Improving Quality Care for Children with Autism Spectrum Disorders in Doctor’s Office or Outpatient Clinics

Shafiqa Mohammed Al-Sharif1, Suba Sivakumar2 and Manikkavasaghar Thiruvasarh2
1Emergency Department, King Abdul-Aziz University Hospital, Jeddah, Kingdom of Saudi Arabia
2Bracebridge Court, London, Canada

Abstract

Psychological problems, communication challenges and cognitive impairment are often present in children with Autism spectrum disorders (ASD). When children with ASD require medical treatment, healthcare teams’ inability to access relevant medical and behavioral information, lack of awareness of these challenges, and poor preparedness to deal with unusual and unexpected behaviours can lead to suboptimal care. Children’s behavioral issues can hinder proper diagnosis and necessary medical procedures that need to be performed by health care professionals. This paper briefly describes the behavioral and psychological issues in children with ASD and raises awareness for interventional measures and best practices that could be adapted by health care professionals at family practice to improve quality care for children with ASD.

Keywords: Children; Autism spectrum disorders; Outpatient clinics; Medical records

Introduction

The World Health Organization estimates that one in 160 children has an autism spectrum disorder (ASD). About seventy two percent of these children also have additional psychiatric conditions [1]. Children with ASD exhibit wide range of behavioral and psychological problems. Cognitive and social behavioral abilities of children with ASD can range from gifted to severely challenged and totally independent to needing help with all their daily basic routines. Thus this wide spectrum of symptoms and psychological issues, challenges service providers such as healthcare teams in hospitals, clinics and doctor’s offices. To develop personalized quality medical care for children with ASD, healthcare teams needs to understand each child's medical, psychological and behavioral issues, stimuli that triggers stress situation and all relevant past history and events in diverse social settings such as doctors office, clinics and schools. It is suggested that irrespective of how the symptoms are displayed by children with ASD, they all have some core deficits; Deficits in: perspective taking, comparative thought process and interpretation, understanding and adaptability to change, creative thought, decision-making, and memory of past events. Primary care physicians or family doctors who have consistent interaction with children with ASD are in a better position professionally, to identify and record core deficits for a given child with ASD. It has been suggested that the development of comorbid psychopathologies is a reaction to the core deficits [2]. To provide quality care for children with ASD, it is important for primary physician to perform timely diagnosis of core deficits for each child with ASD, interpretation of such data into useful knowledge by utilizing psychological research about children with ASD; converting such knowledge to apply in clinical settings, implementing effective medical recording and delivering health information technology.

Psychological and Behavioral Challenges

The initial clues that a child may have ASD are usually noted between the ages 18-24 months and include difficulties with communication, abnormal social interaction, and performing repetitive, and stereotyped behaviors such as , twirling strings or spinning [3,4]. Early diagnosis and intensive treatment can help some children (25%), but most of these children (75%) have lifelong disability [3]. Children with ASD demonstrate a greater rate of anxiety and depression problems which could have significant impact on their overall adaptation, separation anxiety and obsessive-compulsive disorder [5,6]. At outpatient clinics or doctor's office due to anxiety children with ASD may have meltdowns or angry, hostile and violent behavior and may cause harm to themselves, their care givers or the health care team [1]. Children with ASD are more likely to be in a disadvantage position to receive quality therapeutic and specialty care due to behavioral challenges [7]. These children also have sensory issues such as sensitive to light, sound or touch [3]. It is important for primary care physicians to identify these children early and take prompt steps such as refer to a specialist for definitive diagnosis if needed or refer these children to speech and language therapists and occupational therapist for timely interventions and treatment at the earliest opportunity even if the definitive diagnosis has not been made.

Family Interventions

Most parents of children with ASD may learn and utilize unique strategies to calm their children. Involving parents or care takers to calm their child with ASD during health care encounters is an important and effective strategy to enhance treatment effectiveness [3]. Physicians could create essential information card with the diagnosis, medications, emergency contact information for parents/caregivers for these children and we recommend to specifically including core deficit information to use in clinical setting. These cards should be carried by the child and the parents should be requested to bring these cards whenever they visit a clinic or hospital. Parents should be informed to
add or update information on their child’s difficult behaviors and hints to improve compliance [8]. Asking the parents or child what calms them and what actions or procedures make them anxious early in the encounter would help the child, families as well as the health care team. Sometimes telling these children that they can express their feelings, fear, frustration and anxiety also calms them down [9]. Many children have special objects such as a toy or a blanket that they find comforting and parents should be told and encouraged to bring them. Coping kits such as, social stories, and sensory regulation items such as ear muffs, sensory input activities (a spinning wheel or a plastic ring that can be licked or bitten into) have also been shown to be useful in autistic children [10].

Effective Measures at Outpatient Clinics or Doctor’s Office

With increasing number of children with ASD, doctor’s office and outpatient clinics will be serving more of such children. As ASD includes wide range of psychological issues, it is essential for each clinic to develop strategic plans and protocols with their available resources to provide better care to suit each child with ASD.

When scheduling doctor’s appointments for children with ASD, it is advisable to reduce wait times and also accommodate the most suitable time for the child when he/she feels calm and also the time when the child’s family can help with the visit. It is important to understand that these children may be unpredictable and medical institutions should make necessary arrangements and adequate staff to handle any unexpected behavior [3,4]. Maintaining consistent time slots for children with ASD may improve these children’s comfort level [11-12]. When addressing health issues for core ASD symptoms and other co-occurring health issues, some of the following practices such as establishing routine bookings for outpatients clinics early to ensure that the child has a consistent schedule and environment for the visits, for example the family being put in to the same examination room every time, the nurse taking the weight first before doing any vital signs and the doctor letting the child touch the stethoscope before examining the child may help with compliance. Electronic devices such as ipads and other visual cues such as pictures, mini picture stories have also been shown to be helpful for children with autism spectrum disorders [12,13].

Medical records are maintained to facilitate the medical team to provide quality care and continuity, assessment of care and aide in investigation. In different medical clinical settings medical records are generated using paper or electronically. When creating medical records for children with ASD, it is recommended to identify unique needs and requirements for these children; such as specific temperament pattern being highlighted in the medical records to draw doctor’s initial attention. This information should be clinically available for health care teams to serve such children better [14-17]. The disparity in support at doctor’s office between children with highly-educated parents and parents with poor background could be minimized by developing personalized care for children with ASD utilizing efficient information capturing and sharing methods. Medical recording and other procedures at healthcare settings could be re-engineered utilizing modern information technology solutions to provide secured personalized quality care for children with ASD.

Conclusion

Children with ASD have medical, psychiatric and behavioral issues that often need visits to doctor’s office, clinics and hospitals. We believe that medical community should work together to identify unique needs and challenges in providing quality care for children with ASD. We recommend effective measures should be developed by different clinics with their available novel resources to better serve the community of children with ASD and their families. Health care teams in doctor’s office and outpatient clinics should be continuously trained and educated to manage and provide better care for the increasing population of children with ASD.

References