LESSONS FROM THE ADAPTIVE CARE TEAM:

Strategies for Working with Patients with Developmental Disabilities

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As I started my career in child life, I imagined implementing medical play preparation with school-aged patients, using bubble wands and light spinners for distraction, and having play sessions in the playroom. However, what I had not pictured was developing a passion for working with patients with developmental disabilities.

During my child life education, the emphasis was primarily on understanding the behaviors and reactions of neurotypical children. While this knowledge is essential for our profession, it leaves a gap in preparing us to effectively engage with children who do not fall under the category of "typically developing." Throughout my internship, when tasked with providing services to patients who had developmental disabilities or exhibited behavioral concerns, I frequently experienced discomfort and a sense of unpreparedness. Healthcare students do not receive adequate training in working with patients with these types of disabilities, making them feel less competent and prepared when working with this population (Sharby, Martire, Iverson, 2015). Due to the lack of training and experience, I often prioritized other patients with whom I felt more comfortable working.

Upon completing my formal education, I worked as a therapeutic rec specialist on a pediatric inpatient psych unit. During this period, I gained experience in responding to intense behaviors, such as physical and verbal aggression, self-injury, and suicidal ideation. I developed essential skills in de-escalation strategies and crisis intervention. After a while, I took a position as a Certified Child Life Specialist working in a large children's hospital on the Adaptive Care Team. In essence, the Adaptive Care Team (ACT) is a group of child life specialists dedicated to supporting patients with developmental disabilities who encounter challenges in coping and cooperating during hospital encounters.

Since starting this work, I have gained a fresh perspective on working with patients with developmental disabilities and behavior challenges. Our team's priority is identifying each child's stressors/triggers and providing preventive recommendations. This approach addresses the child's specific needs, minimizing escalation risk and facilitating a productive visit through the thoughtful collaboration of staff, caregivers, and patients. I realized my previous hesitation in working with this population was due to my lack of understanding.

Adaptive Care Team Approach

A large part of my role is to help create an "Adaptive Care Plan" for each patient, which is documented in the patient's chart. Our team provides support in outpatient clinics, but the plan can be accessed by staff in all areas of the hospital. We can easily identify the patients scheduled for outpatient appointments each day and prioritize support based on the patient's coping ability, current behavior concerns, and the invasiveness of the appointment.

These interventions often entail extensive pre-visit planning and involve discussions with the caregiver regarding the demands of the visit, relevant behaviors, transition needs, useful preparation materials, and items in the visit that may aid in coping. This information is then communicated to the interdisciplinary team that will encounter the patient. Specific adaptations for a patient may involve bypassing the waiting room and going directly to a designated exam room, reducing the number of staff present during the visit, limiting touch time and clustering care, and/or removing unnecessary equipment from the exam room. For procedure-based appointments, such as a blood draw, we also coordinate with prescribing providers to determine the appropriateness of using anxiolytic medication.

If I have assessed that the procedure is not safe, I ask myself, "Could the patient return at a later time with additional support or a more effective coping strategy in place?". If the procedure isn't urgent, it may be beneficial to consult the patient's primary care provider regarding behavioral observations and the potential need for medication. At times, caregivers may insist on proceeding despite safety risks. I emphasize the patient's emotional well-being at that time, highlighting the potential long-term impact on trust and future procedures.

Additional Education and Training

I've had numerous opportunities to learn and develop personally in my current position. Each child life specialist on the Adaptive Care Team must complete Therapeutic Crisis Intervention training, a training dedicated to proactively preventing and de-escalating potential crises. This training gave me the knowledge and confidence to create a therapeutic space and aid in crises. TCI also provides hands-on teaching for physical interventions that reduce the risk of harm to

patients and staff. Another similar program that may be beneficial is Crisis Prevention Institute Training.

My most impactful learning experiences have undoubtedly stemmed from hands-on practice and guidance from mentors. I am a "learn by doing" individual, finding that I gain comfort and confidence through active engagement. Engaging in challenging patient scenarios has been instrumental in helping me identify my personal biases and areas where I lack confidence. Being part of a team of multidisciplinary professionals has provided me with the opportunity to collaborate, experiment with interventions, and receive valuable feedback. In hospitals without dedicated adaptive care staff, it may be beneficial to shadow and collaborate with staff who often work with patients with developmental disabilities. Some examples include occupational therapy, speech therapy, behavioral health facilitators, and psychiatrists. These individuals may be able to provide insight on strategies including visual supports, language and prompting, the use of medications, and ensuring safe positioning during care.

In my previous position, I often felt helpless in escalating situations and followed the lead of others around me in reacting. With experience and a team that helps me grow, I recognize factors that may play into a patient's behavior. In situations where escalation occurs, I have a toolbox of strategies to implement before physical interventions. I work diligently to inform other staff members on what to expect and how best to respond to the behavior. I love getting to highlight each patient's strengths and celebrate the things they can accomplish.

Supportive Strategies

1. Assess the environment and its potential impact on the patient. Environmental modifications may be beneficial, such as dimming the lights and limiting noise levels.
2. Use visual aids such as visual schedules and timers to provide ongoing reference points to track progress and establish predictability.
3. Utilize a slow, calm approach with few words. Repeat requests and allow extra time for the patient to process what is being said.
4. Avoid unnecessarily touching the patient, such as rubbing their hands, touching their face, or patting their back.
5. Silence can be effective during escalation. Use brief statements like "I understand you're upset" or "this is hard." Encourage non-essential staff to step out, allowing the child to calm down.

References:

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