
Optimizing the Office Visit for Adolescents with Special Health Care Needs



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Youth with special health care needs (YSHCN) experience health care disparities and often need additional support to receive optimal medical care, particularly in adolescence as they prepare to transition to adult care. Many medical practices struggle to address their needs. Here, we discuss approaches to improve medical care in office-based settings for YSHCN. Office visits can be optimized by training staff in developmentally appropriate care and ensuring that the physical office space facilitates care. Participating in previsit preparation, including managing patient registries of YSHCN, engaging in regular team huddles, and incorporating previsit planning, can improve preparation and ensure that important needs are not overlooked. Additionally, approaches to improve patient and medical provider comfort with office visits

with YSHCN, including approaches to measuring vital signs, examining patients, and communicating with patients with various disabilities, are reviewed. Finally, we discuss methods of supporting adolescents with special health care needs in developing self-management skills that will allow them to be better prepared to enter adult health care settings when appropriate. Although YSHCN can present challenges to medical teams, their care can be improved by developing office-based changes and processes to support improved care for these patients. This may help overcome the health care disparities they experience and increase comfort for all members of the medical team.

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As children reach adolescence, many experience changing roles in their participation in health care. Although this change in role can impact all adolescents, it is more complex and challenging for youth with special health care needs (YSHCN), such as those with physical or developmental disabilities. YSHCN have been shown to experience health care disparities.¹ Below, we discuss approaches to optimize care for this vulnerable population.

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Creating the Right Office Environment

One's ability to access health care is tightly linked to the location and space in which this care is provided. When caring for YSHCN, it is important to consider the office environment and ensure that proper measures are taken to provide a setting that is both physically and culturally appropriate.

Recently, it has become very common to speak of cultural humility, which is the ability to maintain an interpersonal stance that is other-oriented in relation to the most important aspects of another's cultural identity, in the clinical setting.² Cultural humility also involves the ongoing process of self-reflection and introspection into one's own biases and beliefs as they relate to interactions with others.³ The most widely accepted definition of culture is that of Bates and Plog (1991) which states that, "culture is a system of shared beliefs, values, customs, behaviors and artifacts that the members of a society use to cope with their world and with one another."⁴ It is also critical to recognize that culture is dynamic and may change over time. While there has been significant focus on

understanding culture in the context of ethnicity, religion, and sexual preferences, little discussion has occurred related to the culture of disability.⁵ Programs caring for YSHCN should integrate practices and protocols that are mindful of the culture of disability in order to provide an optimal clinical environment.

Training of the entire care team, including front office staff, the office manager, medical assistants, pharmacy staff, social workers, nurses, and mid-level and physician providers, is critical to ensure that the care provided is patient-centered and delivered in a respectful and effective manner. The care team should receive training that promotes comfort in caring for YSHCN and flexibility in meeting patient needs.

Comfort in Caring for YSHCN

Education about the key diagnoses managed in the clinical program will assist staff to understand why certain behaviors may occur and to identify more effective means of communicating and interacting with patients and families. Team meetings, where diagnoses and challenges in care for specific patients are discussed, will also help to alleviate discomfort in working with certain patients or families. Staff training on reading patient cues and adjusting interactions accordingly should be provided. Patients may need movements to be slow, actions explained in advance or sensory stimuli minimized in order to have a positive experience in the office or clinic. Recognizing patients with anxiety or obsessive-compulsive or repetitive behaviors that may interfere with obtaining vital signs or a complete examination allows for advance planning on how to approach the situation. Staff also require training on safety strategies and ways to de-escalate aggressive or impulsive behaviors that may be triggered by the stress of a medical visit. All measures should be taken to

We always take the first appointment of the day and ask to be roomed right away, as he [patient] can't handle all the kids in the waiting room. They make him anxious, very very anxious.
— ***Parent of young adult with Autism Spectrum Disorder***

ensure that staff feel competent in caring for YSHCN in order to minimize anxieties for the patient and caregiver.

Flexibility in Meeting Patient Needs

Clinic staff and providers must be flexible with regards to protocols and practices that may be difficult for YSHCN to follow.

For example, special exceptions may be permitted when patients arrive late due to difficulties with mobility or transportation. With regards to communication, staff and providers should ask how best to communicate with the patient and family and have resources on hand to optimize all interactions. Examination may also be limited due to sensory abnormalities or difficulties the patients may have in following instructions. Providers may tailor the examination to the comfort level of the patient and use progressive desensitization techniques over time to increase the patient's tolerance of various procedures performed during the office visit.⁶ Office staff may assist in scheduling a social visit to familiarize the patient with the office.⁷ Adaptability and creativity are key in order for the patient and family to feel comfortable.

Physical Space

In addition to developing respectful and understanding relationships that address patient and family needs, the physical space must also be set up in a manner that promotes accessibility and minimizes barriers to proper evaluation. There needs to be an accessible path for the patient to and from the exam room, including a door width that allows for safe maneuvering through the entrance of the room. Wheelchair scales, height adjustable beds, presence of

It's always a challenge getting out of the house. We were all loaded in the van ready to go and then she soiled herself all over the place. Back into the house, washed her up and we were an hour late for the visit. Luckily they still saw us.
— ***Parent of young adult with Cerebral Palsy***

staff or lifts to facilitate transfers, and rooms large enough to fit stretchers, if needed, are some examples of the accommodations that may be required.⁸ If possible, supports for transfers, such as rails, straps,

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