



USING ORAL HISTORY FOR PATIENT EDUCATION: THE GIFT OF EXPERIENCE II: CONVERSATIONS WITH PARENTS ABOUT HEMOPHILIA

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Goal:

To provide a book that illustrates, through oral histories, the challenges and strategies of parenting a young child with hemophilia. The book describes a community of parents that share similar challenges who give their gift of experience, knowledge, understanding and encouragement to families with a newly diagnosed child.

Objectives:

- Utilize oral history to educate, empower and guide newly diagnosed families.
- Provide insight into the emotional, financial, medical, social, educational and spiritual challenges that families confront.
- Validate feelings and reactions to living with hemophilia from diagnosis to age 6.

Parent Interviewees:

- Parents of children with hemophilia A or B, ages 4-12 receiving care at the Boston Hemophilia Center with:
 - Diverse ethnic and socio-economic backgrounds
 - Children with range of severity
 - Children with and without inhibitors
 - Family history or previously unknown mutations

Approach:

- Developed an interview guideline and scheduled interviews with 18 parent volunteers.
- Enabled families to share a highly emotional and deeply personal story by:
 - Giving parents a choice of location for the interview
 - Offering option of anonymity to maintain privacy
 - Providing families with editorial control and final approval
- Captured, recorded and transcribed oral history for 19 interviewees.
- Extracted and organized quotations from transcripts and sent to interviewee for review, editing and approval.
- Requested photographs to further document the family story.
- Obtained signed authorization for use and release of information and images.
- Publish book (expected release fall of 2014).



I had to really educate myself and take charge of my child's healthcare. I couldn't assume that the doctors know best necessarily. I had to be an advocate and obviously I'm not sure of everything but for the things that I am sure of, I make sure that message gets across. I've realized that doctors are human and some of them know more about one thing and others know more about other things.

—Ann-Grete

When he was first diagnosed I felt very sad that my perfect baby wasn't perfect and that the defect was because of me. I felt guilty. I just felt like I was personally inflicting pain and suffering on my child and that was terrible. I don't know how you ever fully get over that feeling but it definitely gets less and less.

—Christine



I really think that getting involved in the community is very helpful because you will find the support you need to really get through tough times. It's a unique group of people and no matter where you come from, whether you're an introvert, an extrovert, from the U.S. or from any other country, this community has a lot to offer and it embraces everybody that comes into this world of hemophilia. Being part of the community truly helped us manage and almost enjoy hemophilia. It has become a much bigger part of our lives and it's actually something that we don't completely hate. I never thought I would have said that.

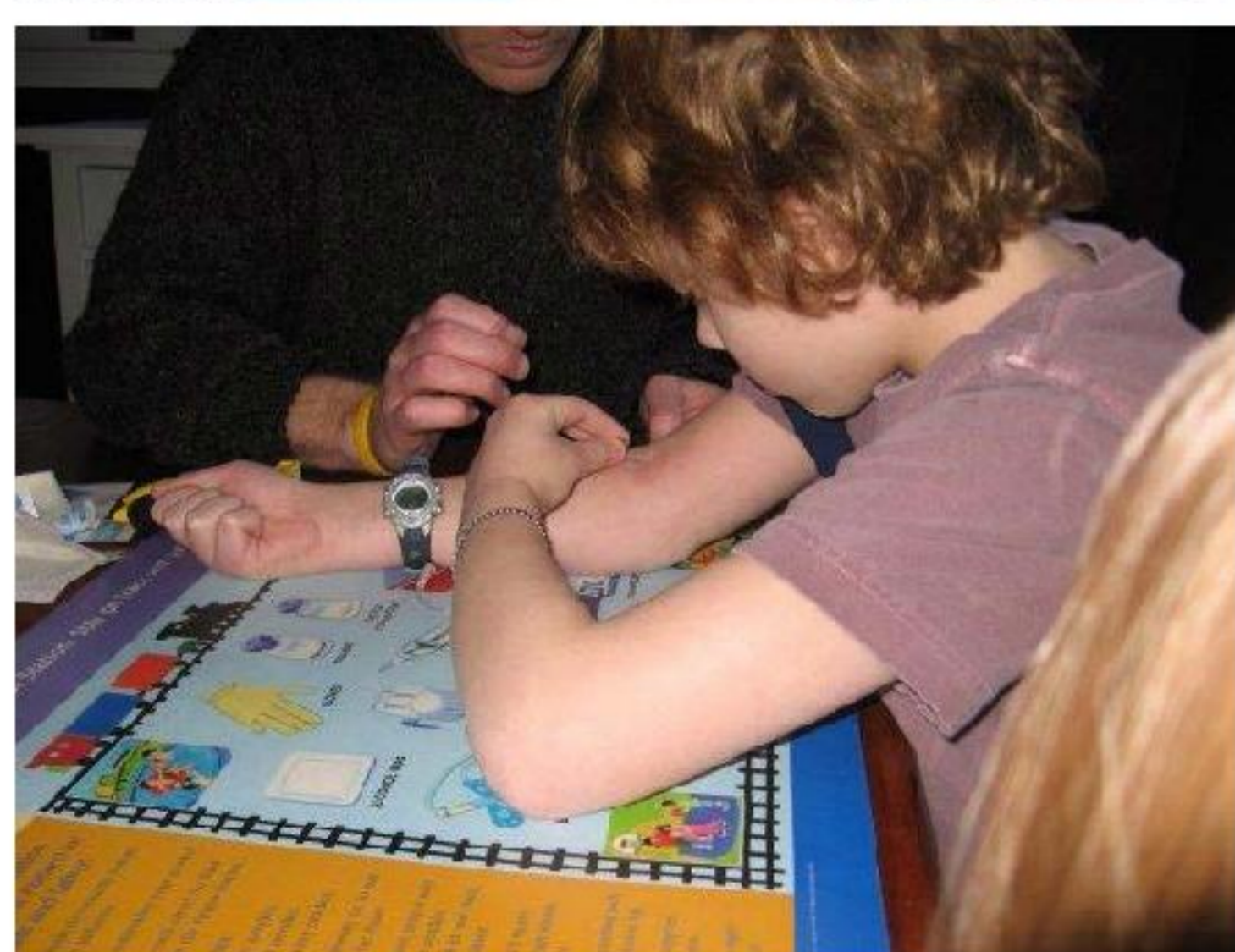
—Carolina

If you have a child who needs special care then you're being trusted with something special. Having a disease is a chance to be closer to God.

—Xavier

Someone once said to me and I don't know who it was and I don't know the exact wording but the idea was that parents of regular kids have to keep their kids safe for them to grow up normal. Parents of hemophiliacs have to let their kids get hurt for them to grow up normal.

—Patti



Observations:

- Storytelling is empowering and therapeutic for the interviewees.
- Interviewees were motivated to help newly diagnosed families
- Interviewees uniformly presented hope and encouragement while acknowledging stressors and challenges
- Knowledge and new skills build self-esteem, empowering to all participants
- Family history of hemophilia affects treatment decisions and trust in health providers
- Home infusion nurses' presence could be initially intrusive, but provided essential emotional comfort through friendship
- Bleeding disorder community support and friendships described as being a benefit of hemophilia
- Mild families often still relied on others to infuse, often not as secure in decisions about treatment.
- Experiences are similar and parents follow parallel stages from diagnosis to "new normal"
- Shock and upset
- Anxiety, anger, helplessness, isolation
- Early acquisition of resources and knowledge
- Emotional readiness to move forward to mastery of: skill building (incl. infusions), education, ownership of care, advocacy, connection with community
- Competence in assessment of treatment needs
- Ability to advocate for child's needs
- Recognition and pride in newly learned skills
- Sense of well-being, having achieved a "new normal"
- "New normal" incorporates, but does not revolve around hemophilia



When Lucas was 15 months I went to the local hemophilia association. They had their annual festival and that helped me a whole lot. It showed me that even if I put him in a bubble, he could still have a hematoma and even if I prohibit him from running, he could still have a joint bleed. So I told myself Rosaura you need to relax. Your stress is being passed on to him. My stress about his running is hampering his growing up a normal kid.

—Rosaura



Moms are supposed to kiss the boo-boos and make the hurt go away, but I couldn't do that with him. When the infusion nurse taught us about infusions, I felt calm. I felt that, OK, so if Ken and I can't kiss the boo-boos away, we could most definitely help with treatment. We learned about the different veins, what a joint would look like and what the joint would feel like when he has a bleed.

—Jen

I know there are some people who know ahead of time so they're kind of prepared for it. If you're not prepared for it, it's craziness, everything kind of falls apart. When you go in to have a baby, you think you're going to bring home a healthy baby and your life's going to be perfect or normal. And then, oh, no, that's gone now. You're not having normal anymore. You have a new normal.

—Jackie



Conclusions:

- Hemophilia Treatment Center, home care nurses and community are equally important, and provide complementary roles in supporting families
- Empowering families to be essential members of the medical team, fosters trust, sense of agency and competence
- Education, support, peer mentorship help families' cope and develop skills that lead to a "new normal"

three essential partners: supporting families to a new normal

Hemophilia Treatment Center (HTC):

- Offers primary medical support for hemophilia
- Lays foundation for ongoing education, medical and emotional care, collaborative treatment planning
- Establishes connection to home infusion nurses
- Aids in building relationships with community organizations and other families
- Empowers and supports independence

Home Infusion Nurses:

- Builds on HTC's approach to care
- Reinforces education provided by HTC
- Provides detailed instructions, hands-on experience in environment close conducive to learning
- Provides emotional and treatment support for child/family at home, in school
- Builds relationships with other families
- Encourages new skills
- Supports independence

Community:

- Supports teaching, reinforces relationship with HTC and home infusion nurses
- Normalizes emotions, experiences and models "new normal" way of life
- Offers formal learning opportunities, peer to peer mentoring, learning from others' experiences, developing skills
- Provides a sense of belonging to an expanded family that is united, supportive, non-judgmental and accepts them
- Celebrates successes
- Encourages avenue for emotional support for the entire family
- Empowers family to live life with hemophilia, not centered on hemophilia

Recommendations:

- Hemophilia Treatment Center, home infusion nurses and community should think strategically about how to work together
- Identify how parents learn, what they are ready to learn, and where they are best able to learn (learning styles and the priorities of individual parent)
- Support is needed to help families in establishing connections and engaging with other families and community resources
- Annual home visits over the first 4 years from Hemophilia Treatment Center member recommended for patients to "tell their story" as a way to identify strengths, needs, progress, challenges, interventions and referrals

Acknowledgment:

We wish to thank those who mustered the courage to tell their story, offering a gift to help newly diagnosed families.

