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Our page 1 stories look at how to use measurement-based care on a weekly basis, and coparenting to help treat postpartum depression.



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Free Parent Handout...

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Treatment progress

Implementing weekly measurement-based care in child intensive treatment programs

By Ariel Gianukakis and Justin Parent Ph.D.

Measurement-based care (MBC) refers to the routine collection of patient reports to track progress throughout treatment. The provider shares this information with the patient and uses it to guide future treatment decisions. MBC has the potential to enhance youth clinical care by improving the therapeutic alliance and informing ongoing case conceptualization. It also has the potential for organizational applications, such as quality improvement (Jensen-Doss et al., 2020). MBC has been shown to provide

several benefits in hospital programs, including evidence of improved patient outcomes (Lavender et al., 2021).

Using MBC allows programs, such as partial hospital programs, to determine whether they are achieving their clinical goals. The Joint Commission requires these types of organizations to utilize MBC for this reason. Children's Partial Hospital Program (CPHP) at Bradley Hospital has utilized MBC since its opening in 2012 [See Treatment progress, page 3...](#)

Perinatal depression

It takes a village: Broadening coparent support to enhance perinatal mental health

By Rachel Herman, Ph.D., and Rebecca Newland, Ph.D.

One in five women will experience depression during the perinatal period (defined as the period from pregnancy to 1-year post-childbirth), making it the most common complication of childbirth. Rates are even higher among women of color and those with lower incomes who face numerous societal inequities, including discrimination, barriers to quality health care, and inadequate family leave policies. The COVID-19 pandemic has only worsened the outlook; rates of perinatal depression appear to be significantly higher than they were pre-pandemic (Tomfohr-Madsen et al., 2021). While maternal perinatal depression has received substantial empirical attention, the developing literature on paternal depression suggests that fathers are also at increased risk for depression during the transition to parenthood. Studies indicate that approximately 10% of new fathers experience elevated depressive

symptoms during the perinatal period; the prevalence is as high as 50% among men with severely depressed partners (Paulson & Bazemore, 2010).

Decades of research document the consequences of untreated perinatal depression on the entire family system. Prenatal depression is associated with negative developmental outcomes in children, higher levels of interparental and family-level conflict, and an increased risk of long-term mental health problems for mothers and fathers. Pregnant women experiencing depression are also at greater risk for adverse pregnancy outcomes, including intrauterine growth restriction, premature delivery, and low birth weight. When two caregivers experience depression, the risk for children and families is even greater than the sum of the individual effects of each parent's depression.

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Keep your eye on...

...the need for telemental health for infants

The stress, related often to harsh circumstances associated with COVID-19, affects parents of infants and young children. These vulnerable parents can benefit from home visiting models, which enhance outcomes for parents and infants when these services are delivered in person. But less is known about the effectiveness of remote visits, which have become more common as in-person visits are rendered difficult or impossible by the pandemic. However, adaptations made in some parts of the world to allow telehealth delivery, with strategies for assessing whether interventions maintain fidelity, are now being studied. A special section of the *Mental Health Journal* looks at these adaptations. Papers include the following: evidence of the increased risk of maltreatment during COVID-19 for many families, and thus the need for home visiting services; how to reach families through telehealth; implementing Attachment and Biobehavioral Catch-up through telehealth with fidelity at similar rates seen through in-person services; and procedures for collecting physiological data from infants and parents while conducting assessments remotely. [Dozier M. Introduction of special section of Infant Mental Health Journal: Meeting the needs of vulnerable infants and families during COVID-19: Moving to a telehealth approach for home visiting implementation and research. *Ment Health J*. 2022 Jan 10. doi: 10.1002/imhj.21966. Online ahead of print.]

...recommendations for COVID-19 vaccinations from AAP

The American Academy of Pediatrics (AAP) recommends COVID-19 vaccination for all children and adolescents 5 years of age and older who do not have contraindications using a COVID-19 vaccine authorized for use for their age. Any COVID-19 vaccine authorized through Emergency Use Authorization or approved (through a Biologics License Application) by the US Food and Drug Administration, recommended by the CDC, and appropriate by age and health status can be used for COVID-19 vaccination (primary series, additional doses, or booster doses) according to CDC guidelines for children and adolescents. Children with previous infection or disease with SARS-CoV-2 should receive COVID-19 vaccination, according to CDC guidelines. Given the importance of routine vaccination and the need for rapid uptake of COVID-19 vaccines, the AAP supports coadministration of routine childhood and adolescent immunizations with COVID-19 vaccines (or vaccination in the days before or after) for children and adolescents who are behind on or due for immunizations (based on the CDC/AAP Recommended Child and Adolescent Immunization Schedule; <https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html>) and/or at increased risk from vaccine-preventable diseases. Pediatricians are encouraged to promote vaccination through ongoing, proactive messaging (i.e., reminder recall, vaccine appointment/clinics), and to use existing patient visits as an opportunity to promote and provide COVID-19 vaccines. [Committee on Infectious Diseases, American Academy of Pediatrics: COVID-19 Vaccines in Children and Adolescents. *Pediatrics* (2022); 149(1): e2021054332.]

...the role of school nurses in teen mental health

An integrative review across levels of practice — individual, community, and systems — found that the research on how school nurses help teens with depressive symptoms, anxiety, and stress is limited to only 18 studies, from 1970 to 2019. Primarily these studies looked at how nurses responded on the individual level, but whether these interventions were evidence-based was not clear. Over the years, mental health concerns in this age group have increased, but the dearth of studies has made it difficult to find out how school nurses are affecting the problems. In the meantime, school nurses feel unprepared and undersupported, according to this article, which urges more research and more support for school nurses in addressing mental health at all levels of practice. [Hoskote AR, et al. The evolution of the role of U.S. school nurses in adolescent mental health at the individual, community, and systems level: An integrative review. *J Sch Nurs*. 2022 Jan 12: 10598405211068120. doi: 10.1177/10598405211068120. Online ahead of print.]

Treatment progress

From page 1

(Barnes et al., 2020). The program designates a psychology assistant to administer questionnaires to every child at admission and discharge. In addition, parents are asked to complete questionnaires regarding their child's feelings and behaviors at admission and discharge. This information is useful for identifying initial treatment goals at admission and understanding how the child's symptoms have changed from the beginning to the end of treatment. However, the current system only allows for data collection at two time points to illustrate overall change from admission to discharge. Transitioning to a weekly tracking system would provide more comprehensive data to see the specific course of change throughout treatment. Indeed, the joint commission has recently suggested the use of measurement to assess treatment progress during admissions as well.

Weekly MBC consists of weekly measurement of symptoms throughout treatment. When goals are established at the start of treatment, this system allows them to be measured and monitored for each patient. Tracking symptoms and problems weekly makes it possible to see if and how the patient's progress changes throughout treatment. This information allows the clinician to make informed decisions regarding treatment based on the child's questionnaire responses each week. It can also provide useful information to the patient and clinician regarding the patient's readiness for discharge to a different level of care (Lavender et al., 2021).

This system also creates a helpful point of discussion and collaboration between patients, families, and clinicians. Children who struggle to identify their own progress can review their quantitative reports throughout treatment to see the change. In addition, children who underreport at the beginning of treatment may be able to recognize their increase in symptoms in the context of becoming more open with their provider. Differences between child and family viewpoints can become a useful target for treatment. In this way, incorporating quantitative measurement into standard therapy can enhance the treatment that children receive.

CPHP is an excellent candidate for implementing weekly MBC based on

previous research. Access to electronic health records, motivation from The Joint Commission, and staffing resources are factors that improve the odds of successful implementation (Childs & Connors, 2021). At CPHP, each child is assigned a treatment team consisting of a clinician (psychologist or social worker), a behavioral health specialist, a nurse, and a psychiatrist. These teams work closely to manage each child's treatment. Given the multidisciplinary nature of these teams, and that each member has a different training background, communication is a necessity. Collecting a standard weekly assessment for each child creates a common language for each team member regarding each child's progress and current standing in treatment.

There has not been widespread use of MBC in child programs, and even fewer implementations in child partial hospital programs across the country (Sommerhalder et al., 2021). Previous research has shown that MBC has the most success when the program chooses appropriate assessment tools, efficient use of technology, and when an emphasis is placed on ensuring that the data collection is aggregated and shared in a meaningful way (Lavender et al., 2021). We aimed to incorporate these considerations when implementing weekly MBC in CPHP. Thus, we initiated a weekly MBC pilot program to assess feasibility and effectiveness and to identify the best implementation practices for the program.

Case study

The purpose of this case study is to illustrate how we integrated weekly MBC into the standard clinical practices of a child partial hospital program. We chose three patients to pilot weekly MBC in CPHP. All three patients were males between the ages of 8–12, exhibiting irritability, mood symptoms, and behavioral dysregulation.

To minimize the burden on treatment teams and families, we chose brief, targeted surveys that would be straightforward for children and parents. The Behavior and Feelings Survey (BFS) consists of just 12 items, rating the frequency of each thought, feeling, or behavior on a scale of 0–4 (Weisz et al., 2019). The BFS was designed for weekly progress monitoring in youth outpatient psychotherapy and has three scales that can be used to measure progress: Internalizing Problems (e.g., anxiety, depression), Externalizing Problems

(e.g., rule-breaking, arguing), and a Total Problem score. The broad applicability of internalizing and externalizing symptom domains in intensive treatment settings and research showing the BFS is sensitive to therapeutic change made it an ideal choice for standard weekly assessment. Together, completion of these surveys took approximately 3–5 minutes for caregivers and children. The clinician worked with the child to complete the questionnaires in session. The caregivers were asked to complete the questionnaires either during family meetings or while waiting for their child at program pickup. This system proved to be feasible, given that clinicians meet with patients daily, and with families twice a week.

The results of the pilot study were valuable and informative. While the three children showed very different paths of progress, the information obtained proved to be a useful tool for clinicians to incorporate into treatment. The graphs below illustrate the three children's progress through weekly child and caregiver responses on the BFS. Higher scores indicate more severe symptoms.

10-year-old boy

Figure 1 presents the Total score for Child 1. This 10-year-old boy did not identify himself as in need of treatment and did not acknowledge many symptoms. However, concerns from his family were the primary driver of his admission. Parent management training for externalizing symptoms was the primary intervention and this led to a notable decrease in parent perception of child symptoms.

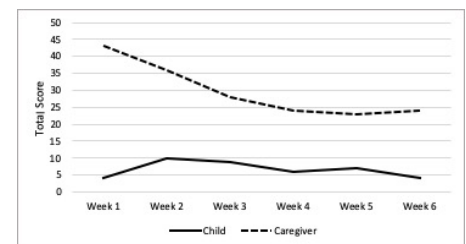


Figure 1. Child 1

Figures 2 and 3 presented divergent treatment progress trajectories.

In Figure 2, Child 2 was an 8-year-old boy who presented with such severe irritability and dysregulated behavior that he was not able to complete questionnaires. His parents had extreme difficulty managing his behavior at home, and though there was initial progress, the child moved to an

Continued on next page...

inpatient level of care in the fourth week of treatment. Weekly assessment provided a clear visual of lack of progress, which can be used when making determinations about stepping up into a more intensive setting.

12-year-old boy

In Figure 3, Child 3 was a 12-year-old boy who was open about his symptoms from admission, and experienced symptom relief over the course of his first week in the program, followed by some variability and ultimately improvement. His parents noted a steady linear decrease in symptoms from admission. The trajectory of change during treatment for Child 3 is evident in the graph and was used when making decisions about stepping down to a lower level of care. Each of the clinicians used this data to inform and update weekly treatment plans, report on progress during rounds, and present this information during family meetings as feedback to parents about treatment progress or lack thereof.

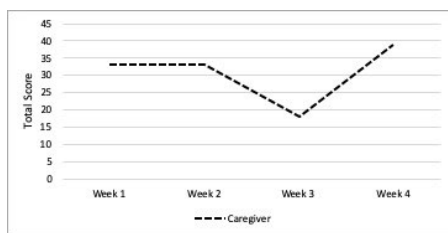


Figure 2. Child 2

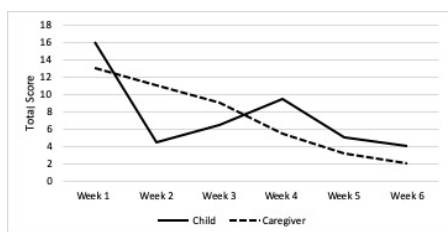


Figure 3. Child 3

Challenges and changes

While incorporating weekly MBC into CPHP, an initial challenge that we faced was determining which questionnaires to administer. We explored different questionnaires with good psychometric properties that had been adapted for both parent and child use. We ultimately found that brief questionnaires which target the patient's specific symptoms and treatment goals were quite effective. However, intensive multi-modal child treatment settings may also focus on other psychopathology or health domains, so we will also be testing the best way to supplement the

broad BFS with patient-specific domains of irritability, sleep disturbance, and suicidality. One example relevant to the cases presented is chronic irritability as all three youth demonstrated, which can be assessed by the Affective Reactivity Index. This is a short seven-item parent and youth report survey regarding irritability and the problems it causes (Stringaris et al., 2012). Another common co-occurring presenting problem is sleep disturbance, which can be assessed using the PROMIS Sleep Disturbance scale; a short weekly measure (four- or eight-item) with parallel youth and caregiver versions (Meltzer et al., 2020). Alternatively, programs could consider idiographic or person-specific goals such as the Top Problem Assessment, which is a three-item interview designed to help identify and monitor youth problems that are important from the perspectives of the youth and the caregiver (Herren et al., 2018).

Given the structure of our program, we also sought to find an appropriate time to administer questionnaires without disrupting the program routine. By incorporating these questionnaires into blocked times of the day, such as individual therapy, family meetings, and pick-up from the program, we found that we were able to minimize any inconvenience. These ratings are then entered and made available to clinicians, including quick-view options such as the percentage of symptom change from baseline or graphs of trajectories to share with patients.

Another consideration for launching the pilot trial was the need to inform clinicians of the new changes and to explain the benefits of these changes. Benefits that may be particularly salient are the use of the BFS for improving clinical care and for including easy-to-use data into weekly treatment plans to provide specific evidence for progress on treatment plan goals. Initiating open conversation about these changes allowed us to create an MBC system that is best adapted for our program. Naturally, as we continue to expand the use of weekly MBC in our program, we will continue to adapt and evolve the practices to best fit our needs. To programs who may be looking to incorporate weekly MBC into their standard practices, we recommend asking members of the treatment teams to openly share their concerns, observations, and ideas, as we found this to be paramount.

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Perinatal depression

From page 1

Social support and coparenting quality

There is compelling evidence that parents' mental health is interconnected and that the quality of the partner relationship influences how new parents cope with the transition to parenthood. One specific aspect of the partner relationship — coparenting quality — is a potent contributor to new parents' mental health. While the term "coparenting" sometimes refers to separated or divorced caregivers, all caregivers, regardless of relationship status, must coordinate and negotiate parenting responsibilities. Simply put, coparenting involves the way two or more caregivers work together to raise a child, including child-rearing beliefs (e.g., behavioral expectations) and decisions about who does what division of child-related labor. Coparenting ranges from navigating differences in religious beliefs and expected gender roles to day-to-day caregiving decisions related to sleeping arrangements and screen time.

There is some disagreement in the field about when coparenting begins. Does coparenting begin in pregnancy or when a baby is born? While there is no consensus, there is growing recognition that coparenting relationships originate during pregnancy and that prenatal coparenting behaviors can predict coparenting dynamics after childbirth. That is, the way in which individuals support each other, manage conflict, and communicate during pregnancy is related to coparenting dynamics and behaviors after a baby is born. Positive coparenting relationships, characterized by shared decision-making, sensitivity and respect for each other's perspectives, and limited undermining are associated with lower depressive symptoms for caregivers and positive developmental outcomes for babies. Therefore, supporting positive coparenting relationships early in pregnancy is an important strategy to enhance family wellbeing.

Who are the coparents in a family? There are endless configurations. Coparents are the adults responsible for the care and socialization of a child in a family and are typically the central attachment figures for a child. As McHale and Sirotkin (2019), two leading family scholars put it, "*Claims about who a child's coparents truly are or*

who they should be miss the basic point that in any given family system, they are who they are... Children see their families as the collection of individuals who love and care for them." Some coparenting systems involve two caregivers while others include three or more caregivers. Coparents may or may not be romantically involved, live in the same household, or share a biological relationship with each other or the child. As a generalization, coparenting configurations involving extended kin tend to be more common among families of color and among young mothers. Specifically, Black and Latinx women are more likely to share parenting responsibilities with their own parents than White women. Unsurprisingly, young women are also more likely to reside and coparent with their own parents and extended kin.

There is no ideal or aspirational coparenting structure; every coparenting configuration is as significant as any other. Indeed, a positive coparenting relationship is protective for mental health both among women coparenting with romantic partners and women coparenting with their own mothers. While less is known about the relationship between depressive symptoms and coparenting quality in other configurations, it is reasonable to assume that all coparenting systems can be sources of support or strain. For example, some pregnant people may turn to a cousin for transportation to prenatal appointments and support in developing childbirth plans and to their grandmother for assistance with infant care. These relationships should not be overlooked in their importance to the parent, child, and family system.

Despite the strong relationship between mental health, social support, and coparenting quality, many prenatal supports and treatments for depression focus on the individual rather than explicitly targeting the family system. While there have been increasing (and laudable) efforts to enhance father involvement during the transition to parenthood, these efforts do not always encompass the diverse coparenting configurations and strengths within many families.

Adopting a family-centered care approach means valuing and supporting the efforts of every family that is caring for — or preparing to care for — a child. Some general recommendations for family support professionals and health care providers are as follows:

- Family support professionals (e.g., home visitors, WIC providers) and health care providers should inquire about social support and coparenting early in pregnancy. It is first important to understand who is (and is not) part of the coparenting system. Do not make assumptions about coparenting relationships based on relationship status, residency, age, or any other variable. Providers should use open-ended and inclusive language. For example:

"Who are the important people in your life?" "How would you describe these relationships?"

"Who do you imagine will be the important people in your baby's life?"

"Who will help share in the care of your baby?"

"Tell me about your sources of social support"

"Who do you turn to when you have a problem?"

- Provide psychoeducation to families about the known association between social support, coparenting quality, and wellbeing. Highlight the ways in which all coparents contribute in important ways to parents' mental health and children's adjustment and development.
- Pregnant people may avoid bringing nontraditional coparents (e.g., friend, aunt) to prenatal appointments due to stigma or fear of negative judgment. Actively welcome and include all coparents in home-based services, medical appointments, and childbirth education classes. Coparents or support persons who are less commonly included in services may require explicit and enthusiastic permission to attend appointments, share concerns, or ask questions.
- Communicate that all coparent configurations are valued. Inclusive paperwork, reading materials, and office visuals send meaningful signals to families.
- Consider referring caregivers experiencing depressive symptoms or reporting low social support to group-based services in addition to needed individual supports. For example, Postpartum Support International (PSI) offers free pregnancy and parent support groups to all

Continued on next page...

caregivers. In addition to depression-focused referrals, relationship counseling or family-based services may be an appropriate referral for some families.

- There will be individuals who, due to circumstance or choice, lack access to consistent or safe support persons or do not plan to coparent. These individuals may be especially vulnerable to isolation and poor mental health. Group-based prenatal care may be an appealing option in these situations. For example, Centering-Pregnancy brings small groups of women together for group prenatal care and support; the model has been shown to reduce perinatal depressive symptoms and decrease the risk of preterm birth.
- The American College of Obstetricians and Gynecologists recommends that all pregnant people be

screened for depression during pregnancy and after childbirth using a validated screening instrument (e.g., Edinburgh Postnatal Depression Scale). Providers should also consider screening fathers and other coparenting partners for depressive symptoms during and after pregnancy.

Bolstering social support and positive coparenting relationships early in pregnancy may help prevent the development or worsening of perinatal depressive symptoms. Given that women of color are more likely to experience depressive symptoms during the perinatal period, and are more likely to coparent with extended kin, supporting and strengthening all coparenting configurations is an important strategy to reduce known maternal and child health inequities.

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Terminal cancer

Book sheds light on how to help child dying from cancer, by child psychiatrist dad

By Alison Knopf

Written by a child psychoanalyst, *A Short Good Life* documents the author's life with his daughter, Liza, during the two years after she contracted leukemia until her death at the age of six. The book is not sentimental, but heart-rending. Twenty-five years have passed since Liza died, but the pain remains; still, so does the learning, and the many lessons for parents and, especially, the health care system in the way it handles both parents and patients during this process.

CABL interviewed author Philip Lister, M.D., after the book was published last fall. Below is a summary of our interview, in which he talks about what he and his wife Elena, and Liza's older sister Molly, went through during those years.

CABL: Who needs help the most, the parents or the child?

PL: Whether a child with cancer needs help directly depends on a variety of things. There are many adults around the child and those adults probably need all the support they can get. The parents of the child

are the most influential supports. But how well-resourced the parents are is going to be a huge factor in how much they have available to give to their child, and also how they think about their child. These same factors affect the medical staff, who become very important supports to the family and the child. All of us, no matter what our training is, have a lot of feelings about dealing with vulnerable children. So, it's important to give support to the medical staff, so they can give their best to the family and the child.

CABL: Did your training as child psychiatrists affect the way you treated Liza as parents?

PL: Our training as child therapists caused us to be interested in following Liza's curiosity. We viewed her curiosity as a strength. To whatever degree she was curious about her illness, we wanted to answer those questions. We did not give her answers she didn't want, to questions she didn't ask. But if she was curious, we were going to provide education at an age-appropriate level.

CABL: Liza was obviously an unusual child, in being so curious about her illness, many adults don't even want to know as much as she did. How did you decide what information to give her and what would make her feel better?

PL: We tried to take into account that she was in a situation in which she had very little control. So, we wanted to look for ways she could have control. One way she could have control is about the flow of information from us.

CABL: What about the flow of information from medical staff? Was that just to you, leaving her out of it, or was she involved as well?

PL: Often the medical staff would say they wanted to prioritize efficiency, so they would just ignore the fact that the child was there. If we had a sense that what they were saying, or that including her, was likely to be disturbing to Liza, we would check to see if she wanted us to take the conversation into the hallway. If we saw that something was disturbing and stimulating, or if we saw that she wanted to hear about it, we respected that. But she pretty much always appreciated us taking the conversation into the hallway.

CABL: What were they thinking, these health care providers, talking about a child's terminal illness in front of her?

PL: I think it's easy for them to think, "It's just a little kid, she's not going to take in any of what I'm saying, I'm using fancy words like neutropenia, and we could just talk about that and the child won't care at all."

CABL: Did she care?

PL: Even when the child doesn't understand it, it doesn't stop the fantasy and the fear.

CABL: How did she and you handle the information that the cancer was terminal?

PL: There is a scene in the book about that. We first have the conversation in which we and Liza learn that she is going to die from her illness. We go home and Liza becomes confused. She thinks that "Maybe there is a medicine that is going to cure me." Elena and I are unsure of how to deal with this. We don't want to say "Stop it, we know you're going to die," but we didn't want to say "You're not going to die" because that didn't feel right either. So, we said "Why don't we meet with the doctor, he can answer your questions."

CABL: How did this meeting go?

PL: We weren't sure if she would even bring the questions forward. This is the meeting where the doctor said, "We think you'll live to be six, not seven." She said "I want you to try every medicine there is. I want you to say it back to me, so I know you understand." This is a powerful moment when she is so poised. At the end of the meeting, she said she wanted to see what her blood cells look like, so he kindly took us to a microscope and he pointed out the sick lymphocytes. She said, "Does it have to be my favorite color?" (Because of the dye, the cells were blue.) It was very respectful of the doctor, honoring her request.

For a serious illness diagnosis like cancer, the palliative approach should be present from the beginning. That is my pitch. The message should be that "This is going to be an emotionally challenging journey." Instead of ignoring that, care providers should make it explicit, and should say that they want to offer support so that the psychological stress can be worked with sooner rather than later, and that all suffering including emotional can be minimized.

CABL: Sometimes parents have a hard time bonding with a child who is going to die, it's a kind of self-protection, probably one that a psychoanalyst wouldn't resort to. But for the rest of us?

PL: This brings to mind a vignette in which a boy was very near the end of his life, and the parents were not willing to tell him that he was dying — and not willing for the staff to tell him that he was dying — because they didn't want to rob him of hope. I wouldn't say they failed to bond

with him, but there was a huge distance created between them and their child out of this well-intended kindness. They were trying to allow the child to stay hopeful, but in that way created a gulf, because the parents were feeling anguish, and they couldn't be open with their child. The question that I asked them was: "Have you considered that your kid might be lonely? It's plain as day that things are getting worse, not better." This led to opening up a conversation about what they were afraid of happening, if they were honest with their child about his imminent death. Then they saw that they could connect, and be sad together, and in the sadness there was togetherness. There are other situations in which parents pull away from their kid, usually out of a fear of heartbreak.

CABL: Do all children react with as much maturity as Liza to a terminal diagnosis? What about children who do not understand it?

PL: These were not in the book, but there were times when she didn't want to take her medicine, when she got very obsessive, picking her nails, staying on the toilet forever, wiping her bottom 1,000 times, so we, even though we're child psychiatrists, went to someone for help.

CABL: What could be done for a child who is exasperated at hospital procedures, day after day, night after night, not being home?

PL: At one point, during a long hospitalization when Liza was difficult with the nursing staff and with us, we did create a behavioral plan. Using a design with cows (Liza's favorite animal), there was a star chart. When Liza cooperated, she got the cow of her choosing added to the chart. This solution was the result of a discussion I had with a child psychologist. I vaguely recall the psychologist at first had trouble listening to us. But after she did listen, it was easy to create the behavior chart plan.

CABL: What would you recommend to child therapists working with families in this situation?

PL: I am saying child therapists can help the team, the medical care team, appreciate the richness of the child's mind and the child's response to the treatment. The child therapist can also help the parents appreciate how the child is processing the (trauma of) the medical interventions, and the entire medical journey. So, the first thing for psychologically astute clinicians to do is to simply open their minds and

hearts and listen to the family about what is going on, to give them a chance to voice their experience and worries. That's what the hospice person did for Elena and me. She gave us a sanctuary and a haven where we could voice our experience uninhibitedly to a caring listener. And we could hear each other in a way we couldn't before. That's an incredible experience, a chance to cry, grieve, express our exasperation, our struggle to take care of Molly and what her needs were. This was a child psychotherapist, like us.

CABL: How did you and Elena decide who would be in charge in communicating with medical professionals — you are both M.D.s.

PL: If you have two parents in a room, one might be the primary spokesperson. If the goal is to get the information, you only need to hear from one person. But if the goal is to bear witness, you need to hear from both people. The benefit is enormous, especially in families where one parent might be the primary caretaker, and the other is trying to keep the financial ship afloat. That parent might drift away. Just asking that question, "How is this going for you?" is helpful.

CABL: Who would you like to be the primary readers of your book?

PL: I hope this book can have a wide readership, as all of us contend with love and loss. More specifically, I'd love for health care trainees in medicine, nursing, and child life to benefit from the view of the patient/family experience. Also, I hope that other bereaved parents and their friends may take comfort in seeing that they are not alone and in seeing how much we have to offer one another.

CABL: I notice you did not put "M.D." after your name on the cover of your book. Is there a reason for that decision?

PL: While I am proud of my training, my M.D. is not the heart of what allowed me to write this book. Also, I am painfully aware of ways in which medical training creates armor that makes rich interpersonal contact between patient and provider rarer. What I am drawing on in writing this book is my life as husband and parent and my devotion to the craft of writing. Yes, my medical training and career does contribute in an interesting way to the book, but I am not writing as a medical professional or expert.

For more about the book, and Liza, go to <https://ashortgoodlife.com/>

Commentary

Increases in prevalence rates for autism spectrum disorder: Clinical considerations

By Anne S. Walters, Ph.D.



Among those working with children across a variety of disciplines, an increase in children presenting with symptoms of autism spectrum disorder (ASD) has been questioned. Further, questions about whether this is truly an increase in incidence or related to improvements in diagnosis and identification have been widely discussed. At times professionals are reluctant

to assign a diagnosis because we are trained to think that autism is a “rare” diagnosis. In fact, when I was first in practice many years ago, the rates were one in 10,000, and intellectual disability along with autism was common.

This picture has clearly changed, and recent statistics on the CDC (Centers for Disease Control and Prevention) website provide corroboration. A report from the Autism and Developmental Disabilities Monitoring system suggests that the prevalence of ASD among children aged 8 is one in 44 (Maenner et al., 2021). The same report notes that ASD is 4.2 times as prevalent among boys as girls and overall rates are similar across racial and ethnic groups. Children with IQ scores less than 70 had an earlier identification than children with IQs above 70.

What does this mean in our clinical work? First, if this diagnosis is a common one, we need to broaden our training in both diagnosis and treatment. There continues to be a sense that a diagnosis of ASD requires specialized training to recognize, and this may mean that we delay a diagnosis because education and mental health professionals do not put together the symptom picture or feel that they are not qualified to make the diagnosis. And this is completely understandable, for two reasons: first, preoccupation with Pokémon at age 5 is not likely to be as noticeably atypical as at 10, if he or she does not have any concomitant intellectual disability. The social demands are not as prominent at these early ages. But by the time children enter middle school — when social conformity is more valued by peers — social isolation and even targeting by peers can be more common. Second, the diagnostic process is complicated (and never more so than with masks!) and is best achieved with specialized assessment processes such as the ADI (Autism Diagnostic Interview) or the ADOS (Autism Diagnostic Observation Schedule). Training in these “gold standard” interview and observational assessments can be costly and difficult to find. If we can broaden the base of those trained to routinely assess for autism in its more subtle forms in early childhood and elementary years, then treatment can be available earlier and perhaps mitigate co-morbid diagnoses such as anxiety and depression.

Further, there is a reluctance to “make the diagnosis” out of fear that it will be overly stigmatizing. This too is understandable when what we think of as autism is the most impairing form of the disorder. Raising the question can also raise concern that you are limiting a child’s opportunities or placing them on a path to reduced

expectations. If we learn to see the more subtle forms of ASD, we should also be able to reduce stigma as the range of outcomes will be broader than previously thought as well.

In qualifying for accommodations or modifications to education, the primary question for any disability is “does it impact the educational process?” And for children on the spectrum, especially those with excellent rote memory or high IQ, there may not be obvious learning effects early on. And yet, as schools place more emphasis on socio-emotional learning, this would clearly be an area where children on the spectrum could benefit from increased support, even in the early years of schooling. Some schools already provide these “informal” interventions to children who do not have a 504 or an IEP — options such as lunch bunch or weekly check ins with a counselor are common. Unfortunately, these informal interventions tend to disappear as children enter middle school when they have multiple teachers and shifting groups of peers. At that point, parents must find a professional both to make a diagnosis and to advocate for increased services — all of which takes time and resources. Sometimes children fall apart as this is underway. Though some districts have developed a team of professionals with experience and training in working with children on the spectrum — it is often still the case that these are the most significantly impaired children.

Early intervention for ASD is not a new concept, and those children with a clear diagnostic picture from an early age are provided with services that are undoubtedly critical. We need to do better for the children that are more diagnostically subtle; broadening the training of our early- and elementary-aged clinicians and education professionals to provide formal, standardized assessment and treatment, and ensuring that increased services and supports are available.

Maenner MJ, Shaw KA, Bakian AV, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years- Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018. *MMWR Surveill Summ* 2021; 70(11):1-16.

Pediatricians call for ‘reproductive justice’ for young patients

By Alison Knopf

Declaring that young people need more autonomy in their reproductive decision-making, pediatricians are calling for “reproductive justice,” which sets the stage for interactions with adolescents’ care providers. This discussion goes way beyond the abortion controversy and focuses on the lack of training most pediatricians have in contraception counseling, according to a viewpoint published last year in *JAMA Pediatrics* describing how the “reproductive justice” movement fits into pediatrics.

The definition of reproductive justice is “the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities,” according to the 2017 publication “Reproductive Justice: An Introduction,” cited by the authors of the *JAMA Pediatrics* viewpoint. The concept of reproductive justice started in 1994 by the group Women of African Descent for Reproductive Justice, and focuses on the need for going beyond the individual patient to a broader societal understanding — beyond even reproductive “rights.”

Unlike “reproductive health,” which focuses on services provided to an individual patient, “reproductive rights” focus on the legal protection of the right to certain services — including abortion. But “reproductive justice” goes farther, with a call to “understand and root out reproductive oppression to achieve human rights and social justice,” according to the 2017 publication.

The reproductive justice movement recognizes that marginalized communities have even less access to contraception and abortion care. Marginalized communities also have been subject to forced and coerced sterilization, the viewpoint notes. And these “services” have been carried out by the medical community.

Special issues facing pediatric patients

Some of these rights — to abortion, certainly, but even to contraception — are difficult enough to maintain for adults. What about for minors?

Comprehensive contraception counseling is standard of care in pediatrics, and many clinicians now try to increase access to long-acting reversible contraception instead of counseling alone.

“Many pediatricians express concern about the age of patients making reproductive choices and, as such, advocate for long-acting reversible contraception in all adolescent patients,” the authors of the viewpoint write. “While

this may be discussed flippantly, real harm is perpetuated by prioritizing public health goals over an individual patient’s reproductive goals and bodily autonomy.”

And paternalism is abundant in pediatrics, with some clinicians still believing that an adolescent’s top priority should be a delay in childbearing. The authors of the viewpoint assert that this attitude is often fraught with implicit bias, in which “the fertility of certain patients is valued over others.”

Forced sterilization is no longer legal, but there are more subtle attempts to influence contraceptive decision-making, mainly by providing financial incentives, pressuring patients to choose specific methods, or refusing to remove long-acting reversible contraception until after a trial period. The viewpoint claims that the medical profession has not acknowledged its “untrustworthiness with respect to populations who historically have been and continue to be marginalized.” Just acknowledging that this is a problem would be the “first step toward change,” the authors write.

Listening to patients

The authors assert that clinicians should “trust that young patients do know themselves better than we can when it comes to this deeply personal aspect of their life.”

Contraception is not a “bandage solution” for poverty, but it is sometimes used that way, the authors write. The main reproductive challenge young people face is not unintended pregnancy, but rather socio-economic inequalities which give some people more bodily autonomy than others, the reproductive justice movement holds.

Used as a tool against marginalized communities, control over reproduction, especially in young people, is not a good way to begin a relationship with medical providers.

Of course, pediatricians aren’t the only specialists helping young people with reproductive health. Family medicine and obstetrician-gynecologists have already integrated reproductive justice into their training. But pediatric trainees report low confidence with contraception counseling, according to a recent article by Davis et al.

Contraception and other reproductive decision-making is not something pediatricians are used to, the authors write, but it is an important part of the transition from adolescence to adulthood, and from pediatric care to adult care. “As pediatricians, we owe it to patients to model

justice-oriented, patient-centered care that affirms their autonomy and dignity,” the authors conclude.

Cohen RE, Wilkinson TA, Staples-Horne M. The need for reproductive justice in pediatrics. *JAMA Pediatr* 2021 Dec 1; 175(12):1207–1208. doi: 10.1001/jamapediatrics.2021.2978.

Also see:

Davis SA, Braykov NP, Lathrop E, Haddad LB. Familiarity with Long-acting Reversible Contraceptives among Obstetrics and Gynecology, Family Medicine, and Pediatrics Residents: Results of a 2015 National Survey and

Implications for Contraceptive Provision for Adolescents. *J Pediatr Adolesc Gynecol* 2018 Feb; 31(1):40–44. doi: 10.1016/j.jpag.2017.09.007. Epub 2017 Sep 21.

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