

Family Centered Care and Theraplay Services in a Pediatric Intensive Care Unit
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Jimie was a 5 year old diagnosed with serious congenital heart disease. He underwent three cardiac surgeries before he was three, involving multiple, lengthy hospitalizations and separation from his parents. He also experienced seizures and displayed a mild developmental delay. Jimie had a 2 ½ year old brother also with a cardiac condition and his mother was pregnant. His parents reported significant financial and marital stressors related to these chronic medical issues, demands on their time with work and other children and distance to the hospital.

Jimie was admitted to our university hospital with worsening heart failure in September 2008 and I was his care coordinator. He was placed on the heart transplant list with a high priority designation. He was noted to have several behavioral issues including refusal of food and medication, spitting, screaming, swearing, and hitting. A psychology consultation resulted in a diagnosis of disruptive behavior disorder and feeding difficulties; recommendations included using a picture schedule and the suggestion that Jimie be allowed to do preferred activities when he had completed non-preferred activities. Jimie's mother initially refused behavioral intervention as she believed the problems would resolve when he returned home. After stabilizing Jimie's medical status and assisting his parents to secure local housing, our team agreed to allow Jimie to wait for his heart transplant at home with his family. I arranged home nursing care, and Jimie was discharged after five weeks of hospitalization.

Two days later Jimie was readmitted with new medical problems and it was eventually determined he would wait in the hospital for his heart. Jimie's behavior problems worsened. A family member reported that he had always been demanding and would bite and kick his mother if he did not get his way. Now he screamed at and occasionally kicked the nurses. Jimie's parents also acknowledged that his behavior had deteriorated. A psychiatric evaluation resulted in a diagnosis of adjustment disorder with anxiety; recommendations were for high structure, routine, firm boundaries and consistency to make Jimie feel more secure. There was an improvement in Jimie's behavior until February when his baby brother was born. Jimie again yelled and swore in an attempt to gain his mother's attention and displayed more aggression when frustrated. Another psychological evaluation found disruptive behavior disorder. Additional rules were set up about informing Jimie of his family's plan for visiting; responsibilities of the family and nursing staff were outlined and posted. It was recommended that if Jimie was inappropriate, the staff should ignore him until he engaged appropriately or completed whatever task he was attempting. This was particularly difficult for our nursing staff. They often took the behavior personally and utilized time outs frequently. Sometimes Jimie was in time out most of the day. I spoke to the staff about the difference between being neutral and punitive and suggested periodically reminding Jimie what he was supposed to do during the time out. Another positive technique was to play with Jimie for 2-5 minutes, warn him of the ending of the play time, remind him to ask to "play please," and to play again as soon as he requested this calmly.

In June 2009, Jimie's little brother accidentally damaged Jimie's heart assist device. Jimie reacted to the incident with extreme anxiety and fear. His behavior worsened significantly; he became even angrier with his mother and was less interested in activities that he used to enjoy. Depressive disorder was added to Jimie's diagnosis; the staff also wondered if he was developing an attachment disorder. Our mental health team recognized that Jimie was a bright, inquisitive child who understood a great deal about his condition and what was happening to him. They felt that his behavioral issues may have been a reaction to family deterioration. The transplant team and family opted not to pursue the suggested medication trial. I discussed treatment options with the family; they decided they wanted to try a hands-on therapeutic approach.

Jimie had been hospitalized for almost nine months when we began Theraplay treatment. We completed the Marschak Interaction Method (MIM) assessments of parent-child interaction and held separate feedback sessions due to the parents' difficult schedules. In my discussion with dad, I explained that the goal of our therapy sessions would not be to modify Jimie's behavior, but rather to address Jimie's current unmet emotional needs, to help him feel more deeply connected to his parents and key caregivers and to help him express his fears, needs and wants. I indicated that we could expect an improvement in Jimie's behavior if he realized that his emotional needs could be met by dependable adults in a safe and structured environment.

During her feedback session Jimie's mother cried and said she was overwhelmed by being away from home, moving, and the expectation that she stay overnight in Jimie's room. I shared positive feedback about the attuned behaviors she demonstrated in the MIM and the many ways that she and Jimie

showed that they loved each other. There were elements of insecure attachment, there was medical trauma and there were circumstances (hospitalizations, siblings, marital problems, mental health issues, environmental instability) that interrupted their ability to maintain a healthy relationship. Despite Jimmie's many instances of aggression towards her, his mother did not allow this to stop her from interacting with him. His mother did not want to pursue individual therapy at that time, but I felt she would gain some therapeutic benefit from participation in Theraplay.

We scheduled a team meeting to discuss handling Jimmie's behavior. The past behavioral recommendations did not support time out, but, rather, temporary withdrawal of attention until Jimmie could make an appropriate request. During tantrums, I advised removal of attention or avoidance of eye contact while monitoring him to make sure he was safe. Swearing or other inappropriate language was to be ignored. I developed handouts to introduce the Theraplay®, strategies I would use during treatment sessions. We put together a binder that included a list of Jimmie's "jobs" (brushing teeth, taking medications, allowing vital signs). I offered to provide on-going staff support for consistent handling of his problem behaviors. The staff was encouraged not to use punitive responses, i.e., once a problem behavior was over and appropriate natural consequences had occurred, it was not to be mentioned again nor was Jimmie expected to apologize for his outbursts.

We started Theraplay in July 2009. Jimmie's mother was unable to be there because she had to move. The unpredictable availability of parents was very disruptive to Jimmie's emotional status. I had invited the PICU social worker to assist me. Jimmie was initially excited to see us, but quickly became uncooperative. It was obvious that he was disappointed that his mom was not present. He swore and moved to the top of his bed and kicked at me with his feet. Eventually I was able to get him to engage with lotion prints of his foot. We talked about when he was a baby, prints that would have been done at the hospital, and how little he was as a baby. He displayed good eye contact and interest. We did the newspaper punch and Jimmie was very proud that he was able to punch through 5 pieces successfully. Jimmie tried to control the interaction by suggesting different ways to play a game or verbal refusals, but we worked through this.

I met again with his team to discuss avoidance of time outs. I offered to provide support to nursing staff during difficult routines such as tooth brushing or taking medication. Bedtimes were problematic because there was not a clear plan as to whether or how long the parents would stay. Jimmie often woke afraid or lonely and wanted to call his parents. He began to wet his bed at night. I met with mother again to review the plan for more predictable daily parental involvement. Also, one parent was expected to be present for Theraplay sessions.

Prior to the second Theraplay session, I met with father to prepare him for activities and to cue him to follow my lead, especially in regard to any aggression or resistance. Jimmie was excited to have his father in the session, but then demonstrated significant difficulty with the initial nurture task. It appeared that gentle and nurturing tactile activities made him uncomfortable. He withdrew, used inappropriate language and became physically aggressive. We acknowledged his discomfort and worked on using words rather than actions to express dislike of an activity. His father appeared embarrassed and angered by the behavior and found it difficult to not intervene physically. I assured him that I would handle it. I wanted to communicate to Jimmie that there would be no negative consequences and that when the behavior was over, it was over. Jimmie asked what would happen if mom and dad couldn't come to a session. Dad replied, "Oh I think one of us will be here every Monday." Following the session Jimmie was calm and wanted to continue to interact with his dad and me despite earlier telling us he hated us and he was never going to play with us again.

Father was supposed to participate in the third session, but was not there when it was time to start. Jimmie was eager and cooperative with activities. He attempted to negotiate certain parts of each activity, but responded well to structure. Father arrived on the unit a half hour later but chose not to participate in the session. When Jimmie saw his father, his face lit up, but then his father walked away. Jimmie continued to participate in play but demonstrated increased resistance. However, Jimmie already showed an increase in compliance with daily "jobs" of taking meds, vitals, brushing teeth. The PICU staff also reported improvements in Jimmie's mood and interactions.

Jimmie's father was not present again at the fourth session. Jimmie participated well in activities. He was better able to accept nurture and was very interactive and talkative. He still attempted to change activities quickly, probably due to emotional discomfort with engagement and nurture and also due to reduced attention span. There was no swearing or aggression the entire session.

At the fifth session, neither parent was present again. Nurture tasks were becoming easier for Jimmie and he accepted lotion on his feet. Jimmie enjoyed being wrapped up and swung in the blanket while we

sang; he even wanted the social worker and me to have turns. He thought it was funny that neither of us could be picked up, but we pretended to swing. Jimmie had demonstrated significant difficulty with touch, nurture and structure in the past sessions but he continued to show improvements in his ability to integrate all of these dynamics. After our session, his RN appeared with his medications. He initially said he wouldn't take them, but I suggested if he took them quickly he would be able to have computer time. He took both of the meds in less than a second and grinned at me.

Jimmie was beginning to integrate more positive interactions and behaviors to his life on the unit. Our staff shifted their focus to presenting positive reinforcers instead of negative consequences and all staff noticed a reduction of problematic behaviors. He would yell at anyone who passed by his room "Hey, can you play?" He supervised housekeeping on how he would like his room cleaned. He came up with a few suggestions for cardiothoracic surgery team on how they might do things differently with wound care.

Jimmie's father came to the sixth Theraplay session. There were some really nice interactions between Jimmie and his dad; they leaned against each other, whispered that they loved each other and looked at each other closely. Jimmie usually became anxious when asked to do unfamiliar tasks, especially gross motor tasks which he perceived as risky. I tried to expose Jimmie to activities that physically challenged him a bit to show him that he could be successful in new situations, to decrease his anxiety, and to learn to trust and lean on adults for comfort and support. Jimmie loved the blanket swing in the previous session, so we showed it to his father. Father appeared to really enjoy watching Jimmie swing, smile and giggle while in the blanket. Then Jimmie wanted his dad to take a turn. Father initially refused, but I instructed him to go ahead and lay down and we would find a way to swing him. Jimmie LOVED watching dad rock in the blanket. Jimmie was less physical in his resistance today. He also tried to verbally negotiate before he resorted to swearing. We again reassured him that we were not leaving him when he was having such a difficult time and that we would keep him safe.

At a parent conference with father we discussed the Jimmie's status. The father reported significant improvements over the past three weeks, which coincided with what we observed in the Theraplay sessions. His father was concerned about the transition after hospitalization. We discussed the possibility of continuing therapy sessions as an outpatient and stressed the importance of his participation in future sessions as he will be the consistent person who will be present for Jimmie.

Mother was present at the seventh Theraplay session. Jimmie was having a difficult day and refusing most requests. When I entered the room he was on his bed and informed me that he wouldn't participate in our session unless his mother left. I reminded him how excited he had been when we completed the play assessment with his mother and said I was excited to play with him and his mother. Jimmie agreed he would play if his mother carried him to his spot. I prompted mother to come pick Jimmie up and carry him to his spot, and they sat together on the floor. Jimmie became very excited and asked to do several activities we had completed in the past. It was obvious he wanted to engage with his mother. He sat touching her or on her lap. Mother was very playful, but had more difficulty being nurturing. We worked on regulation through activities which alternate stimulation, challenge and engagement with tasks that are more calming and nurturing. Jimmie readily accepted lotion on his feet, arms, and back and was no longer anxious or resistant with touch. We completed a lotion/powder print of Jimmie's feet and talked about how this would compare to when he was a baby. Mother said she had a picture of Jimmie's feet from when he was a baby and that she would bring this to the hospital. I asked mother to share some stories about when Jimmie was an infant and she recalled several memories. She talked about some of the photographs hanging in the room and brought out several more. Jimmie really enjoyed looking at the photos and hearing the stories that went with them. He sat on his mom's lap and would reach for her, and hug her periodically. We completed a game of passing a nice touch or sound around the circle. We read a book together called "Owl Babies" about maternal separation; for the first time Jimmie was calm during the mention of difficult feelings. Jimmie wanted to show his mom the blanket swing. He delighted in swinging but also wanted his mother to experience it. He lay on top of her and they giggled about how silly it was since we couldn't actually lift them off the floor. At the end of the session, Jimmie jumped up off his mat and fell. I caught his head but his leg twisted and he began to cry. He appropriately sought comfort from his mother.

We missed a week of therapy due to a holiday. The staff reported that during this time, Jimmie was less compliant and displayed more swearing and other inappropriate language. They also said he was less energetic. I apologized to Jimmie for missing our regular session and indicated we would be back on our regular schedule. Jimmie was excited about the session. He was very calm, interacted appropriately, accepted nurture, engaged in all play activities and readily accepted new tasks. He was able to state his

preferences when he was uncomfortable with a task and he delighted in repeating preferred activities. His father was present and was relaxed, attentive and nurturing.

Jimmie was really excited at the beginning of session nine, but became fussy and refused lotion for the hand stack. The adults repeated the activity a few times and eventually Jimmie decided he was missing out on the fun and joined us. I introduced the toilet paper wrap up and bust out. He stood still while we wrapped him up, grinning from ear to ear. Jimmie wanted to wrap up his father. His dad agreed although he was less than thrilled. Father was increasingly gentle with Jimmie. He also appeared to be more comfortable with some of his own issues with sensory input, touch and being vulnerable. I allowed Jimmie to pick the final activity. He chose the blanket swing and to blow kisses to his dad as his signal to stop and start. We saw some nice carry over from session to session; episodes of resistance and aggression had lessened over time.

Jimmie was approaching the one year anniversary of his hospitalization and his 6th birthday. He was not feeling well and we postponed his regularly scheduled Theraplay session. His blood contained yeast, and he was placed on the inactive transplant list until the fungal infection was gone. Unfortunately his medical condition continued to worsen. He experienced a cerebellar bleed and emergency brain surgery. After several weeks of an increasingly unstable and worsening condition, Jimmie's parents met with cardiology and pediatric intensive staff and decided to withdraw his life support. I was called at home and went into the hospital to sit with Jimmie, and share stories with the family. Jimmie passed away on Halloween, one of his favorite holidays.

On what would have been Jimmie's 6th birthday, the staff celebrated by gathering on the rooftop of the hospital to share our memories, including his love of superheroes. He believed Superman could fly and Spiderman could sling webs. In honor of his life, a large Spiderman balloon was released followed by individual balloons with a special note of remembrance from each of us whose lives were touched by him.

In the end I felt there had been a shift in our staff--something that occurred subtly over time. A child who once had exhausted and exasperated so many became a teacher of patience and determination. We learned to accept and love him because of his spirit, will to fight, and the way in which he manipulated and controlled his environment to insure his survival.

The balloons flew off to the northwest and we watched as they disappeared from sight. We wait to see if a memory note is brought back to us by someone who has found our balloon in some distant place. We wait for Jimmie to come back to us if only for a moment. He was a part of our family and I believe we were a part of his.