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PALLIATIVE CARE CASE OF THE MONTH

With News from the Institute

Resolving Family End of Life Conflicts in a Dying Pediatric Patient

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Case: D.S. was a 41 month old male born with Hypoplastic left heart syndrome. He underwent three heart surgeries before he turned two-years-old. For the first two heart surgeries he was discharged to home after an appropriate hospital stay. After his third procedure, D.S.'s condition began to decline. In June of 2009 a gastric tube was placed. He subsequently developed respiratory distress and a tracheotomy was performed and he was placed on ventilator support. Over the next year D.S. remained hospitalized and battled recurrent infections, blood clots, seizures, cerebral fluid buildup, along with complications of a long hospital stay. In late August 2009 his biological mother relinquished her parental rights to the maternal grandfather, who became the medical POA, as she had substance abuse problems and was to enter into rehab. The biological father was incarcerated at the time and he had relinquished parental rights. In July of 2010 a new court order was obtained stating the maternal grandmother now had all parental rights and medical POA as she and the maternal grandfather were living apart. D.S. was discharged to his maternal grandmother's home with ventilator support, enteral feedings and 16 hour a day nursing service. He returned to the hospital 18 hours later with complaint of increased agitation and back arching "spells." He stayed in the hospital another two weeks to adjust his medications. During this time a family meeting was held where medical team informed the family that nothing else medical could be done. We were asked to assist in his home care from a palliative point of view with the goal of preventing multiple re-hospitalizations for problems that could be corrected at home.

He was admitted to our palliative home care program. From the first visit goals of care were discussed with his maternal grandmother, the medical POA. Over the next couple of home visits she stated that she did not want D.S. sent back to the hospital. This led to the discussion of the conflict in code status versus stated wishes. The POA was instructed that with private duty nurses in the home and D.S.'s code status a full code, the nurses must send him back to the hospital anytime his condition warranted it. The POA then, with full understanding of the implications, changed his code status to CMO.

The next home visit was a meeting with the biological mother and father where we continued the discussion of code status and the patient's condition. During the time between visits D.S. had required around the clock dosing of prn benzodiazapams for his tonic / clonic seizure activity. Both the mother and father where distraught at the changes in his condition, and the use of medications to control the seizure activity. D.S.'s mother made the statement that her child was no longer interactive with the family and maybe it was time to consider removal from ventilator support. The father at this time was against the idea. Two days later on the next visit both the biological mother and grandmother were present. Given that D.S. was now non-responsive the discussion turned to removal of life support. They were instructed that this was a non-reversible decision and it needs to be discussed with the rest of the family, especially the biological father. They asked about the legality of such a decision, and were instructed that it was in their legal right to remove him from life support. Our social worker and clergy were called to assist the family with their conflict. Two days later a phone call was received from the biological father stating that the entire family was in agreement that D.S. should be removed from ventilator support. The medical care team was called and orders obtained to do so, as were orders for opiates. A home visit was made and the family were instructed on the possible outcomes could be, from immediate cessation of respirations to spontaneous respirations that may continue for quite some time. D.S. was removed from ventilator support and died 3 hours later with his family holding him in their arms.

Discussion: When dealing with dying children it is important to take into account the multiple conflicts that occur, from caregiver guilt, to the cultural, ethical and legal consequences of any decisions made. For this family one of the underlying conflicts was a concern that they could somehow get into "trouble" by removing life support. This concern came up in the many discussions with family members. It was also important for them to maintain a relationship with the child (1). Even though he had spent most of his short life in the hospital, the mother was still his mother and his father his father.

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Also important for them was for D.S. die with all of them present in his home (2). We also used our interdisciplinary team to assist the family in resolving their conflicts. Our MSW assisted in help with the final arraignments for D.S. and our clergy helped with their moral conflict. In conclusion with open communication with all members of the family by the interdisciplinary team, in a setting that was non-threatening, and inclusive of all concerns, they were able to come to the realization that D.S.'s medical care had been optimized and he was no longer suffering for life, but now was suffering toward his death.

References:

1. Klass D. The Spiritual Lives of Bereaved Parents. Philadelphia: Taylor and Francis; 1999
2. Sarniak AP. A Student a Nun and a Professor. Pediatric Crit Care Med 2001; 1:176-178

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Lyndley Maddox Receives the 2010 Amdur Fellowship


Lyndley Maddox, recipient of the 2010 Amdur Fellowship

Lyndley Maddox received the Amdur Fellowship this summer. The Amdur Fellowship in Palliative Care provides an intensive, one-month internship in palliative care social work under the guidance of one of the nation's leading academic palliative care programs. Designed for graduate level social work students with prior hospital experience who would like to consider professional specialization in palliative care. Lyndley worked with the Department of Supportive and Palliative Care for the month of July. Throughout the month she was able to work side by side with Charlene Amato, worked with the social workers at the Department of Medical Ethics at UPMC Shadyside, and was able to spend a week at Family Hospice's Center for Compassionate Care and making hospice home visits with a social worker at Family Hospice. Throughout the fellowship Lyndley learned that palliative and hospice social work can be one of the hardest, yet most fulfilling careers. Lyndley is currently in her last semester at the University of Pittsburgh Graduate School of Social Work. She would like to pursue in hospital or hospice social work.

The Institute Welcomes Lori Spahr

Lori Spahr joined the Section of Palliative Care and Medical Ethics as an Administrative Assistant. She earned an Associates Degree in Information Processing from the Monroeville School of Business. Lori has over 17 years of administrative experience. She recently worked for West Penn Allegheny Health System as an Executive Assistant in the Finance area. Lori will be responsible for Dr. Robert Arnold's Communication Skills Retreat planning and administrative support for the Section.

Jamie Uy Receives the 2010 Gleitsman Award


Jamie Uy, recipient of the 2010 Gleitsman Award

Jamie Uy received the Alan Gleitsman Student Research Fund in Palliative Care, which provides financial support for a medical student's summer learning in the Palliative Care Program. Students may, for example, work with faculty of the Institute to Enhance Palliative Care on a research project, and/or see hospital patients with the Palliative Care Team in the hospital to gain a better understanding of the nature of palliative care, the therapies associated with it, and the benefits it can provide to patients and families. All medical students at The University of Pittsburgh are eligible to apply for support from the Alan Gleitsman Student Research Fund in Palliative Care. While students typically have the most flexibility for summer projects between their first and second year, more senior students who are devoting elective time to their Scholarly Projects should also consider an application. Jamie is a second year medical student at the University of Pittsburgh. Originally from Princeton, NJ, she obtained her undergraduate degree in Finance and International Business at New York University. After a year working in finance, she decided that medicine was her true calling and began the process of applying to medical school. This past summer she worked with Dr. Amber Barnato studying the nature of physician involvement in end-of-life decision making. By analyzing recorded stimulated encounters between physicians and a standardized patient with end-stage cancer, physicians were categorized into four distinct roles: informative, facilitative, collaborative and directive, based on their level of involvement in end-of-life decisions.