

A Roadmap to Emotional Health for Children and Families With Chronic Pediatric Conditions

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LIFE WITH A CHILD WITH A CHRONIC CONDITION

Ms Pickles

My son Jake has critical congenital heart disease. In 23 years of complex care at a top-notch hospital, I do not ever remember a doctor asking Jake or myself how we were coping emotionally. But there were many times when my husband and I, and Jake, were not coping well. And although Jake has half a heart, the mental health struggles have been the more painful part of our journey in many ways. It is not enough that Jake has survived; he needs to thrive.

Ms Lihn

In my work with Sisters by Heart, I talk to many parents whose children have congenital heart disease. One evening, I received a call from a mother whose anxiety and depression peaked while she was in inpatient services with her infant daughter. She was desperate, expressing that she felt like jumping off the hospital roof. She had shared her mental health concerns with the children's hospital staff more than once, never receiving assistance. I validated her stress and sadness and reminded her that she was not alone. On my recommendation, she walked out the hospital doors to the emergency department next door. She was seen by a provider who listened, counseled, and provided emergency treatment. That was 5 years ago, and sadly, little has changed for families of children with chronic conditions.

Ms Pickles and Ms Lihn

In September 2016, we (D.M.P. and S.L.L.) attended an American Board of Pediatrics (ABP) meeting focused on partnering with patients and families. The agenda included an overview of the ABP Strategic Planning Committee's conclusion that the most important gap in pediatric training and practice was the emotional, behavioral, and mental health of children and adolescents. All the patient and parent attendees confirmed mental health issues as a critical need. Despite the range of pediatric medical conditions represented by the 30+ parents and patients in the room, our feelings and experiences were universal. The overriding theme was of being overwhelmed, with our children's conditions affecting every aspect of our lives and everyone to whom we are connected. There are multiple stressors and often a lack of consistency in daily life for families of children with chronic conditions. There are impacts on friendships and social life for children and parents and educational impacts on children who miss school and/or have neurologic impacts from their diseases. There can be behavioral challenges, either from the child with the health issue or siblings. For parents, there is little time to exercise, eat right, or give enough attention to other children. We feel isolated and as if our family and friends do not truly understand. Children are in and out of the emergency department and/or hospital, causing trauma for the child

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and family. Medical emergencies cancel vacations and special events. Many families have significant, ongoing financial strains. The ongoing, day-to-day upheaval causes mental health impacts. Parents often experience shame, feeling that they should be able to cope, and fear asking for help. When families do consider mental health referral, they often lack access to affordable mental health services. Not everyone has all of the same stresses or has them all at the same time, but most families experience many of them, and the stressors frequently build up over time. Some days or months are better, but it is unsettling not knowing when the other shoe will drop.

Many children with chronic illness have a shortened life expectancy. As a parent, it is difficult to live with that knowledge every day and still function. And, without recognition and support, how can parents who are struggling with grief, depression, anxiety, and trauma raise children who do not mirror those same struggles?

WHAT WE KNOW ABOUT EMOTIONAL HEALTH AND RESILIENCE IN CHILDREN AND FAMILIES WITH CHRONIC CONDITIONS

Dr Boat

As Ms Pickles and Ms Lihn have so eloquently expressed, many children and adolescents living with chronic conditions and their families navigate extremely challenging issues that often cause stress and alter coping mechanisms. These can lead to exacerbations in their conditions, challenges in self-care and treatment adherence, and delays in reaching developmental milestones.¹ Furthermore, these effects can persist long-term, with associations seen between childhood chronic physical illness and adult depression and anxiety.² Chronic conditions in children can also have a substantial negative impact on the physical and

emotional health of family members, including parents^{3,4} and siblings.^{1,5}

There have been numerous successful efforts to improve the physical care of pediatric patients living with chronic conditions. We rightly celebrate our therapeutic achievements. However, more children are living longer with disabling and life-threatening chronic disorders. There has not been commensurate focus on enhancing emotional health and building resilience. But we are beginning to understand that if you do not support the emotional health of children and families, everything else is at risk of falling apart.

In a recent large national study of commercially insured children and their parents, patients with chronic medical conditions and co-occurring mental health or substance use disorders had annual insurance payments that were 2.4 times that of patients with a chronic medical condition only.⁶ Most of the increase reflected medical services rather than mental or behavioral health services. This difference translated to a greater estimated annual expenditure of \$8.8 billion. Parents of these children also had insurance payments that were 59% higher than those of parents whose children had only a chronic medical condition. Additionally, studies across pediatric populations have demonstrated poorer adherence to medical regimens in children and adolescents with behavioral or emotional dysfunction.⁷ These findings suggest potential benefits from preventing or reducing the impact of mental health disorders among children with chronic medical conditions.

Resilience-based interventions, such as strengths-based cognitive behavioral therapy and mindfulness techniques, can assist families in identifying their strengths and recognizing protective factors and resources they can use and can provide opportunities to practice

strategies to improve coping and family functioning.⁸ But as my colleagues and I have noted, “Pediatric chronic care medicine must more effectively deliver interventions that promote family wellness and resilience.”⁹ This effort will depend on recognition of need and full participation by pediatricians and will be most effective if conducted in an interdisciplinary setting that prospectively attends to the behavioral dimensions of health for the child and for the entire family.

IDENTIFYING THE NEED FOR THE ROADMAP INITIATIVE

Ms Pickles and Ms Lihn

During the ABP meeting, we also heard of research that validated our experiences, specifically that clinicians are not comfortable asking pediatric patients and their parent caregivers about their mental health needs and fail to do so. After the meeting, we and another mother who attended wrote to the ABP’s chief executive officer and said, “We believe there is a valuable opportunity to work across chronic diseases to address the important issue of emotional support and mental health for children with chronic illness...If the ABP were willing to invest resources, we might be able to truly generate a roadmap for new strategies and interventions.” We felt there was a watershed opportunity for the ABP to provide leadership in the pediatric community, with patient and parent partners, to tackle this issue, dig in, and make an impact.

THE ABP’S SPONSORSHIP, ROADMAP’S APPROACH, AND INITIAL LEARNINGS

Dr Lannon

As recently as 2013, 65% of pediatricians surveyed by the American Academy of Pediatrics indicated they lacked training in recognizing and treating mental health problems.¹⁰ Although the

population of children requiring care for behavioral and mental health problems has been increasing dramatically, pediatricians feel inadequately prepared to manage children with common behavioral and emotional health complaints. Because the ABP certificate must signify that a well-trained pediatrician is ready to handle the health care needs of today's children, the ABP has been working intensively with many partners to help training programs, trainees, and pediatricians address the mental health crisis. The ABP funded The Roadmap Initiative beginning in February 2017 as part of its strategic priority to address the mental health needs of children and families. Roadmap aims to increase the resilience and emotional health of children with chronic conditions and their families by doing the following:

- raising awareness among patients and families to normalize stress and promote self-care, and among clinical teams to address these issues and provide support, and
- providing resources and connections for clinicians and families.

This article reviews what we have learned so far, provides tools and resources to help pediatricians and subspecialists achieve Roadmap's aims, and outlines next steps.

From its inception, Roadmap has been a partnership among patients, families, subspecialty clinicians, representatives from stakeholder organizations, and quality-improvement specialists. Initially, we used a systematic process to better understand patient and family needs for emotional support. We also conducted a literature review and identified initiatives in learning networks for pediatric chronic conditions and in other stakeholder organizations. Key themes that have emerged (including relevant

parent and clinician quotes) are as follows.

- You do not have to be a mental health professional to make a difference. Parents emphasize they do not expect their pediatricians to be mental health experts. But the pediatrician's interest and support is tremendously valued, and validating the stress patients and families feel can open the door to discussion.
 - "Subspecialists may feel it isn't their 'area of expertise' to discuss, but they are often the ones we trust most." (Parent)
 - "A good doctor treats disease; a great doctor treats the patient. We are more than treating test results; we should be understanding how that disease is affecting them as families." (Cardiologist)
 - "Clinicians worry about scaring us when, really, there's nothing you can tell us that will scare us more than we already are." (Parent)
- Begin conversations about emotional health and resilience early, at the time of diagnosis and/or shortly thereafter, and address it at many or most visits. Highlight the importance of self-care for parents.
 - "Start discussing emotional health from the very beginning so psychosocial issues don't escalate to where they take up [the] clinic for an extra hour." (Pediatric psychologist)
- Realize parents may have difficulty acknowledging their feelings of vulnerability or stress and underreport the extent of their distress.
 - "We don't want to appear to be unable to care for our child. ... We want to seem to have our act together even though we may only be holding on by a thread." (Parent)

- "I believe we looked like we were doing okay. I pretended we had it all together. I sobbed everywhere privately, just not in front of our doctors." (Parent of a hospitalized child)
- "I saw how busy the doctors and nurses were in the NICU, so when I was asked how I was doing, I just said 'fine.'" (Parent)

ROADMAP TOOLS AND RESOURCES

To address the substantial need in patients and families with chronic pediatric conditions, we have developed a number of free tools and resources (www.abp.org/foundation/roadmap) to help pediatricians and subspecialists achieve Roadmap's aims.

- A 5-minute video ("How Are You Doing?") for clinician, patient, and parent audiences aims to raise awareness of the need to support resilience and emotional health, build will and a sense of urgency to address this issue, communicate key messages, and reduce stigma.
- A "Change Package" is a practical document that includes ideas for changes to improve the mental health and resilience of patients and families. It contains background material; a summary of evidence and best practices; strategies, tools, and examples that can be applied to the work; and a logic model that depicts the linkages between Roadmap's aim, facilitating factors that can help achieve the aim, and the strategies.
- To support clinician comfort and confidence in initiating discussions about resilience and emotional health, a set of 4 example conversations focus on common touchpoints with patients and families: at the time of diagnosis (younger children and teenagers), when conducting surveillance during follow-up visits, and when introducing depression screening for teenagers. Each conversation

includes a sample script along with considerations and reminders. A set of associated teaching slides is available for training settings.

Additional resources are in development, including brief videos demonstrating the example conversations and Maintenance of Certification (MOC) Part 2 and 4 activities. MOC Part 2 will provide evidence for the importance of addressing these issues (eg, the relationship of emotional health to treatment adherence and improved health outcomes). A pilot learning collaborative with teams from 9 children's hospitals will test additional specific and feasible practice changes to support patient and family emotional health, and example measures for monitoring improvement over time that will be used in an MOC Part 4 module. We are also working with the Committee of Pediatric Subspecialties, the Association of Pediatric Program Directors, and others to identify how Roadmap strategies could be tested and implemented in children's hospitals, subspecialty settings, and fellowship and residency programs.

CONCLUSIONS

We must act now to improve the emotional health and resilience of children with chronic conditions and their families. We urge widespread adoption of the Roadmap strategies and resources in pediatric subspecialty care and training and conduct of additional research to

identify the most effective and feasible approaches.

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ABBREVIATIONS

ABP: American Board of Pediatrics
MOC: Maintenance of Certification

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