeming neglect of neuroblastoma when we first arrived at PCMC)</li> <li>• Transfer of care between Mott and PCMC should have been better prepared. Situation was very complex, and our intended new oncologist had just left PCMC. We were unable to manage transfer effectively with all our other stuff (move to Utah, ITP, etc.) New doctors needed to interface more effectively with Simon's doctors in Michigan who knew him well, but they dropped contact very quickly.</li> <li>• Insurance/hospital billing confusing and inconsistent, especially with several different treating institutions and/or hospitals that use a lot of subcontracted providers that bill separately. Time consuming. Trails on into bereavement.</li> <li>• We were so unprepared for this journey. An information session at the outset about possible scenarios for the foreseeable time of treatment would have been helpful, e.g., a dressing change every three days, an in-patient stay for a couple of days every 3 or 4 weeks likely after each chemo; etc. On the other hand, we were trying to absorb so much information at diagnosis that perhaps we got this orientation and don't realize it.</li> </ul> |