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Changing Medicine and Building Community: Maine’s Adverse Childhood Experiences Momentum

Leslie Forstadt, PhD; Sally Cooper, MD; Sue Mackey Andrews

ABSTRACT

Physicians are instrumental in community education, prevention, and intervention for adverse childhood experiences. In Maine, a statewide effort is focusing on education about adverse childhood experiences and ways that communities and physicians can approach childhood adversity. This article describes how education about adversity and resilience can positively change the practice of medicine and related fields.

The Maine Resilience Building Network brings together ongoing programs, supports new ventures, and builds on existing resources to increase its impact. It exemplifies the collective impact model by increasing community knowledge, affecting medical practice, and improving lives.

PHYSICIANS AND ADVERSE CHILDHOOD EXPERIENCES

Fifty physicians sit in a darkened room, listening to an atypical grand rounds presentation. Rather than a focus on the latest in medical treatment or an in-depth case study, the topic is “What You Should Know about Adverse Childhood Experiences” (ACEs). For the next 75 minutes, the physicians learn about the ACE Study, complete the ACE questionnaire, and respond to an invitation to integrate the information into their medical practice. No specific recommendations and guidelines are articulated, but the question-and-answer session is ripe with ideas, questions, and uncertainty about next steps.

The ACE Study, by Vincent Felitti, MD, and Robert Anda, MD, MS,1 was published in the late 1990s and was a collaboration between the Centers for Disease Control and Prevention in Atlanta, GA, and Kaiser Permanente in San Diego, CA. The study found that early childhood experiences correlated with adult health and behavior outcomes. Ten types of childhood adversity were included in an intake questionnaire: emotional, physical, and sexual abuse; emotional and physical neglect; and five types of family dysfunction—a mother treated violently, a mentally ill parent, an alcoholic (or other substance-abusing) parent, losing a parent through abandonment or divorce, and a family member in prison.

In this study of 17,471 insured Americans, a score between 0 and 10 (called the ACE score) was determined on the basis of the 10 categories of early childhood adversity described in the preceding paragraph. A score of 1 indicated that the person had experienced at least 1 event in the selected category. No additional numbers were added even if there were multiple occurrences in a single category. For example, the experience of physical abuse and an alcoholic parent would equal a score of 2, even if there had been multiple occurrences of physical abuse and/or more than 1 alcoholic parent. Almost two-thirds of the participants in the ACE Study reported experiencing at least 1 ACE. As the number of ACEs increased, so did the risk of heart disease, cancer, obesity, depression, and autoimmune disorders.

The ACE Study findings are supported by more recent research on childhood toxic stress and trauma. The list of potential stressors is longer than 10, and the potential long-term impacts are infinite. A growing collection of evidence related to ACEs and other childhood stressors is available: ACEs have an impact on health and substance use, mental health, health care utilization, psychotropic medication use, and autoimmune disease. The overarching point is made: the impact of trauma in childhood is lasting. The long-term effects are seen in the health status and behavior of adults. What happens in childhood lays a foundation for multigenerational illness, adversity, and disparity.

If trauma represents one side of the coin, the antidote for trauma is resilience. An accompanying and powerful body of research is building about resilience and the capacity of humans to thrive in the face of traumatic life events. Resilience is the ability to respond to experiences, fostered by the clinicians, teachers, friends, family, and community in one’s life. Support from others, referrals as needed, and the simple act of having a trusted provider listen nonjudgmentally and with compassion can provide support. Then, if needed, patients can be referred to additional services they believe would support them. The patients’ own insights about personal motivation on their journey toward health and well-being are both respected and reinforced by their clinicians. This interaction between medical professional and patient does not change the past experiences of the patient; however, it can change their experience moving forward.

NATURAL QUESTIONS

During the question-and-answer period of the grand rounds, response is mixed. Clinicians want to help, yet there is a finite amount of time with patients. There is skepticism as to the amount of training needed to delve into the patient’s childhood experiences.
In one corner, there is a collective overwhelmed sigh at the thought of adding one more task to a full and overburdened plate. In another corner, there is a glimmer of curiosity and bubbling of ideas about how to implement the information. Many of the questions center on unfamiliarity with the ACE Study and corresponding uncertainty about how best to use the information.

The first results of the ACE Study were published 15 years ago, with 100s of articles published since then, and yet the study remains unknown to many in the medical profession. The ACE Study found that many of the seemingly destructive behaviors of patients (eg, smoking, overeating, or promiscuity) were, in fact, ways that patients were self-medicating in response to trauma and stress.

Jeffrey Brenner, MD, a family physician and MacArthur Fellow from Camden, NJ, comments, “In my training … I was told not to pull up the lid on something you didn’t have the time and training to deal with.” However, he acknowledges that the lack of awareness of the ACE Study and the unwillingness of physicians to understand the effects of trauma reflect a failure of the profession. He believes “we need more trauma victims to publicly discuss how their early life experiences have impacted their life and their health and we need more physicians to talk publicly about the importance of this issue. We also need research on ways to bring ACE scores into routine primary care.”

One way to bring ACEs and trauma into medical practice is to change the conversation. In the column, “Protecting Children from Toxic Stress,” journalist David Bornstein articulates this change. As physicians understand the science of ACEs, toxic stress, and brain plasticity, Bornstein believes we should change the question from “What’s wrong with the person?” to “What happened to the person?” and “What’s the best response?” The ACE score provides language for conversation, but the score itself does not predict the degree of resilience of an individual; deciphering resilience becomes the work of the treatment team and the individual.

There is also a need to calm the fear of opening a Pandora’s box. In a 2007 commentary, Edwards et al proposed that because of the association between trauma and health, the practice of medicine might, in fact, be improved if physicians understand and incorporate identification of the signs and impacts of trauma into their medical practices. When physicians learn about the impacts of trauma in general, and the experiences of their patients in particular, this understanding can lead to improvements in relationships with patients, adherence to medical protocols, and health outcomes. The ACE score is one way to provide a common language in that it facilitates the process of referrals for services for children and adults with complex needs, particularly those individuals with challenges that are affecting their health and their ability to participate effectively in their own health care in a functional and sustainable way. The ACE score can help clinicians ask different questions that address the complexity of an individual’s case.

Following is a sample of ways that ACEs and resilience can be incorporated into medical practices. Some of these methods, where noted, are being explored in Maine.

• A Maine psychologist, Mark Rains, PhD, consults with physicians and other professionals who are interested in engaging patients in conversation. He has developed a nonspecific type of ACE inquiry that focuses on strengths and introduces the ACE survey in a simple and straightforward manner. Without asking for extensive detail, or even needing to know the specific categories of ACEs, one can ask questions such as “How did what you experienced in childhood affect you?” and “Are you still bothered by any of the things that happened to you?” and “If you are no longer bothered, how has this happened?”

• Maine obstetricians are beginning to have ACE-specific conversations with expectant families by incorporating ACEs and the Protective Factors (parental resilience, social connections, concrete support in times of need, knowledge of parenting and child development, and social and emotional competence of children). In these conversations, physicians ask about preparation and readiness for the birth, what parenting practices the expectant parents have experienced that they will use with their child, and, conversely, what they will change and what supports they need. This ongoing dialogue helps to provide support, validation, and resources to parents through the relationship that the physician has cultivated by asking, “What happened to you that may affect your parenting?”

• In the pediatric practice of San Francisco’s Nadine Burke Harris, MD, children are screened for various types of adverse experiences that increase their risks of long-term health problems associated with ACEs. The treatment model is multidisciplinary in the primary care setting and includes home visits to support families where they are. The treatment provides a “complete spectrum of response,” working with both primary prevention and secondary care and includes, as well as goes beyond, protocols and tools for early detection. Dr Harris established the Center for Youth Wellness in San Francisco, CA.

• Philadelphia pediatrician Kenneth Ginsburg, MD, focuses on finding strengths in his adolescent patients by focusing on the future and on small steps toward reaching personal goals. He “flips” the trauma story, finding the dedication, ingenuity, and creativity of people to overcome their challenges and demonstrate resilience in daily life. Dr Ginsburg co-edited a comprehensive curriculum titled “Reaching Teens,” which is based on his strengths-based approach to working with teens.

• The Center on the Developing Child at Harvard University in Cambridge, MA, provides a variety of videos and research-based materials explaining the damaging impact of toxic stress on the developing brain. The resources are effective tools for personal and professional development, and facilitate meaningful conversations with parents about their important role in promoting resilience in their children.

• Maine is incorporating supports at home to assist with patient follow-through, attachment, and skill building through strong relationships between the physician community and Early Head Start, the Public Health Nursing Program, and Maine Families. These evidenced-based
programs provide home visiting services to expectant families and those with young children. Their parenting curricula and additional resources and referrals complete the circle of support that is essential to ensure adequate protective factors for all children and their parents. This community-based approach integrates education and prevention, and professionals are trained to make referrals in the community when interventions are needed.

CASE IN POINT
At the Edmund N Ervin Pediatric Center at Maine General Medical Center in Waterville and Augusta, ME, the staff provides programs incorporating trauma-informed care into every aspect of the clinical process. The ACE survey provides a common language for the Pediatric Rapid Evaluation Program (PREP), which provides evaluation to all children on entry into the custody of the Department of Health and Human Services, from five counties in Maine. All children in this clinic start with one point on the ACE survey because of their separation from their family of origin. Most also have been exposed to physical violence, sexual abuse, neglect, and a family member's mental health and/or substance abuse issues. The goal for the PREP team, which consists of a child psychologist and a pediatrician, is to provide a baseline assessment of the child’s medical, educational/developmental, emotional, and physical needs on entry into foster care.

One important purpose is to help clinicians identify the child's strengths in addition to his/her needs. Teamwork and knowledge of where to refer patients are key. The medical professional who may be the expert in heart disease or family medicine is greatly empowered when the resources for referral for treatment of substance abuse, domestic violence, and mental health issues are within reach. Better yet, the fears about Pandora's box can be abated when the confidence in being part of a team, with referral within reach.

Teamwork starts with relationships built through opportunities across disciplines to come together and develop protocols that include response and referral strategies. This is true at Maine General Medical Center, where the PREP team coordinates and collaborates to provide care among staff from multiple disciplines in the clinic (psychology, social work, developmental pediatrics, psychiatry, speech therapy, physical therapy, occupational therapy) as well as primary care physicians in the community. Referrals are bidirectional, allowing for identification of needs and pathways for access to services at multiple points of entry into the system of care. It is essential that every contact point and process in the system is trauma-informed. Even the most apparently insignificant interaction with a clinician in the medical system is an opportunity to promote resilience.

MAINE'S MOMENTUM
The grand rounds presentation was successful. Many of the physicians signed up for future communications about training sessions, and some started exploring ways to incorporate ACEs and resilience in conversation with their patients. In addition, there was resounding support for a Part 2 training to practice and share specific strategies.

Grand rounds are one of many educational offerings about ACEs and resilience in Maine thanks to the Maine Resilience Building Network (MRBN), a multisector collaborative using the collective impact process. A variety of stakeholders are engaged in exploring how ACEs and resilience can be applied "on the ground" through practice and skill building. Educational presentations similar to the grand rounds are tailored to different audiences and range from a 45-minute brief session to a 6-hour intensive workshop, with a variety of individually structured opportunities in-between. The offerings have expanded to a 3½-hour workshop on ACEs and resilience called the ACEs Summit. The MRBN is creating a "menu" of opportunities that are cumulative in content, are informed by participant evaluation, and engage statewide partners such as THRIVE, Maine Behavioral Health Organization, and the Maine Chapter of the American Academy of Pediatrics. This "menu" currently includes the Summit; a skill-building seminar on resilience promotion called "Bring it On"; a self-care/trauma prevention seminar; and technical assistance in administration of the ACEs screening tool in multiple formats for medical, health care, early care and education, and community-based organizations.

In the first 2 years since the MRBN formed, the network has grown to more than 50 sites around the state. The overall purposes of the MRBN are to create community conversations, increasing awareness of ACEs and resilience among Maine citizens, and to provide collegial support among professionals from multiple disciplines in Maine. To do this, there are public education sessions, conferences, grand rounds, trainings in agencies, regular network meetings, and a Web site at www.maineaces.org. These efforts increase the understanding that what happens in childhood affects adulthood, and correspondingly, the way adults present at physicians’ offices and the way they act in schools, social service agencies, or even in the grocery store might relate to experiences from childhood.

Among professionals, the MRBN functions as a support group and think tank for new projects, and as a facilitator for planning projects that involve the whole state of Maine. For some of the nonprofit organizations involved, the educational work is sometimes “in-house” to educate all professionals in a single organization.

The value of the MRBN is bringing together practitioners from multiple fields to talk about how to educate about ACEs. Each meeting (about five per year) begins with an orientation for new members, including an overview of the ACE Study. The remainder of the meeting flows in two directions: 1) what people are doing independently and 2) what collective projects can involve everyone. The
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Efforts of some regions, such as the ACEs screening with expectant parents and families with young infants, serve as powerful examples of local capacity building. As the MRBN continues to establish a foundation statewide, both horizontal collaboration with other statewide entities and state agencies, and lateral collaboration with local county collaboratives, early childhood staff, physician teams, and behavioral health and human service agencies occur.

SHARING THE MOMENTUM
Maine’s accomplishments are possible partially because of the rural nature of the state, which has a population of more than one million people. Members of the MRBN believe it is possible for every town, family practice, and school to be educated about ACEs and the power of community members to build resilience. Each state, city, and town has its own strengths and barriers. A committed group of individuals can create the momentum and garner the type of financial resources necessary to establish a foundation for incorporating ACEs in medical homes.

The MRBN’s presentations and Summits are the core of the momentum’s success. These venues provide opportunities for professionals to reflect, to talk to one another, and to strategize about changing practice. In response to demand and to continue the momentum, the next step is developing ongoing technical assistance for professionals to have the support they need once they choose to implement changes in practice. This multifaceted approach will build confidence as professionals begin talking about ACEs and resilience.

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