APPD 2017 Workshop 32
Friday, April 7 1:15-3:15pm

Not Just at the Bedside: Harnessing the Power of the Patient and Family Voice in Pediatric Educational Activities Outside of the Clinical Care Environment
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Abstract:
Understanding the patient and family perspective and communicating effectively with families underlie many of the pediatric milestones and sub-competencies within interpersonal and communication skills, professionalism and systems-based practice, and are integral to the practice of pediatrics. Training programs are, in fact, tasked by the ACMGE (1) with assuring that trainees “communicate effectively with patients, families, and the public, as appropriate, across a broad range of socioeconomic and cultural backgrounds” and “demonstrate the insight and understanding into emotion and human response to emotion that allows one to appropriately develop and manage human interactions.” With a growing national focus on Patient-Centered Care and the Patient-Centered Medical Home, residents and fellows are actively engaged in communicating and partnering with patients and families.

There is, however, a golden opportunity for trainees to learn from patient families outside of the clinical care delivery system that is often underutilized. Utilizing the voices and experiences of patients and families as catalysts for learning, can be incredibly powerful for adult learners. Telling their story also allows families to create meaning of a child’s illness, since, as Charon (2) writes, “much of the telling of self is critical, formative and transformative”.

In this workshop, participants will first identify barriers to involving patient families as educators, and then work to identify ways to overcome those barriers. There are many ways in which patients can be involved in educational experiences and examples of using the patient family voice through written narrative, formal presentations, patient-provider co-facilitation and videos will be discussed. We will then work in small groups to create outlines for implementing patient family educational opportunities in your home institutions.
While we welcome you to use our materials, and we would really love to collaborate with you further. Please contact us at:

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Hearing Patient and Family Stories:  
Paving the Way for Trainees to Receive the Gift of Listening  

Susan Hata, MD

Residents and students are at a unique point as human beings. They are in a training period unlike any other profession, in which they are allowed into the most intimate moments of a family’s experience, and yet they find themselves in these sacred moments as learners, not experts.

In some ways, they are still anchored in the compassionate ideals that drew them to medicine. The current generation of housestaff tends to have an acute sense of social justice, and a great desire to respect patients and families. (This is a strength of the millennial generation.)

And yet, in other ways, their day-to-day demands of work and sleeplessness, and the sheer volume of patients they see every day can cause them to feel distant from their own humanity, and for the awe of patient experiences to become dulled. Some studies describe that empathy erodes during training.

Residents and students know they are caught between the physicians they long to be, and the reality of where they are, and they often describe a sense of inadequacy when it comes to relating to patients and families. They fear they will not have “the right words” or the “right thing to do” to help a family in a time of crisis. In addition, they are acutely aware of the way that their daily tasks distance them from patients. We as their attendings require them to get their orders in, notes done, patients discharged, and all of this keeps them on the computer and not at the bedside. Interns in particular feel distressed over the distance this places between them and their patients. These concerns are fed by the common narrative in the popular media of patients reporting that they felt unheard by their physician, or that their physician was hidden behind the computer screen. Between the residents’ own insecurities, and the prevailing cultural narrative about residents, the housestaff’s default assumption is that the families will find them lacking. As such, they are in a state of vulnerability when listening to patients and families describe their experience.

This does not mean we need to protect them from hearing patient voices. Residents are resilient and able to handle difficult experiences, and there are many ways in which it may be comforting to them to hear the patient’s story. However, as their mentors and program directors, we can help prepare them to hear patient stories with openness, and forestall some reactivity.
Some contextual factors to consider as you plan the session:

**Size/degree of interactivity**
Is this a large and impersonal format like Grand Rounds (or some daily conferences at larger programs)? Or is it a smaller, more interactive setting? Will there be opportunities for questions and answers?

**Audience**
Will the residents be listening to the parent or patient in a group of only their peers, or will it be a mix of attendings and residents? Will there be other patients in attendance? Will there be students?

To what degree do the listeners already have a sense of “safe space” and community established amongst themselves?

**Degree of knowledge of the case**
It is important that no trainees in the room know the family or patient speaking. If a few years have gone by since the family's experience, that is ideal to protect confidentiality.

**Longitudinal context:**
Is this session occurring as a one-time event? (A one-time grand rounds or noon conference?) Or is it occurring within a regularly occurring curriculum of reflection/wellness/communication?

**Advance preparation of housestaff:**

There may not always be an opportunity to prepare residents or students ahead of a session in which patients/families are invited to present in person, but if there is a separate time before the patient or family session to make some preparatory comments, that may be helpful. If facilitating a discussion of a video, these suggestions can help to frame the discussion before the video is shown.

**Set the stage**

*What we can learn*
Emphasize that the purpose of bringing patients and families to speak to physicians, is to give us a precious opportunity to hear from those we care for. This is a priceless window into an aspect of our work that we cannot understand apart from being patients ourselves. It is typically not necessary to explicitly state the need for respectful listening, since residents are very conscious of this already. It is important to avoid any tone of trying to teach doctors a lesson about being more sensitive to patients. Assume that the residents have a deep desire to understand
their patients better, and send the message that this session will enhance their already strong impulse to care for their patients well.

**What we can feel**

(Note: I would not address the following issues if the patient or family is present in person, since we do not want our patients to worry about how the residents will feel. It is our responsibility to take care of our own response, not the patient’s responsibility. These comments are more appropriate made at a previous session, or before the patient arrives, or in the context of showing a video testimonial.)

Acknowledge the emotions that can arise when listening. Hearing a patient or family member speak may remind listeners of other patients they have cared for. It may bring up feelings of insecurity about whether they would have known the right thing to say or do in a similar situation, or it may bring up past losses or experiences in the resident’s personal life.

**Handling our reactions**

Suggest the tools of mindfulness, and naming one’s feelings as a way of handling that. Encourage residents to ask themselves curious/wondering questions about the feelings.

One potential format for naming emotions is:

“When I heard ____, I began to feel/think about _____. I wonder if I feel that way because ______.”

Examples:

“When I heard the mother describe the way the specialist insensitively gave her the diagnosis, I began to feel defensive. I wonder if I feel that way because I worry that I could also be accidentally insensitive when I am giving bad news.”

“When I heard the little girl talk about doctors waking her up early to examine her, I thought about all the times I have done that, and I started to feel guilty.”

“When I heard the parents share their gratitude for the care they have received, I felt proud to be in this profession, and hopeful that one day my patients will feel grateful for my care.”

“When I heard the parents describe their journey of healing after their daughter died, I felt amazed that people can survive something like that. It’s encouraging to know that parents do find ways to go on.”

**We are not responsible for other physicians’ actions.**

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If a patient or family shares something that they found hurtful from another physician, sometimes residents can feel responsible, as representatives of their profession. They are especially prone to feeling this if the patient shares a story about a resident, or if the patient speaking was cared for in their hospital. It can be helpful after the session to reach out to residents and let them know that they do not need to take on blame or feel responsible (or, if facilitating a discussion after a viewing of a video testimonial, be prepared that this may come up in the discussion and you can redirect the residents). The most helpful thing is to feel compassion for that patient’s experience, learn from it, and move on with greater awareness.
Choosing and Preparing Patients and Families for Pediatric Educational Activities

Sandra Clancy, PhD and Blyth T. Lord, Ed.M

At the Massachusetts General Hospital for Children, patients and families participate in educational activities in the hospital setting at Grand Rounds, resident conferences, and in communications workshops where they discuss scenarios in which clear communication between providers and parents is necessary.

In all these settings, the patient and family voice is valuable. For better or worse, patients and their families often develop expertise and deep insight into the workings of the health care system so that they are able to provide a perspective that is not automatically available to learners. Given the complexity of healthcare decision making and a culture in which guardians are expected to choose among options, parents of pediatric patients appreciate the importance of good communication and can often outline the components of it. Learners gain many insights from patients and families such as the emotional terrain that accompanies having a child with an illness, the difficulties inherent in making complex decisions about a loved one, how parents need to translate medical language into ‘everyday language’, and how procedures that medical professionals come to think of in medical/scientific terms can illicit unsettling feelings for families. Learners gain understanding of parents’ priorities, parents’ sense of fear and unfamiliarity in hospital settings, factors parents deem important that learners might never have expected, and possible questions to ask to solicit more information, all with the goal of improving care.

Identifying Patient and Family Participants for Rounds, Workshops or Videos (e.g. Courageous Parents Network)

Family Advisory Council Members: In our experience, parents and family members who have served on the Family Advisory Council are good candidates for medical education opportunities. They have interacted with staff on the Council, have some knowledge of the internal workings of the hospital, and have experienced firsthand how much their insights are valued.

Parent-Provider Partnerships: Partnerships that involve a long-term productive relationship between parents or family members and a provider or providers are especially effective. Often a level of trust has developed so that both parents and providers are willing to reflect on moments of frustration, anger, confusion, and systems challenges in a non-charged way. It can be very illuminating for learners to hear a patient or family member provide their perspective and then the provider offer their perspective.

Hearing from a senior attending who is willing to reflect on ‘lessons learned’ and how he/she would have done something differently is especially powerful in the context of a partnership with a parent, as is learning how a parent/provider relationship endured through challenges.

Parents who might be able to say “I was probably labeled a difficult parent” and can provide insights into the challenges they faced in a non-threatening way are often the best speakers. Similarly,

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providers who can discuss mistakes or missteps honestly and frankly alongside families make powerful speakers.

Providers whose children have been pediatric patients are able to provide insights from both the perspective of the parent and that of the provider.

Speakers who are at some distance from their experiences often can have the benefit of reflection so that they can not only tell their story, but provide analysis of it.

Parents who seek you out because they ‘want to use their experiences, both positive and negative, to ensure that families who come after them have an easier time,’ generally make good candidates, as do family members who value good communication.

Speakers who have the ability to speak honestly but constructively about their challenges, frustrations, and even anger can be especially powerful. We highly recommend, ahead of time, talking with families about their experience, to hear how they speak of it, to ensure that their remarks will be constructive and invite learners in as opposed to creating a defensive mindset in the audience. Your experience as a medical provider may allow you to anticipate something that might be received in a way other than the one intended.

**Helping Speakers Prepare for a Live Presentation: Building Comfort and Confidence**

Whatever the setting, it is important to prepare the patient or family member to participate.

“What did you learn that you wished you had known beforehand?” is a good prompt for speakers, to help them prepare their remarks.

For the family/parent videos, we invite the speakers to engage in a conversation and ask them to imagine they are talking to fellow parents or the types of providers they have had on their child’s team. “What would you like parents or providers who are watching to know?”

Be willing to go over a patient’s or family member’s presentation with them or even help them structure it.

Parents may be intimidated to speak in front of medical personnel. Assure them that providers really learn a great deal from them and that their reflections are valuable.

If a person is giving an oral presentation, be very clear about the amount of time he/she has to speak.

Provide as many details about the format as possible to ensure that the speaker is comfortable. Explain the precise purpose of the event. For example, if it’s Grand Rounds, explain the format, who will be in the audience, who will introduce the panel etc. If pediatric patients are speaking, bring them to the location beforehand so they can familiarize themselves with it.

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Creating a Learning Opportunity Using the Patient/Family Voice

Topic:

Learning Objectives:

Format:
Consider time, setting, learners (what level(s), mixed audience?), live versus video or reading, formal presentation vs discussion based

How will you frame the learning activity?

What might discussion prompts be (if video or written) or guidance for patient families (if live)?

Resources Needed:

Participant Preparation Needed:

Contingency Planning (what could go wrong):

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Sample Video Narratives:

On Diagnosis
There’s a fine line between Hope and Acceptance (2:42)

On the Medical System
Parents feel pressured to be liked by the medical team. (2:43)

On Decision-Making
You have to make a decision and they’re both bad choices (3:34)

On Having Conversations about End-of-Life with Children
Doctors should know that getting past the fear is the biggest step (1:29)

On Preparing for End of Life
It’s helpful to ask questions about End-of-Life. (2:42)

Sample Written Narratives:

On Helping Children Die the Death They Wish

On Parenting a Child with Life Limiting Disease
Emily Rapp: “Notes from a Dragon Mom” New York Times 2011

Sample Grand Rounds Narratives:

Pediatrics Patients’ Tips for Providers
Matthew’s List of Things that Will Help You Help Other Kids (6:10)

Briana’s What Worked Well, What Could have Gone Better (2:16)