Parents as Medical Educators

Janice L. Hanson, PhD, EdS; Benjamin Siegel, MD; Kathryn Vestermark, BS, MA; Susanna Peyton, RN, MSN; and Virginia Randall, MD, MPH, COL MC USA (Ret.)

CME EDUCATIONAL OBJECTIVES

1. Discuss the rationale for involving parents of children with intellectual/developmental disabilities (ID/DD) in medical education.

2. Identify aspects imbedded in knowledge, skills, or attitudes that parents find helpful in physicians caring for their child with ID/DD.

3. Explain how the community-based preceptor can teach medical students skills that are crucial to providing care to children with ID/DD.

Since the late 1970s, the role of parents in medical education has grown steadily. Their thoughtful insights, grounded in experience, can help young physicians learning to care for children and communicate well with patients and their families. In a review of the literature, Towle and colleagues found that there is a “ladder of involvement” for patients and parents, ranging from simple presence during medical education encounters; teaching; providing feedback to students; developing new curriculum activities within a pre-set structure; and participating in decisions about medical education policy, procedures, and curriculum. Roles for parents include the following:

- Teaching students and residents by hosting home visits, speaking at grand rounds, leading small group discussions, and providing feedback about interview skills;
- Participating in family-centered rounds and education during ambulatory visits;
- Participating in work groups to develop new curriculum activities;
- Assisting in developing simulated patient cases based on their experiences as parents;
- Serving as members of task forces, institutional review boards, and standing committees in hospitals and academic health centers;

Janice L. Hanson, PhD, EdS, is Associate Professor of Medicine, Pediatrics and Family Medicine, Uniformed Services University of the Health Sciences, Bethesda, MD. Benjamin Siegel, MD, is Professor of Pediatrics and Psychiatry, Boston University School of Medicine, Boston, MA. Kathryn Vestermark, BS, MA, is a Parent-Teacher, Herndon, VA. Susanna Peyton, RN, MSN, is Parent Coordinator, Operation House Call, The Arc, Boston, MA. Virginia Randall, MD, MPH, COL MC USA (Ret.), is Associate Professor of Pediatrics, Uniformed Services University of the Health Sciences, Bethesda, MD.

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SIDEBAR 1.

Operation House Call Curriculum

• Develop an approach to interacting with children with ID/DD that is tailored to the individual child.
• Recognize the challenges that families undergo when taking care of a child with an ID/DD.
• Recognize the effect of the child with ID/DD on other children in the family.
• Identify the health, economic, social, and educational challenges families face in advocating for their children.
• Learn directly from families and reflect on the home visit.
• Incorporate this learning into one’s understanding of humanism and professionalism as a future physician.

Source: Hanson J, et al.

• Evaluating medical students’ professionalism, communication, and relationship skills.8,9

Here, we provide examples of our experiences with parent faculty at two medical schools: Boston University and the Uniformed Services University of the Health Sciences. The expertise parents have shared in these two programs can also guide pediatricians in clinical practice, both when they host medical students and residents for clinical rotations, and when they seek to extend their own skills by learning from parents during daily clinical encounters.

‘OPERATION HOUSE CALL’
Parents’ Perspectives

The name Operation House Call (OHC) was given to the educational experience at Boston University (BU) by parents of children with intellectual and/or developmental disabilities (ID/DD) describes children with delays in cognitive, social, and other developmental areas.10 OHC’s curriculum stresses language that focuses on the person rather than his or her diagnosis or disabilities (“a child with special needs” rather than “a developmentally disabled child”), and seeks to identify strengths as well as disabilities in each individual (see Sidebar 1).

Parents have a hand in designing all of the teaching materials and presenting the goals and information about the psychosocial, economic, cultural, and ethical aspects of their experiences as parents of children with special needs. They host students in their homes and share their perspectives and life experiences, involving their children as they do so. The parents also evaluate students on their communication skills and professionalism.

The rationale for establishing such a program derives from the work of Paris and colleagues, who studied the attitude of medical students and physicians toward people with disabilities.11 They concluded that health professionals’ attitudes about and responses to those with disabilities can negatively affect the self-concept of the person with a disability; the quality of care provided; and the beliefs and actions of medical students and residents. This can perpetuate a negative image of people with disabilities.

Program Features

By introducing medical students to those with ID/DD and their families, they come to understand the issues families face. Students attend an orientation session and then visit a family in pairs for 2 hours. Their goals are to be curious, ask questions of all family members, interact with each of the children present, and listen to family perspectives and stories. After, they have an opportunity to reflect on the visits and discuss them with their peers, both in the classroom setting and in an online OHC chat room. The OHC participant — who is a parent of a child with ID/DD — participates in the online chat room to offer students guidance, which sometimes includes highlighting particular resources for children, families, and physicians.

OHC coordinators teach through the use of personal stories and the sharing of materials and resources pertinent to families who raise a child with ID/DD. Important topics discussed include the use of person-first language and thinking; supportive ways to deliver unexpected or difficult news; building communication skills and rapport; an overview of public education and community supports; excellence in care; and sensitivity toward family dynamics, marriage, and sibling issues.

During the last 2 years, the OHC class has also included a half-hour visit from a young adult or teen with ID/DD, who teaches through a structured “get to know each other” interview with the OHC coordinator. Approximately 60 families volunteer to teach by hosting pairs of students for home visits. Most families host one or two visits each year, although some host as many as six to eight visits each year. Family members discuss many personal, sometimes painful, issues during these visits such as: marriage issues; sibling needs; medical treatment; and community and school support or lack thereof.

OHC volunteer families also provide important feedback by completing the evaluation tool that focuses on communication, attitude, and engagement. Skills include the ability to connect and play with the children in the family (with or without disability), the use of person-first language, sensitivity in framing questions, and general curiosity and listening skills.

Families in OHC are eager to be a part of this teaching program, despite juggling schedules, dealing with family dynamics, and addressing stressful topics during the visit. Many are inspired
to join the program out of their gratitude for good care given by medical professionals in the past; many families have received good care consistently, so some find that teaching new doctors gives them hope that potential problems can be avoided in the future.

Families also report that siblings enjoy participating in the visits. Often, parents will speak to the OHC coordinator about the sense of confidence and advocacy strengthened in their child who has ID/DD. Occasionally, parents will remark on how sensitive issues become less difficult to talk about. As one parent teacher said about the program, “We feel strongly that this is a program that will help both the students and the future families who will interact with these students. Thanks for all you do.”

**Evaluation**

An initial evaluation showed that most students (70%) reported having a changed attitude about children with ID/DD after their home visit. After their home visit, many students identified their own need respectively for greater sensitivity, better understanding of available resources, increased ability to facilitate open communication, and greater compassion and empathy. A subsequent study compared students who had completed home visits with their peers who had not. The study found that after a home visit, students reported better knowledge of the medical and educational aspects of intellectual disabilities, and were able to better answer questions, offer prognoses, and deliver bad news to families.

**UNIFORMED SERVICES UNIVERSITY SCHOOL OF MEDICINE**

**Parent-Teacher Experience**

At the Uniformed Services University of the Health Sciences (USU), Drs. Virginia Randall and Janice Hanson asked parents what they found most helpful about their children’s doctors. Parents’ responses included: self-awareness; communication; shared medical decision-making; and advocacy (see Sidebars 2 and 3).

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| **Helpful Attitudes and Skills for Pediatricians**

- Self-awareness — including attitudes about children with disabilities, such as whether they and their families can experience resilience when faced with challenges.
- Effective communication — facilitates understanding with parents, children, and team members.
- Collaboration — involving parents in medical decisions about their children.
- Compassion — advocating for people with disabilities and chronic illnesses at the individual level, and the system level (advocating for policies and practices that benefit children with special needs as a whole group).

Source: Hanson J, et al.

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| **Helpful Activities for Teaching**

Some of the activities that parents have helped develop and teach include the following:

- **Home visits** that introduce students to “the context of a patient’s life.” This helps them begin to think about how physicians can adjust treatment recommendations to better meet a patient’s needs.
- **Bioethics discussions** in which parents describe how they make decisions for their children. This helps students build an understanding of values and priorities that parents consider when making difficult medical decisions.
- **A lecture delivered by the parent, who describes what a diagnosis looks like “in real life” and discusses the implications of the child’s special needs.**
- **A workshop where students spend 2 hours with a parent or a patient, build an understanding of a person’s life, and help the parent or patient develop a plan to solve a difficult challenge.**
- **A home visit to a patient with complex or chronic health care needs in which the student assesses the adequacy of available health care and community resources.**
- **Health supervision case discussions** for the pediatric clerkship, with special attention to communication and knowledge needed for effective health supervision and anticipatory guidance.

Source: Hanson J, et al.

Medical students’ respective abilities to promote resilience among patients and families in health care settings were evaluated by presenting them with written scenarios of encounters with parents in health care situations that presented a mild stress or challenge, then asking students to write how they would respond. Students were presented with the scenarios, pre- and post-home visit and associated discussions, then scored their responses using criteria developed by Edith Grotberg from her research on promoting resilience. Of 53 students who participated in the evaluation, 30 improved their scores, 17 remained the same and six decreased.
Views from a Parent Educator

A parent of a child with multiple disabilities, who has participated in many aspects of the program at USU, shared these in-depth thoughts:

“A beloved physician first introduced our family to USU and the idea of parent/patient inclusion in medical education. We were having significant difficulty breaching the barrier that separated physicians from their patients and families. When I first explored the program at USU, I was impressed and surprised by its goal to include parents and patients as faculty and advisors to medical education. I could not wait to participate. This was the first concrete experience I had that indicated that the future of medicine was embarking on a significant paradigm shift; new experts on a patient’s health were being consulted: the patient and family.

“Several parents gathered to work on developing medical competencies — attitudes, behaviors, professional skills — that patients and families expected from their medical professionals. This group began slowly working through many difficult personal experiences, weaving through the pain to find positive qualities that would aid health care professionals in effectively caring for patients and their families.

“This was one of the most affirming experiences I had in the early stages of living with our son’s diagnosis; this experience provided a sounding board for what did not work well, the hope of what would work well, and how to implement it across the medical education curriculum. When students visit our home each fall in their first year of medical school, they come with specific interview questions for which they need answers. Almost immediately, our family changes the parameters of the home visit and makes it comfortable, relaxed, and less formal. The questions all get answered over pizza, salad, and a dessert at the kitchen table.

“We begin by letting the students feel like members of the family. During the visit, we build rapport, exchange information, and develop mutual respect for what each party brings to the table. The students learn that our goal is to get the best medical care for our son. We, his parents, are remarkable historians and capable partners in the decision-making process. The students get to see that our son, Eddie, is a loved and respected member of our family. This home visit begins the process of developing skills to successfully communicate and build relationships with families that need extra help, extra time and a different level of consideration during clinic visits. This experience will help shape their ideas about communication with patients and families in the future.

“The medical students also have an opportunity to participate in conversations with parents who have had to make serious medical decisions for their infants and young children. The parents tell their stories and describe how medical professionals assisted or hindered their ability to participate in critical decisions for their child’s medical care, decisions that often have been matters of life and death. Experiences such as these, which build the insight and expertise of parents into medical education, help to cultivate medical professionals who can communicate with patients and families, easily developing rapport and trust while providing professional and competent medical care with compassion.”

PARENTS’ EFFECT ON MEDICAL EDUCATION

When parents share their insights about the care they want or need for their children, priorities and objectives in the educational program may shift. For example, when Drs. Randall and Hanson asked parents to define the physicians who had helped them and their children the most, parents noted knowledge, skills, and attitudes that are often found in typical medical school curricula, but their emphasis was weighted toward higher levels of communication skills and shared decision-making than are found in many medical education programs.

The evaluation data about resilience-promoting behaviors provides another example of a shift in priorities. Engaging parents as teachers helps students see not only the challenges that families face, but also the strengths they bring and the ways that physicians can build on those strengths to help children and families address the challenges and thrive.

One of the most devastating things for a parent to hear is a physician convey a difficult diagnosis for their child. Vital information, techniques, and vocabulary are provided to students by parents who have had prior experience with hearing a difficult diagnosis. Parents provide a snapshot of appropriate and professional communication and interaction with patients and families: which words help and which words hurt; which attitudes and behaviors encourage trust and which lead to discouragement; what helps parents/patients feel secure and what causes them alarm, fear and despair. A positive, supportive and meaningful inclusion of parents across the medical edu-
cation curriculum leads to a healthy exchange of ideas and information.

PRACTICAL TIPS FOR COMMUNITY-BASED PEDIATRICIANS

Community-based pediatricians who work with medical students and residents can have a powerful positive effect on their perceptions of “real world” skills in action as they model meaningful and effective interactions with parents and children. Preceptors can model techniques such as:

- Using open-ended questions to start the conversation with the parent/patient;
- Sitting down to establish eye contact with both parent and child;
- Offering a touch on the shoulder or hand, or a tissue if needed, to a parent or child in distress;
- Summarizing the parent’s or child’s concerns;
- Offering a collaborative treatment plan;
- Ensuring that the parent and child not only understand the plan but help develop it in a way that works for them.

Modeling good practice and attitudes such as these integrate the skills that parents value in the education of future physicians, while meeting their needs during pediatric care.17

Pediatricians can integrate parents in medical education in the clinical setting by asking parents how their visits went and if all their concerns were addressed. By asking the parent to provide specific feedback about certain aspects of the visit, the preceptor can help parents to be teachers in the context of children’s visits. Asking the child to give a “grade” to the visit can be fun — and is something everyone understands.

The preceptor should observe at least one encounter between a learner and a parent and child from beginning to end. Several checklists are available to use in recording communication during the history and physical (including details of the physical), which can help the community preceptor organize the observation and provide meaningful immediate feedback to the learner. The preceptor can enhance the role of parents in medical education by emphasizing the communication and interpersonal relationship aspects of the visit that are important to parents.18

Students and residents may also express curiosity about parents’ reactions to treatment decisions, such as guidelines for antibiotic treatment for otitis media. Often learners are impressed by the level of understanding parents demonstrate when discussing questions about their children’s care.

CONCLUSION

Parents and older children with chronic illnesses and disabilities have an important role to play throughout the continuum of medical education. As we incorporate family-centered approaches to care and education, their participation in providing feedback to learners and shaping their educational experiences becomes increasingly important. Any medical educators can encourage and plan for parents’ ideas, insights, expertise and perspectives, to enhance medical students’ and residents’ ability to the needs of children and families.

REFERENCES