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Review

Healthcare Issues in Children with Developmental Disabilities (Autism)

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ABSTRACT

Developmental disabilities (DDs) refer to a group of conditions that influence the early development of children and cause changes in their normal developmental pattern affecting their physical, language and mental abilities or behavior. Children with DDs just like normally developing children have health issues that need to be addressed. This special group of children especially those having autism frequently suffer from associated conditions such as gastrointestinal disorders, eating and feeding challenges, seizures, sleep disturbances, attention deficit and hyperactivity disorder, and anxiety among others. These health problems affect the health of these children in different ways and extent. Thus, children with DDs need to access healthcare services and receive quality medical care just like their normally developing peers. However, the health needs of children with DDs particularly autism are not being met as required even though this special population are more likely to seek medical care due to their disabilities and associated conditions. Children with autism and other DDs experience disparities in health and healthcare service utilization. Autism is linked to many health conditions such as epilepsy, gastrointestinal problems and other mental disorders. These health problems affect each individual with autism in a unique way negatively affecting his/her existing social interaction and communication impairments. Again, health facilities and medical equipment are not disability-friendly making it difficult for this special group to effectively have access to quality care. In addition, most healthcare providers do not possess adequate knowledge and skills required to make critical decisions regarding this very special group of persons. Furthermore, due to cultural differences certain diagnosis and treatment regarding autism and other developmental disabilities may not be welcomed. The public health sector of all nations has the duty to promote health and prevent diseases for all including persons with disabilities.

Keywords

Developmental disabilities; Children with autism; Health conditions; Disparities in health; Disparities in healthcare service utilization.

INTRODUCTION

Developmental disabilities (DDs) refer to a cluster of disorders that affect children early in their lives due to abnormal development. Autism, learning disabilities, visual impairment and down syndrome among others are some examples. These disorders alter children's normal developmental pattern and affect their physical, language and mental abilities or the way they behave.¹ With some disorders such as Down syndrome, the abnormal development may affect both physical and mental abilities of the child. Children with DDs just like the normally developing children have health issues that need to be addressed.

This special group of children especially those having

autism frequently suffer from associated conditions such as gastrointestinal disorders, eating and feeding challenges, seizures, sleep disturbances, attention deficit and hyperactivity disorder (ADHD), and anxiety among others.² These health problems affect the health of these individuals in different ways and extent. Thus, children with DDs need to access healthcare services and receive quality medical care just like their normally developing peers.

However, this special population experience major health and healthcare service disparities. Health disparities are differences in health outcomes (which could be avoided) within groups in the population reflecting the behavioral, sociocultural, biological, and environmental factors or social inequalities that exist within the population.³ Developmental disabilities particularly autism and its

associated co-morbidities influence the health of each individual in unique ways and varied degrees. Literature reveals that adults with disabilities most commonly report fair or poor health conditions compared to their normally developing counterparts (40.3% vs 9.9%). In other words, persons with developmental disabilities experience major health disparities owing to their poor physical and mental health states.

Also, in most cases healthcare providers do not carry out a comprehensive physical examination on many children with developmental disabilities.⁴ This may be due to the non-availability of equipment and materials such as weight/height scales, clerking protocols and examining tables among others, adapted to accommodate their varied disabilities. This could have been because of the lack of awareness, poor policy and/or limited resources especially, in resource limited nations like Cameroon.

Disparities in accessing health services, high-quality and safe care for patients with disabilities exist due the lack of adequate systems of care.⁵ This issue is a major problem particularly for persons transiting from children to adult healthcare service providers as their healthcare and social needs are not being met. These disparities in unmet healthcare needs of persons with disabilities particularly those with DDs is a glaring example of what must be done to enhance accessibility to healthcare.

For instance, there are few standardized models prescribing the guidelines for caring for this special group such as the adult disability medical healthcare (ADMH) developed for patients with developmental disabilities. This model advocates for the delivery of a complete, compassionate, coordinated and continuous patient- and family-centered care based on evidence, which is accessible to adults with developmental disabilities.⁶ Therefore, persons with DDs should be able to access healthcare services that do not only meet their physical health needs but also the psychosocial and mental aspects of their health including health promotion and disease prevention. This paper sought to:

1. To critically examine disparities in health and health services experienced by individuals with developmental disabilities particularly autism.
2. To describe the health conditions frequently associated with autism and their treatment options.
3. To critically examine challenges faced by individuals with disabilities in accessing appropriate medical, dental, and mental health services.

DISPARITIES IN HEALTH AND HEALTH SERVICES EXPERIENCED BY CHILDREN WITH AUTISM AND OTHER DEVELOPMENTAL DISABILITIES

Children with autism experience high rates of morbidity and reduced life expectancy (particularly the disadvantaged) compared to typically developing children.⁷ A variety of physical and mental-health problems are commonly associated with autism such as gastrointestinal problems, epilepsy and anxiety among others. Despite the fact that children with autism are affected by varied co-morbidities the healthcare needs of individuals with autism are given little

or no attention.⁸ This may be due to inflexible healthcare policy and knowledge gap on the part of healthcare providers.

Worthy of note is the fact that as this special population increases in proportion and becoming fully incorporated into the society it is vital to comprehend their health status and disparities in health and healthcare services.⁸ This will assist the formulation of physical and mental health promotion and disease prevention frameworks that would provide the unique needs of this special group of individuals. It is important to note that in this paper autism spectrum disorder (ASD) and autism are used interchangeably. The following subsections examine disparities in health and healthcare services experienced by children with autism and present a public health approach to reducing health and health service inequalities among persons with autism and other developmental disabilities.

HEALTH DISPARITIES EXPERIENCED BY CHILDREN WITH AUTISM

Health status and life expectancy vary between children with autism and typically developing children, as well as among children with autism. Literature reveals that persons with ASD experience increased morbidity and early mortality compared to normally developing individuals.⁹⁻¹¹ In addition, literature has clearly documented huge disparities experienced in terms of accessing early diagnosis and support services by persons with autism who are disadvantaged due to their culture, gender, race, and ethnicity among others. This results in even higher disparities in health status and decreased life expectancy experienced by disadvantaged individuals with autism.

Furthermore, disadvantaged persons with autism reported poorer access to healthcare services and increased risk for negative health outcomes compared to typically developing children and children with autism who are not disadvantaged. However, persons with autism who are not disadvantaged have a life expectancy that is averagely 28-years lesser than the normally developing individuals.¹²

Children with autism having comorbid intellectual disabilities (ID) are more prone to physical health problems while those without ID are highly susceptible to mental health disorders as well as unusual suicide rates.¹³ Among persons with autism without ID suicide is the greatest cause of premature mortality (they die 12-years earlier). Thus, it can be seen that premature mortality rates are considerably higher among this special group compared to the so-called normal individuals.

Thus, there is absolute need to put in place strategies to promote health and prevent diseases for children with autism. According to the Fundamental Causes Model of contextual health disparities, health disparities provides an insight of the extent to which individuals can potentially avoid risk.³ In other words, understanding the concept of health disparities directs the putting in place targeted interventions to decrease disparities and improve health outcomes.

In addition to the disparities mentioned it is stated that higher rates of adverse physical health outcomes occur among adults with autism while gastrointestinal disorders, sleep and feeding problems, as well as epilepsy are common in children with ASD.¹⁴ Also, evidence for high rates of cardiovascular problems and mental health conditions including early signs of Parkinsonism have been found in adults with autism. Again, it has been reported that adults with autism are usually affected by visual and hearing impairments, which negatively affect their existing impairments in social interaction and communication.

Finally, there exist disparities in etiology between ASD and other related developmental disorders. Autism is said to be associated either with chromosomal abnormalities, Fragile X, single gene mutations, genetic syndromes, Tuberous Sclerosis and *de novo* copy mutations among others.³ Also, biological factors such as increased oxidative stress, shortened telomere length, perturbed proteostasis and the malfunctioning of hypothalamic-pituitary-adrenal axis among others may increase the likelihood of developing autism. It is important to mention that little or nothing is known regarding health disparities in ASD among the middle age and older adults. This needs to be taken in to consideration in order to establish accurate health outcomes especially for persons who are moving towards their end of life. This will ensure that children with DDs grow healthily through adulthood.

DISPARITIES IN HEALTHCARE SERVICE UTILIZATION

Literature reveals that there exist disparities in healthcare service utilization in relation to cost for persons with disabilities. Up to 15% of individuals with disabilities are unable to access medical care due to cost compared to six percent of individuals in the general population. Despite the fact that children with autism are associated with higher healthcare utilization rates, they experience poorer access to healthcare services and medical homes compared to normally developing children.¹⁵

In addition, children with ASD experience disparities with respect to accessing early diagnostic and intervention or support services. Even though, autism can be diagnosed as early as 12-months of age most children with autism are usually diagnosed at about four years or later.¹⁶ It is believed that socioeconomic status, race, neighborhood disadvantage and culture play a major role in the disparities in ASD diagnosis. For instance, African American children receive their first autism diagnosis at least one and a half years later than their European American counterparts do.

Similarly, children from households with poor socioeconomic status and/or from high disadvantaged neighborhoods,¹⁷ are also more likely not to be given an autism diagnosis on time. Worse still in resource limited nations Cameroon inclusive, most children with autism are not being diagnosis. In addition, there exist disparities in the availability of and access to autism treatment services. For example, children from poor socioeconomic background have access to fewer hours of autism treatment services, while others particularly from less developed countries such as Cameroon may not even have access to treatment services. This may result in increased adverse physical health outcomes in the lives of this special

group of individuals in the future.¹⁸

Furthermore, parents of poor socioeconomic status having children with ASD stated poorer access to care for their children; they do not get early and continuous access to care. Again, others have reported disparities in the quality of healthcare and access to general and specialist medical services.⁷ Some studies have reported disparities among parents of children with autism in terms of getting referrals as required.

Literature reveals that most often some children with autism do not have access to specialist care especially children from developing nations such as Cameroon, African American and Latino among others. For instance, a study revealed that children with autism from Latino and African American experience lower rates of neurologic screening and scarcely see gastroenterologists, nutritionists, neurologists, psychiatrists and psychologists.¹⁹ The situation is even worse in some African countries like Cameroon where most healthcare provider are not aware of autism and its associated health conditions and the available specialists are only found in urban areas.

Moreover, there are disparities with respect to gender and geographical location.²⁰ Literature holds that among children with autism having similar clinical and/or health service utilization needs females are more likely to receive psychiatric or emergency department services than their male counterparts are. Talking about geography, it is known that children with autism living in rural areas, especially those with multiple comorbidities, are more likely to travel to urban settings to use emergency department services than those found in urban areas. This is due to the lack of availability of specialist services in rural areas.

PUBLIC HEALTH APPROACH TO REDUCING HEALTH AND HEALTH SERVICE INEQUALITIES AMONG PERSONS WITH AUTISM

The Public Health Ministry or Sector of every nation has a vital role to play in promoting, improving and maintaining the health of the general population and ensure equity in health status for everyone including children with disabilities. As mentioned earlier in addition to their disabilities children with developmental disabilities frequently experience other chronic diseases and problems.²¹ Hence, the healthcare needs of children with autism is of paramount importance to the public health department since this group within the special population is highly vulnerable but hardly access existing healthcare services. Therefore, it is vital for every nation to meet the delicate health needs of persons with autism especially children. As it is mandatory for them to equally access healthcare services and receive quality care.

This however, requires the putting in place population-based strategies to inform and empower the target group and stakeholders.⁶ For instance, organizing health screenings yearly that incorporate practices, which are 'autism friendly' and promoting increased autism awareness among medical professionals, could help meet the comprehensive health needs of children with autism. Also, improving access to healthcare services by reinforcing

health and human services workforce capacity, could go a long way to reduce health disparities for individuals with autism and other developmental disabilities. Persons with developmental disabilities should be included in public health programs, and strategies for emergency preparedness and readiness should equally be put in place taking in to account individuals with disabilities in general. This will ensure that at any point in time issues related to health pertaining to children with developmental disabilities will always be included in health priorities.

Furthermore, data on disability should be regularly gathered and utilized to make decisions regarding public health activities.¹³ The following subsections present some of the ways by which the public health sector and related organizations can address health related disparities among persons with developmental disabilities and reduce inequalities.

INCORPORATING INDIVIDUALS WITH DISABILITIES IN PUBLIC HEALTH PROGRAMS AND SERVICES

Despite the Centers for Disease Control and Prevention (CDC) scheme calling on the total inclusion of individuals with disabilities in all programs, the society usually focuses on the disability rather than the unique abilities of these individuals. As a result this special group is often excluded from the usual public health programs and services. This leads to discrimination and isolation which in turn increase unemployment rates among this special population¹³ making most of them to live unfulfilling lives. This put individuals with disabilities in a disadvantaged position with great health consequences. Hence, if persons with disabilities are effectively included into health promotion policies and activities it will greatly improve their health and decrease inequalities in health and healthcare services.

EMERGENCY PREPAREDNESS AND READINESS TO PROTECT HEALTH AND SAVE LIVES OF PERSONS WITH DISABILITIES

Persons with disabilities are particularly vulnerable during emergencies and when disasters occur, since they are less likely to escape or be evacuated on time due to their disabilities. Emergency preparedness entails making plans and be ready to arrest and adequately handle the different types and stages of the multiple man-made and/or natural disasters that may occur. This plan that entails system-level responsiveness should consider including at all the stages of preparedness, evacuation, and recovery of every individual with a disability and his/her support systems within the community.¹³

Such emergency preparedness, health protection and live saving plans for persons with disabilities particularly children should also consider plans for modified shelter accommodations within the community.⁶ Also, the plan should make provision for the training of individuals with disabilities and families before, during and after disasters. Furthermore, organized planning and commitment is required to better address in particular, the needs of children with disabilities.

ACCESS TO HEALTHCARE AND HUMAN SERVICES

Children with autism have the right to fully access healthcare and healthcare services like the so-called normal or typically developing individuals. Health reforms are available that stipulate exceptional consideration for persons with disabilities including autism and condemns discrimination of any form among this special group.⁶ Hence, governments of nations particularly developing and underdeveloped countries need to respect these reforms in order to adequately meet the health needs of persons with disabilities and reduce inequalities in health and access to healthcare services.

Generally, literature reveals that children with disabilities do not have full access to healthcare facilities and services partly because their structures and equipment are not disability friendly. For instance, it was found that in California less than half of the primary healthcare facilities are fully accessible. In addition, these healthcare facilities have limited resources and equipment to accommodate people with disabilities⁸; what more of developing and underdeveloped countries. Since some of the medical equipment and materials employed to conduct complete medical examinations for this special population are not adapted for this special group, the care they receive is obviously limited. Healthcare providers especially nurses need to make their services accessible to all children with disabilities.²²

The disparities in accessing healthcare and healthcare services can be decreased by making the architecture of every health facility disability friendly and the available equipment and protocols should also accommodate all individuals with disabilities.¹³ The specifications should conform to the Architectural and Transportation Barriers Compliance Board (Access Board) standards for defining accessibility of medical equipment established in 2013. This will go a long way to enhance accessibility to care which will in turn ensure a comprehensive and quality care for all persons with disabilities particularly children with autism and other developmental disabilities.

ACCESSING APPROPRIATE AND TIMELY HEALTHCARE

Health promotion and disease prevention for children with autism in particular and adults in general are important parts of public health activities. The Westminster Commission on Autism advocated for preventive healthcare for adults with autism supporting the need for the detecting and managing individuals with autism's unmet health needs.²³ It is mandatory to organize autism training that includes staff awareness (nurses in particular), communication and reasonable adjustments with respect to environment and procedures. In addition, behavior management to support children with autism should be taken into consideration. Also of importance is the implementation of the Royal College of General Practitioners (RCGP) Autistic Spectrum Disorder toolkit, which could help make clear a range of modalities such as support in the delivery of reasonable adjustments, access to formal autism training, and clarifying issues of diagnosis and referral pathways.¹⁵ This will go a long way to make primary care practices autism friendly and ensure access to appropriate and timely healthcare.

STRENGTHENING HEALTH AND HUMAN SERVICES WORKFORCE CAPACITY

Due to the report on the poor health of children with disabilities there is need for capacity building for nurses and other healthcare providers regarding the care of individuals with disabilities. The lack of or limited knowledge and skills regarding the care of children with disabilities among healthcare practitioners act as a major barrier to the provision of competent and suitable healthcare to this special group.²¹ Literature reveals inappropriate care rendered to children with disabilities due to inadequate preparedness and lack of knowledge on the part of healthcare providers. As a result, the complex medical and psychosocial needs of children with disabilities are not met. Hence, building the capacity of healthcare providers (especially nurse who are the first to see these children) with respect to disability care is mandatory.

Such training may involve different topics including Public Health Workers and Clinical Care Providers' Awareness on Disability and Life Cycle, and Care for children with Disabilities among others.²⁴ Empowering healthcare providers with knowledge and skills regarding the care of children with developmental disabilities especially those with autism could go a long way to enhance early diagnosis and intervention for this special population. Approaches to reduce inequalities for children with disabilities are summarized in Appendix.

HEALTH CONDITIONS FREQUENTLY AFFECTING CHILDREN WITH AUTISM

Autism is the most commonly diagnosed among the developmental disabilities and it presents differently in children affected by the disorder. This is because it is a spectrum disorder which manifests in varied ways and degrees in each individual leading to unique experiences. Thus, no two children with autism are the same therefore, their unique abilities as well as challenges direct the type of support required to meet their needs including their healthcare needs.²⁵

Children with autism often face complex and diverse physical and mental health challenges including co-morbidities such as schizophrenia and bipolar disorders, sleep disturbances, seizures, eating and feeding challenges.²⁶ Also, they frequently experience gastrointestinal problems, epilepsy, obesity, ADHD, anxiety and depression. These are serious conditions that are experienced throughout life and which often impact the health and quality of life of individuals with autism negatively as well as resulting in an increased rate of premature death.¹² These conditions and their treatments are described in the subsection below.

Gastrointestinal Disorders

Gastrointestinal disorders (GI) are problems that most commonly affect children with autism when compared to their typically developing peers. Literature reveals that children with autism are about eight times more likely to be diagnosed with one or more chronic GI problems than are their typically developing peers.²³ Common examples of GI conditions include recurrent abdominal pain, di-

arrhea, gaseousness, bowel inflammation, gastroesophageal reflux, painful stooling and chronic constipation. Studies have revealed an association between chronic GI issues and increased severity of the behavioral symptoms of autism. These include social withdrawal, repetitive behaviors, hyperactivity and irritability. It is stated that the link is mostly strong among children with autism who are nonverbal and often have problems communicating pain and distress.

It is believed that unhealthy changes in the normal flora (the microbiome) in the intestinal tract cause both behavioral and GI problems in some individuals with autism. Also, it has been shown that the brain could be affected directly by spikes in toxin-producing bacteria in the intestines through the vagus nerve that runs between the digestive tract and the brain.²⁷ The following paragraphs examine GI problems commonly affecting children with autism.

CHRONIC CONSTIPATION

Constipation can be defined as difficulties producing bowel motions due to hard stools. According to CDC children with autism are more than 3.5 times likely to be affected by chronic constipation or diarrhea compared to normally developing children.²¹ Chronic constipation (lasting two-weeks or more) in patients with autism are mostly linked to insufficient fiber intake and some behavioral medications such as Risperidone. Also, sensory and/or behavioral issues that hamper regular toileting are implicated. Furthermore, metabolic, anatomic, or neurological problems and a sluggish intestinal tract are less common but potentially more serious factors that may predispose a child with autism to chronic constipation.

Constipation is effectively treated using a mixture of medical and behavioral interventions. Medications such as soluble fiber and/or laxatives for example, mineral oil, magnesium hydroxide or sorbitol could be used to manage constipation.²⁷ On the other hand, behavioral treatment entails modifications in diet for instance, eating more fiber producing foods, avoiding foods that cause constipation as well as instructing the individual to increase fluid intake and make attempts to defecate after each meal by sitting on the toilet pot.

CHRONIC DIARRHEA

Chronic diarrhea refers to the passing out of frequent watery stools more than three times a day for two or more weeks. Possible medical causes may include immune dysfunction, inflammatory bowel and irritable bowel diseases, intestinal infection. Recently, researchers have reported unusually high-levels of several kinds of toxin-producing Clostridia bacteria among children with autism.²⁷ It is believed that diarrhea in persons with autism is most often caused by severe constipation. This occurs when hard, impacted stool results in a backup of watery contents which then spill around the hard stool causing abrupt diarrhea.

The treatment of diarrhea depends on the cause therefore, to effectively treat diarrhea the cause must be investigated and addressed accordingly. For example, if diarrhea is found to be

caused by food allergies, over consumption of juice, lactose intolerance or celiac disease, changes in diet may treat the diarrhea.²³ Also, depending on the cause medications may be administered or a surgical intervention may be required.

GASTROESOPHAGEAL REFLUX DISEASE

Gastroesophageal reflux disease (GERD) occurs when the muscle between the esophagus and stomach is weakened allowing partially digested food and liquid mixed with stomach acid to move up out of the stomach. GERD may lead to ulceration of the esophagus and put the child at risk of developing esophageal cancer. Symptoms commonly include sensations of “heartburn”, pain and discomfort in the throat.⁷ It is important to note that pain and discomfort may be communicated by persons who are minimally verbal or nonverbal in atypical ways. These include an increased in repetitive behaviors and displaying self-injurious acts such as banging the head against the wall, as well as challenging behaviors. Sometimes, pushing out the jaw or tapping the throat, straining the neck and unusual body postures may be observed.

Also, the individual may experience chronic sore throat, cough, hoarseness, dental erosions, inability to eat and disrupted sleep.²⁸ In diagnosing GERD a thorough history taking and physical examination is conducted. This assist in eliciting information as to whether the manifestation of the unusual behaviors are initiated or worsened when the patient lies down since the lying position favors reflux of gastric contents. When GERD is severe and chronic specialized tests are ordered in order to identify acid levels and tissue damage in the esophagus.

Tips for relieving the symptoms of GERD include behavioral modifications such as raising the head when sleeping, eating small quantities of food, identifying and avoiding foods that are likely to elicit symptoms, and avoid eating just before going to bed. Medications such as antacids, histamine-2 blockers and protein-pump inhibitors may be administered.²⁹ For chronic and severe cases of GERD the patient is referred to a specialist.

EPILEPSY

Epilepsy also known as seizure disorder that affects just one to two percent of typically developing persons is common in about a third of individuals with autism. It is said that one in every four children with autism has seizures.²¹ Seizures occur due to lesions or cuts on the brain resulting in unusual electrical activity in the brain. Generally, it begins in either early childhood or adolescence. Occasionally, hyperpyrexia and difficulty sleeping contribute to the occurrence of seizures meanwhile if seizures are not managed or controlled sleep is disrupted. Its signs and symptoms most commonly include unexplained staring spells and confusion, severe headaches and involuntary or unusual movements. Also, the person may experience a brief loss of consciousness and or “blackout” and a body convulsion as well as stiffening of muscles and involuntary jerking of limbs.

Less commonly the individual may experience unexplained changes in abilities or emotions as well as sleepiness or

disrupted sleep which can in turn increase seizures.²⁵ In addition, there may be regression in normal development as well as inexplicable irritability or aggressiveness. It is important to note that just like autism, epilepsy is equally a spectrum disorder as it varies broadly in severity. Epilepsy in children with autism may begin at any age; however, literature holds that seizures mostly start in the preschool years and also in adolescence. It is usually difficult to diagnose epilepsy because many individuals with autism have difficulty recognizing and reporting their symptoms, and the symptoms do not always manifest outwardly.

Generally, the diagnosis of epilepsy is made using an electroencephalogram (EEG) in order for the individual to be treated properly and prevent brain damage. Several factors are taken into considerations before selecting an anti-epileptic medication. These include where the seizures began in the brain,²⁹ the kind and extent of seizures and their recorded EEG patterns. Worthy of note is the fact that anti-epileptic medications do not cure epilepsy, but are mostly used to prevent, control or decrease the severity of seizures. Another option is vagus nerve stimulation as well as surgery could be done to remove areas in the brain which produce seizures.

FEEDING AND EATING PROBLEMS

According to Kanner feeding problems are defining features of autism; about 7 out of 10 children with autism suffer from feeding and eating problems. It is estimated that close to half of this number presents with severe problems.¹⁴ An individual is said to have a feeding and eating problems when he/she does not eat enough, eats a lot or does not eat the right types and proportion of food. Generally, children with autism are very selective that is they eat only a few types of foods usually those with particular colors or textures and at times may display troublesome mealtime behavior. Still others exhibit Pica, which refers to the risky habit of eating nonfood objects for instance, ingesting dangerous and poisonous items or substances including nails, broken glass and pins, as well as swimming pool chlorine tablets and paint chips.³⁰

Pica habit can be deadly as it can result in infection, suffocation and perforation of the gastrointestinal tract as well as lead to poisoning.³¹ Other health complications related to pica habits are constipation, broken teeth and other dental conditions, bowel obstruction and chronic lead poisoning.

Eating problems may be caused by anxiety, which may be due to an experience such as vomiting or gagging or choking during or after eating a particular food and rigidity (wanting to eat one particular type of food all the time) among others.

On the other hand, an eating disorder such as anorexia nervosa may occur in young women with autism due fear of gaining weight (body image issues). Unlike anorexia nervosa, chronic overeating (bulimia) has also been reported among persons with autism. This may be due to increased appetite that is, a severe side effect of Risperidone (Risperdal) and Aripiprazole (Abilify) used to treat challenging behaviors such as agitation³⁰ in children and adults with autism. Pica is generally common among children with autism who have intellectual disability.

Eating problems may be manifested as hatred or dislikes for certain tastes, textures and strong flavors. This in turn result in extremely limited food habits, which is often due to autism-related hypersensitivities and/or a strong resistance against change. This usually leads to excessive consumption of high-calorie and low-nutrient foods. Chronic overeating may results when the individual is unable to recognize or sense when the stomach is full and/or when eating has becomes a soothing sensory behavior. There are specialized feeding programs that have been developed, which are being implemented by behavioral therapists and nutritionists in some autism clinics. Also, to an extent, some speech, behavioral and occupational therapists can be of help in the management of pica habits.³²

Medical therapy is employed to treat iron or zinc nutritional deficits, infection as well as infestation with intestinal parasites. On the other hand, behavioral therapies can be effective in reducing pica habits.³³ These include strategies for reinforcing good behaviors such as given rewards to the child (in the form of small food treats) for not putting inedible objects in his/her mouth. Another strategy is to constantly removing the child's attention from the nonfood items to his/her favorite activities as well as continuously blocking the child from any attempts to eat uneatable items.

OBESITY

Obesity is another condition commonly found in children with autism usually caused by chronic overeating and begins early in lives of children with autism. The child may dislike foods containing vitamins and proteins but concentrates on eating more of high calorie foods. However, some studies have associated the likelihood of being overweight or obese with the number of psychoactive behavioral medicines these children take.³

Treatment usually takes into considerations dietary and behavioral measures. Dietary approach to treatment entails introducing healthier food choices while reducing each serving size for breakfast, lunch and supper. At times, if required high-calorie foods are removed from the child's diet while daily exercises in the form of walking and/or riding bicycles is encouraged.³⁴

SLEEP PROBLEMS

Chronic sleep problems frequently occur in children with autism (more than half of children with autism have trouble sleeping). Most persons with autism experience disrupted sleep that is, they have issues with normal sleep patterns.³⁵ For instance, many adults with autism have problems going to sleep while others wake frequently at night, still some may wake up very early and stay awake throughout the day. Lacking sufficient sleep may actually result in a sleep disorder, which can aggravate abnormal behaviors during the day. Sleep disturbances may also pose difficulty in communicating, increase aggressive and repetitive behaviors, as well as inattention, hyperactivity and irritability. Generally, these reduce the quality of life and hamper learning.

According to research, possible biological causes of sleep

problems in persons with autism include mutations in genes that control the body's sleep-wake cycle called the circadian rhythm. In addition, sleep problems may be worsened by undetected seizures occurring at night disrupting sleep brain patterns.³⁶ Again, anxiety may affect the ability to fall asleep and remain asleep for long hours at night. In addition to biological causes of sleep problems, reduced levels of melatonin may cause autism-related sleep problems.³⁷

Some strategies to help improve sleep for persons with autism and get them back to sleep after waking up at night have been suggested. These strategies include integrating daytime exercises and outdoor activities in a manner that will lead to evening routines that limit screen time before bed. In addition, parents are taught how to create visual schedules that help to establish regular bedtime routines. These strategies have been proven to increased sleep time for individuals with autism as well as reduced anxiety, inattention and challenging behaviors during the day.³⁸

MENTAL HEALTH DISORDERS

Mental health conditions such as ADHD, anxiety and depression among others frequently affect children with autism. Averagely 62% of persons with autism suffer from one or more mental health disorders¹⁴ which can greatly worsen autism's behavioral challenges if not identified and treated.

Usually, autism and ADHD have similar symptoms³⁹ as such an evaluation by a specialist is required to differentiate between the two disorders and develop a suitable treatment plan for the individual. Generally, treatment may entail ADHD medication as well as behavioral strategies such as the Applied Behavior Analysis (ABA). ABA is a remarkable treatment therapy for individuals with autism,⁴⁰ which is widely used by healthcare professionals as well as in many schools, autism centers and clinics.

Anxiety

Anxiety disorders are mostly diagnosed among persons with autism; about 42% of children and teenagers with autism are affected with one or more anxiety disorders⁴¹ compared to about 3% of children and 15% of adults who develop normally. Persons with autism are particularly affected by social anxiety, which is excessive fear of strangers, crowds and social circumstances. Anxiety can be elicited at different points in time and caused by various activities including past enjoyable events.

For many children with autism anxiety may be triggered by difficulty participating in social activities and significant sensory sensitivities to lights, tastes, smells and loud noises.

Depression

It is estimated that about seven percent of children and 26% of adults with autism are affected by depression whereas only about two and seven percent of children and adults respectively in the general population are affected. It is worth noting that the rates of depression among individuals with autism increase with age and

intellectual ability.¹⁴ The signs and symptoms of depression may include continuing feelings of sadness, no longer showing interest in his/her desired activities, displaying poor hygienic practices, irritability as well as feeling insignificant and desperate. Severe symptoms of depression are recurrent thoughts of death and/or suicidal tendency.⁴²

CHALLENGES FACED BY INDIVIDUALS WITH DISABILITIES IN ACCESSING APPROPRIATE MEDICAL HEALTH SERVICES

Persons with disabilities face many barriers in accessing and utilizing quality healthcare services. This may be due to the fact that most of the healthcare facilities are costly, sometimes not available and not disability friendly.⁴³ Also, the challenges are usually due to stigmatization and discrimination which are associated with their impairments and differences in race or ethnicity among others. The challenges range from inaccessible physical environments, the lack of the appropriate healthcare providers who can render adequate care to persons with autism to inflexible policies and procedures, social assumptions and prejudices. Furthermore, it was found that parents of children with autism faced unique challenges in accessing referrals and specialized care services.⁴⁴ The following sub-sections describe these challenges and/or the barriers to accessing and receiving quality healthcare by persons with disabilities in general and autism in particular and state World Health Organization (WHO) as well as United Nations (UN's) strategies for reducing the challenges.

LIMITED AVAILABILITY OF HEALTH SERVICES, IN ACCESSIBLE PHYSICAL ENVIRONMENTS AND EQUIPMENT

Usually, the architectural designs of most health facilities are not disability friendly; they are not well adapted to suit persons with disabilities. As a result, they cannot fully access the structure with their wheelchairs or crutches and circulate freely from one section to another. This prevents persons with disabilities to fully utilize healthcare services resulting in low quality care.⁸ It has been documented that most primary care facilities in California do not have accessible healthcare equipment such as weight scales, examination tables, cancer screening equipment and wheelchairs, to move safely and with ease within the health facility.⁴⁵

This is true for almost all healthcare facilities in developing and underdeveloped countries where appropriate health services for persons with disabilities are scarce or very limited. Individuals with disabilities particularly those in rural and remote areas experience high unmet needs for healthcare. In addition, parents of children with developmental disabilities have reported a range of barriers to accessing healthcare services.⁴⁶ These include among others the absence of accurate information regarding available services, misconceptions regarding medical care and the aim of treatment, communication and transportation difficulties as well as fear of stigmatization and discrimination.

The absence of appropriate health services and accessible equipment in many outpatient provider offices leads to fewer

preventive investigations, missed diagnoses, and delayed care particularly, for individuals with mobility impairments. For instance, most ladies with mobility difficulties do not access breast and cervical cancer screening examinations because the available equipment are not adapted to accommodate women with disabilities.⁶ This unequal access to some health facilities' buildings by persons with disabilities due to narrow doorways, no pavements, inappropriate office and bathroom facilities, and inaccessible parking areas as well as inaccessible medical equipment create barriers to the full access of healthcare facilities.

INADEQUATE SKILLS AND KNOWLEDGE OF HEALTH WORKERS AND TREATMENT DECISIONS CHALLENGES

Due to the lack of trained healthcare providers regarding autism parents having children with autism may face major difficulties discussing treatment options with their child's healthcare provider. These challenges may include among others communication difficulties, lack of knowledge on the part of the healthcare provider regarding specific treatments for autism as well as doubts about their role in making treatment recommendations.⁸ Persons with disabilities reported that healthcare providers had inadequate skills to meet their needs, and sometimes they were denied care probably due to difficulties to make treatment decisions.

Talking about communication difficulties some parents have reported the lack of involvement/participation in the choice of treatment options for their child, while others mentioned the fact that their child's healthcare provider/physician made only general recommendations or referrals. In order to foster more effective communication between families and healthcare providers/pediatricians tools such as decision making and practice guidelines should be made available for used by the healthcare providers.⁴⁷ It is vital for the patient/family and physician to work together and arrive at a treatment plan for their child (shared decision-making). This will obviously enhance healthcare provider-patient/family communication and partnership resulting in quality patient care, compliance and good treatment outcomes and patient satisfaction.

Concerning the lack of knowledge on the part of the healthcare provider, knowledge gaps about the treatment of autism and available community resources have reported by both parents and physicians. Also, uncertainty about the pediatrician's role regarding the care of autism has been reported. With respect to the management, pediatrician are generally not so sure about the treatment options as such they are uncomfortable discussing autism related treatments. As a result, parents miss the opportunity to discuss benefits and risks of treatment options.⁴⁷ Therefore, primary healthcare providers need to be provided with treatment/care plans for autism and other developmental disabilities and available resources. These include such tools as the Autism Toolkit and clinical practice guidelines developed by the American Academy of Pediatrics (AAP).

INFLEXIBLE POLICIES AND PROHIBITIVE COST

The policy put in place regarding healthcare and disabilities particularly autism may pose a barrier to healthcare service utilization

by this special group. For instance, the assumption that everyone might be able to complete hospital forms unaided, undress and transfer to high examination tables without assistance, and communicate normally may limit full access of hospital facilities by persons with disabilities needing healthcare. Also, a study conducted by Zhang et al²¹ reported gaps in access and utilization of healthcare services whereby children with private health insurance had access to less services with more out of pocket expenses compared to children with public insurance coverage.

These expenses are mostly with respect to outpatient services and prescription medications for managing various health conditions including dental care. According to Buescher et al⁴⁸ many persons with disabilities are unable to access health services due to cost. Generally, individuals with disabilities in less developed countries do not get the much-needed healthcare due to the cost of transportation and healthcare services.

SOCIAL ASSUMPTIONS AND PREJUDICES

Generally, it is assumed that persons with developmental disabilities have greater access to healthcare but which is not the case. Literature reveals that 68% of participants in a multinational study assumed that individuals with intellectual disabilities had the same or even better healthcare compared to typically developing children. Meanwhile, persons with developmental disabilities do not receive the needed healthcare easily or on time, and may not receive suitable and adequate healthcare because policy makers turn to neglect or underestimate their health needs.⁴⁶

Also, there exist racial differences in the utilization rates of healthcare services among people with disabilities. Because of cultural differences between the Western world and African there may be conflicting ideas between modern service delivery models and traditional beliefs regarding the diagnosis and treatment of autism and its associated conditions.⁴⁹ For instance, in most cultures women are compelled to respect and obey their husbands' instructions including treatment options.

Also, there may be role conflict as mothers are charged with the responsibility of caring for all their children and other family members making it difficult for them to meet up with their commitment to cater for a child with developmental disability. These may pose barriers to the effective utilization of available healthcare services.⁴⁹

WHO AND UN'S STRATEGIES FOR IMPROVING ACCESS TO HEALTH SERVICES FOR PEOPLE WITH DISABILITY

Disability is a public health issue hence, nations should consider taking actions towards including disability as a priority in the health sector, develop and implement strategies to reduce challenges faced by persons with disabilities in accessing healthcare.⁴⁵ This may include strategies to attain equity for people with disability such as improving access to effective health services and cross-sectorial public health interventions, such as good source of drinking water, proper sanitation and hygiene services, as well as maximum protection during disasters.⁵⁰

Also, existing policies and services should be evaluated and put in place strategies to enable disability inclusion in the health sector establishing healthcare standards related to care of children with disabilities especially in resource poor settings and decrease health inequalities. In addition, services such as health promotion, disease prevention, treatment, rehabilitation and palliative health services should be made very affordable and accessible to all persons with disabilities.

Furthermore, the environment of health facilities should be modified and adjusted to facilitate access by all persons with disabilities.¹³ For instance, modifying the physical layout of health facilities to provide effective access for people with mobility problems as well as ensuring their easy access to all public health information.

Above all, healthcare providers should be empowered with the necessary knowledge and skills to meet the individual needs of persons with disabilities both in the hospital and community settings using evidence-based guidelines for assessment and treatment. All these strategies together with the inclusion of individuals with disability in healthcare surveillance could help achieve highest attainable standard of health for this special population.⁶ Below is presented WHO and UN's strategies for decreasing the barriers and improving access to healthcare by persons with disability. In a bid to enhance access to health services for people with disabilities WHO does the following among others:

- Intensifies awareness on disability matters, and encourages the inclusion of disability as a component in national health policies and programs among Member States.
- Develop and implement normative tools and guidelines to strengthen healthcare for all including persons with disabilities.
- Capacity building for health policymakers and service providers regarding provision of care, supporting and protecting the rights and dignity of persons with disability.
- Facilitates the collection of disability-related data and information, and dissemination.
- Encourages the implementation of strategies aimed at educating persons with disabilities about their own health conditions, health promotion and disease prevention activities.

UNITED NATIONS DISABILITY INCLUSIVE STRATEGY

In order to promote sustainable and transformative progress on disability inclusion through all pillars of the work of the United Nations, the UN Secretary-General launched the UN Disability Inclusion Strategy (UNDIS) in June 2019. This strategy compels all UN agencies to make sure that disability is constantly and systematically mainstreamed into all facets of work.²² WHO and UN are working to systematically integrate disability in all programmatic areas, including at the country-level.

CONCLUSION

The health needs of children with developmental disabilities particularly autism are not being met as required even though this special population are more likely to seek medical care due to their

disabilities and associated conditions. Children with autism and other developmental disabilities experience disparities in health and healthcare service utilization. Autism is linked to many health conditions such as epilepsy, gastrointestinal problems and other mental disorders. These health problems affect each individual with autism in a unique way negatively affecting his/her existing social interaction and communication impairments. Again, health facilities and medical equipment are not disability friendly making it difficult for this special group to effectively have access to quality care. In addition, most healthcare providers do not possess adequate knowledge and skills required to make critical decisions regarding this very special group of persons.

Furthermore, due to cultural differences certain diagnosis and treatment regarding autism and other developmental disabilities may not be welcomed. These among others create barriers to the effective provision and utilization of healthcare services by children with disabilities in general and those with developmental disabilities in particular. The public health sector of all nations has the duty to promote health and prevent diseases for all including children with disabilities. This can be done by developing and implementing strategies to include persons with disabilities in all aspects of work as suggested by the UN and WHO. If this is done it will go a long way to reduce disparities in health and barriers to health service utilization especially for children with autism. This will in turn decrease stigmatization, discrimination and enhance the delivery of quality and holistic care to persons with disabilities particularly children with autism and related disorders.

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APPENDIX

A Summary of the Various Means by Which Public Health Sectors of Nations Could Reduce Health and Health Service Inequalities among Children with Autism and other Developmental Disabilities

The Public Health Sectors of each nation should:

- Include disability in crisis prevention and disaster risk reduction and risk assessments, recovery and post-conflict and post-disaster recovery planning.
- Institute policies and strategies to enable individuals with disabilities to effectively participate in health related decision making.
- Ensure conflict and disaster assessments collect disaggregated data on people with disabilities and prioritize needs of persons with disabilities in all UNDP recovery programs.
- Assist in capacity building of persons with disabilities and of their organizations to raise their awareness and foster collaboration between local, national and international organizations working on disability.
- Support local authorities to put in place strategies to maintain pertinent information regarding the location and diversity of disability and implement specific awareness and information campaigns for people with disabilities during and after disasters.
- Encourage full access to basic services.

Adapted from United Nations Development Program (UNDP).²⁵

Original Research

Can Automated Text Messaging Successfully Monitor Antibiotic Adherence for Urban Adolescents and Young Women Managed for Pelvic Inflammatory Disease in the Outpatient Setting

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ABSTRACT

Objective

This study evaluates patient responsiveness to an automated text messaging system for pelvic inflammatory disease (PID) self-care support, and measures the reliability of text-reported adherence.

Design

Patients aged 13-25-years with mild to moderate PID were recruited from urban, academic outpatient settings. Enrolled patients received antibiotics and were randomized into a standard of care or intervention group. During a 14-day treatment period, participants in the intervention arm received a community-based nursing visit and daily text message medication reminders with evening prompts to report the number of doses taken.

Result

Of the 97 participants randomized into the intervention arm, 91 (94%) were eligible for analysis. Most were African American and low income, with a mean age of 18.3 (SD=2.2) years. Participants responded to ~53% (SD=34%) of all dosage inquiry messages. Responsiveness attenuated at approximately 2.2% per day over the treatment period. Ninety-three percent (n=85) of the analyzed intervention arm returned for the two-week follow-up. Despite overall adherence and general responsiveness, text-reported and self-reported medication adherence were not well correlated ($r=0.37$, $p<0.001$).

Conclusion

Our findings show that text messaging is a feasible strategy for reaching urban adolescents being managed for complicated sexually transmitted infections in outpatient settings. However, patient responsiveness to self-care text messages do vary, limiting the adherence monitoring capacity of this technology. Given the number of unanswered text messages and incomplete text-reported adherence data, additional measures to assess adolescents' adherence to PID medications are needed in clinical trials.

Keywords

Pelvic inflammatory disease; Sexually transmitted infections; Adolescents; Outpatient; Text messaging; Community health nursing.

INTRODUCTION

Pelvic inflammatory disease (PID) is a reproductive health disorder that disproportionately affects young,^{1,2} and African American women in the United States.³⁻⁵ Without proper treatment, PID can cause tubal scarring, infertility, ectopic pregnancy, and chronic pelvic pain.⁶ The Centers for Disease Control and Prevention

(CDC) guidelines no longer recommend hospitalization for mild to moderate PID⁷ as inpatient treatment is expensive,^{8,9} and offers limited reproductive health benefits over outpatient management.¹⁰ Despite evidence that youth with PID struggle with adherence to therapy,¹¹ most young women with PID continue to be managed in outpatient settings with oral antibiotics⁷ and no additional clinical support.

For adolescents who make up 20% of all new PID cases,¹² the shift from inpatient to outpatient treatment without additional clinical support may have been shortsighted. Adolescents often engage in high-risk sexual behaviors, like unprotected sex and sexual concurrency that increase exposure to sexually transmitted diseases (STDs) and PID.^{6,13} Once diagnosed, adolescents with PID struggle to adhere to antibiotics and follow-up appointments.¹⁴ A 2010 randomized controlled trial (RCT) investigated the benefit of a 6-minute interventional video on adolescent's adherence to PID self-care recommendations. Participants were found to be only 66% adherent to antibiotics, while a mere 16% of control and 36% of intervention groups returned for the recommended 72-hr follow-up visit.¹⁵

Additionally, poor adherence to therapy increases adolescents' risk for short- and long-term sequelae.^{16,17} Adolescents with PID are more likely than adult women to develop recurrent PID and subsequent STDs.¹⁸ Each PID episode substantially increases the risk of tubal infertility and chronic pelvic pain.¹⁶ Such disparities suggest that youth-focused interventions are needed to improve health outcomes for adolescents and young adult women managed for PID in outpatient settings.

With ~6 million text messages sent each day,¹⁹ electronic messaging may provide a novel and cost-effective means²⁰ to communicate with patients in outpatient settings, and to improve treatment outcomes. Text messages are delivered in real time,^{20,21} making them suitable for promoting health behavior change.^{21,22} Moreover, text messaging is widely accessible among youth,²³⁻²⁵ and there is no digital divide for under-represented minorities.^{26,27} In a 2012 text messaging intervention for urban, minority youth on Depo Provera, 92% of participants had unlimited access to text messaging services.²⁷⁻²⁹ Findings from this study and others^{30,31} demonstrate the feasibility of two-way health related text messaging with minority youth, a population that is often difficult to reach outside of healthcare settings. Text message interventions also improved health outcomes and behaviors for patients with diabetes, asthma, and human immunodeficiency virus (HIV) in prior studies.^{21,30-32} A recent RCT by Wolff et al³³ used text message reminders to increase adolescents' adherence to recommended PID follow-up appointments. However, no study has evaluated the role automated text messaging may play in monitoring antibiotic adherence in youth with PID.

The Technology Enhanced Community Health Nursing (TECH-N) study is a two arm RCT designed to evaluate how text message reminders and community health nursing visits may improve urban adolescents' adherence to antibiotics, and reduce the sequelae of PID.^{34,35} Recently published findings from the larger TECH-N study found that text messaging and community health nursing intervention for adolescents and young adult women with PID decreased subsequent gonorrhea and chlamydia rates, and improved adherence to scheduled follow-up visits.³⁶ This sub-analysis of the TECH-N study investigates the text messaging component of the intervention. Specifically, this study (1) analyzes patient responsiveness to an automated text messaging system designed to monitor antibiotic adherence, and (2) measures the reliability of text-reported medication adherence against self-reported an-

tibiotic adherence for adolescents and young women with mild to moderate PID enrolled in the TECH-N study.

METHODS

Overview

TECH-N is an active Institutional Review Board (IRB)-approved, RCT (# NCT01640379) with previously described methods.^{34,35} Enrolled patients provided written informed consent, agreeing to be randomized, to participate in a community-based nursing visit if assigned to the intervention arm, and to complete research interviews at 2-weeks, 30-days, and 90-days post-enrollment. Nursing visits were conducted in patients' homes, except where patients felt it unsafe to do so per protocol. This quality control analysis focused on the fidelity of the text-messaging component of the intervention, which received human subjects' approval through the Johns Hopkins Institutional Review Board. The analyzed text message and adherence data were collected from September 2012 to June 2015.

Enrollment, Discharge, and Follow-up

TECH-N research staff recruited patients from the Pediatric and Adult Emergency Departments, General Pediatric primary care clinic, and adolescent medicine/young adult practice within a large urban academic medical center in the mid-Atlantic region of the United States. Eligible patients were 13-25-years-old, English-speaking, female, and residents of the local metropolitan area diagnosed with mild to moderate PID and treated in outpatient settings. Patients who were pregnant, hospitalized for PID, had a language or cognitive barrier, or were re-diagnosed with PID were excluded. Enrolled patients were assigned to the intervention or standard of care (control group) using a computer-generated block randomization sequence.^{34,35} TECH-N provided disposable, pre-paid phones for patients in the intervention arm who lacked mobile phones with text messaging capacity for use during the 90-day duration of the study.

Both the intervention and control groups received 28 tablets of 100 mg doxycycline and were instructed to take two doses or 200 mg daily for 14-days, according to the CDC's STD treatment guidelines.⁷ Some patients received additional medications (e.g. metronidazole 500 mg twice daily for 14-days) for concomitant treatment of bacterial vaginosis per provider request. At discharge, patients in the control group were instructed to follow-up with their primary care physicians or the institutional Title X-supported Adolescent and Young Adult Clinic within 72-hours of PID diagnosis. The intervention arm received a community-based nursing visit within five days. All patients were scheduled for an outreach research visit immediately following the 14-day treatment period, where patients self-reported their compliance with prescribed antibiotic treatment. Adherence results from the post-treatment interview were uploaded to an online database.

Text Messaging Intervention

TECH-N staff enrolled patients in the intervention arm in an

online health cloud SMS (HCS) system from Reify Health, LLC (<http://www.reifyhealth.com>)³⁷ through which automated reminders and queries were sent. Patients in the intervention arm received a welcome message on the day of enrollment. During the 14-day treatment period, automated text message reminders to take two doses of antibiotics were sent daily at 9 am, and reminders to text back the number of pills taken for that day: “0, 1, or 2” were sent at 7 pm. Simply texting back 0, 1, or 2 was the only step participants had to complete to report adherence.

According to patients’ responses, the HCS system sent text messages to encourage compliance when doses were missed. However, patients were not prompted to respond to encouragement messages. During the 14-day treatment period, fifteen TECH-N text messages (1 welcome and 14 dosage inquiry messages) requested responses. All texts were automated but signed with “TECH-N Nurses” to foster a sense of connection with the study. Text message design was based on earlier focus groups with sexually active women and prior research with similar populations.^{28,29} Text messages were also designed to be interactive and to comply with the automated text messaging system’s delivery capacity. TECH-N intervention messages are listed in Table 1.

Welcome Message	Thank you for enrolling in the TECH-N study. We will contact you within 24 hours to arrange a follow-up visit. Call us at --- if you don't receive a call. Text 1 if you got this message. TECH-N Team.
Daily Adherence Reminder	Good morning! Don't forget to take your medication twice today with a BIG glass of water. TECH-N Nurses
Daily Dosage Inquiry Message	Good evening! How many doses did you take today? Text 0, 1, or 2. TECH-N Nurses.
Sample Intervention Message 1	That's great! You're on your way to recovering completely.
Sample Intervention Message 2	One dose is good, but you need to take both doses to make sure your body heals properly.
Sample Sexual Health Message 1	Condoms prevent STDs. Stop by the TECH-N Office if you need some. Call XXX-XXX-XXXX to let us know are coming by. TECH-N Team
Sample Sexual Health Message 2	Birth control is a healthy part of a relationship. Call the Title 10 Clinic at XXX-XXX-XXXX if you need family planning help. TECH-N Team

Statistical Analysis

Raw incoming and outgoing text messages data and time stamps from the HCS database were de-identified and downloaded into an Excel (Microsoft Office, 2011) spreadsheet. Messages were sorted according to patient identification numbers, arranged in chronological order, and assigned unique background colors based on message type, i.e. dosage inquiry message, reminder message, patient response (Appendix A). Basic and user-defined excel functions were used to identify messages according to background color or word content for rapid calculation of response rates and sums of text-reported adherence (Appendix B).

Responsiveness

Individual response rates were calculated based on the number of dosage inquiry messages a patient received and averaged. Percent-

age of patients responding to a dosage inquiry message was plotted by day (1-14) and evaluated with linear regression to examine attenuation.

Correlation

The number of pills a patient reported to have remaining in their pill bottle at post-treatment follow-up was downloaded from a separate access database into Excel. This value was subtracted from 28 pills (perfect adherence) to determine self-reported adherence. Zero pills taken was assumed for patients who never texted back. Correlation between total dosage reported *via* text message and total self-reported dosage was evaluated with linear regression for all patients (intention to treat analysis) and for patients with ≥75% response rate (near perfect responders).

Outcome Measures

The primary outcome measure was average patient responsiveness in percent. Secondary outcome measures were text-reported adherence (sum of daily text reported dosages taken), self-reported adherence, and correlation between text-reported and self-reported adherence. The intention to treat (ITT) analysis of correlation was used with the understanding that non-response may be an inherent problem with texting platforms designed to monitor adherence in clinical trials and clinical settings. Additional correlation analyses were included for participants with response rates of 75% or greater (near perfect responders). These investigations aimed to evaluate the correlation between text message and self-reported medication adherence in a population of participants’ who were committed to texting back.

Participants occasionally responded twice to dosage inquiry messages. Whether participants sent a duplicate text message or responded late to a previous dosage inquiry message was unknown. Duplicate response messages delivered on the same day were ignored to avoid over representing responsiveness or total text reported adherence. Participants who failed to respond to a dosage inquiry message on a given day were assumed to have taken zero pills for that day.

RESULTS

Enrollment

One hundred and ninety-two (192) patients were enrolled in TECH-N from September 2012 to June 2015. Ninety-seven of these were randomized into the intervention arm. Three patients were excluded from the intervention arm for either being hospitalized for PID after enrollment, living outside the local metropolitan area, or being previously enrolled in the control group. Two participants were excluded from text message analysis because they enrolled in the HCS late in their treatment period and missed more than five text messages from TECH-N. Another participant was removed from text message evaluation due to continued treatment at the time of data analysis. Ninety-one patients were included in the final analysis. TECH-N maintained a high follow-up rate, with 93.4% of the analyzed intervention group (n=85) returning for

the 2-week post-treatment follow-up interview (see attrition in Appendix C). TECH-N also had high follow-up rates at the 1- and 3-month research visits, with 95% of all participants returning for follow-up.

Demographics

Participants included in this analysis were primarily African American (91%), with mean age of 18.6 (SD=2.2) years. All resided in the Baltimore metropolitan area, and 86.5% were Medicaid-insured and considered low-income. Forty-six (51.6%) had a high school degree or more, 23 (25%) had less than high school education, and 21 (23%) did not provide educational information. These demographics were calculated from 89 participants.

Message Delivery

HCS logs confirmed that 75 (82%) of the final intervention group (n=91) received the welcome message and 89 (98%) received all 14-dosage inquiry messages. The HCS was programmed to deliver welcome messages to patients in the intervention arm only on the day of their enrollment in the study. Some patients registered in the HCS system after their TECH-N intervention group enrollment date due to phone functionality problems (n=16). These patients (n=16) did not receive the welcome message or any reminder or dosage inquiry messages programmed to deliver on treatment days prior to their HCS activation date. HCS logs confirmed that all other scheduled TECH-N messages were received by these patients. There were no Health Insurance Portability and Accountability Act (HIPAA) violations reported. Cell phone ownership was high, and only five participants required a pre-paid phone for study participation.

Text Message Responsiveness

Fifty-six percent of participants who received the welcome message (n=42 of 75) responded, and 86% (n=78) of intervention participants responded to at least one dosage inquiry message. On average, patients responded to 53% (SD=34%) of dosage inquiry messages received during the treatment period. Responsiveness to dosage inquiry messages attenuated over time, approximating a 2% decrease per day ($\beta=-0.022$, 95% CI -0.03 to -0.015, $p<0.001$) (Fig-

ure 1). Average responsiveness to dosage inquiry messages was 61.6% (95% CI, 54.9-68.3%) and 46.9% (95% CI, 43.1-51.0%) for weeks 1 and 2, respectively.

There were 9 perfect responders and 13 participants who never responded. Fifty-nine participants (65%) were actively engaged in interactive texting, responding to more than 40% of received adherence-monitoring messages (Table 2).

Table 2: Breakdown of Participant's Level of Text Message Responsiveness (Total N=91)

Patient Responsive to Adherence Monitoring Text Messages	Number of Participants (%)
Never Responded	13 (14%)
Responded At Least Once	78 (86%)
Always Responded	9 (9.8%)
0 to 20% Responsive	22 (24%)
20 to 40% Responsive	10 (11%)
40 to 60% Responsive	14 (15%)
60 to 80% Responsive	23 (25%)
80 to 100% Responsive	22 (24%)

There were no statistically significant differences in patient responsiveness to automated text messaging when stratified by age (<20-years *vs.* ≥ 20 -years), education (non-high school graduates *vs.* high school graduates) or insurance type (Medicaid *vs.* private *vs.* no insurance). Of the final intervention group (n=91), 85 participants (93.4%) returned for two-week follow-up.

Reliability of Text Reported Adherence

When all participants who returned for two-week follow-up were considered (n=85), the intention to treat correlation between text-reported and self-reported medication adherence was positive, but weak ($r=0.37$, $p<0.001$) (Figure 2). Average total text-reported dosage was 13 (95% CI, 11-15) pills *versus* 24 (95% CI, 23-25) self-reported doses.

Figure 1. Average Patient Responsiveness to Text Messages by Day and Standard Errors

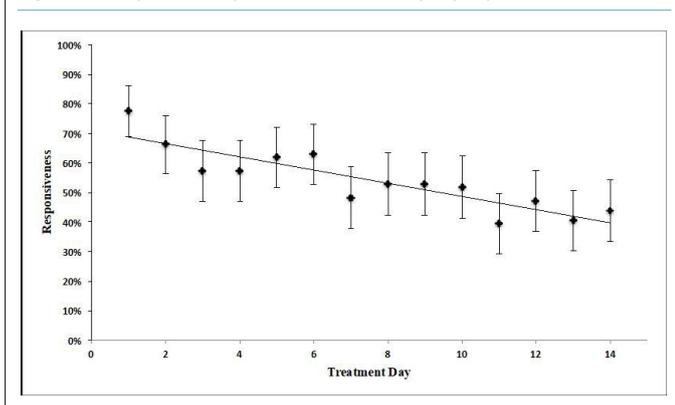
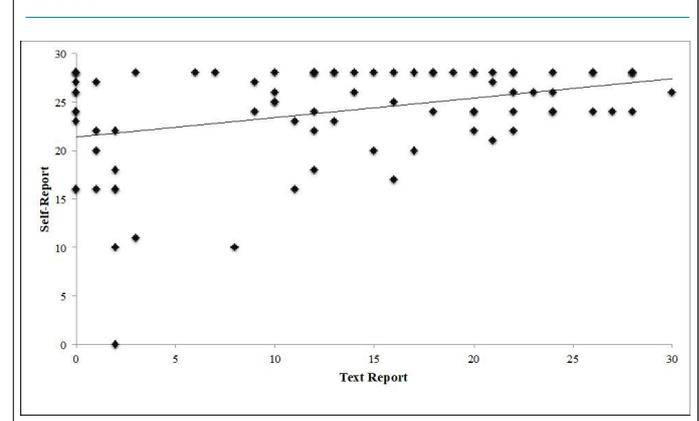


Figure 2. Correlation—Linear Regression of Text-Reported vs. Self-Reported Medication Adherence



A strong correlation (0.82, $p<0.001$) was present when participants who responded to TECH-N messages more than 75%

of the time (N=29) were considered. Near perfect responders had an average responsiveness of 89.3% and an average text reported adherence of 22 (95% CI, 20-24) pills *versus* 24 (95% CI, 21-26) self-reported pills.

Lower text response rates were not linked to low self-reported adherence (Figure 3). One-way ANOVA ($p=0.331$, significance at $p<0.05$) demonstrated no significant difference in self-reported pill count when intervention patients were categorized by text message engagement. Patients who responded to TECH-N messages 0 to 20% of the time self-reported adherence rates statistically similar to those with 80 to 100% response rates. The average self-reported antibiotic adherence was 86% (24 of 28 recommended pills).

DISCUSSION

Our research demonstrates that urban adolescents managed for mild to moderate PID with oral antibiotics in outpatient settings are responsive to two-way text messaging communication for additional outpatient clinical support. However, baseline response rates to self-care text-messages varied (mean=53%, SD=34%) and tended to decrease over time. Baseline correlation between text reported and self-reported medication adherence was poor ($R=0.37$). These findings suggest that response rates and attenuation in responsiveness over time limit the capacity of automated text messaging systems to remotely monitor adolescent's antibiotic adherence without additional clinical assessment. Enhancing patient responsiveness with two-way texting communication is needed to improve the reliability and adherence monitoring utility of automated text messaging systems for PID support in clinical practice and research.

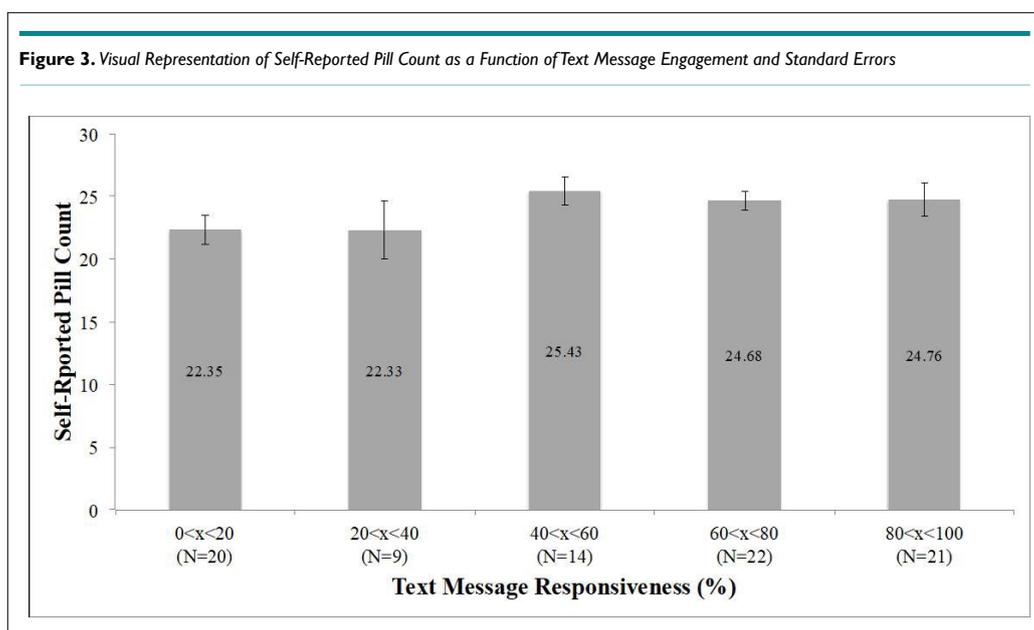
Responsiveness to self-care text messages was not affected by age, education or economic background. This may be explained by the universality/ubiquity of text messaging. Also, responding to the automated text reminders did not affect patient's adherence to antibiotic therapy as TECH-N participants self-re-

ported similar medication adherence regardless of text message engagement. Alternatively, simply receiving text message reminders to take antibiotics may have played a role in TECH-N patient's adherence. Prior studies have shown that 99% of received text messages are opened and that 90% are read within three-minutes of being received.³² Evaluating effectiveness of simple text message reminders *versus* two-way text messaging communication is an area for future research.

Enhancing patient's baseline responsiveness with two-way texting communication to improve the reliability and adherence monitoring utility of automated text messaging systems in clinical practice and research. As most participants completed their treatment months to years before text data was analyzed, a qualitative analysis of adolescents' non-responsiveness to TECH-N text messages was not performed. However, previous studies demonstrate that adolescents and young adult appreciate receiving health-related text messages from healthcare providers, and that these messages enhance their connection to the treatment team even if they do not respond.^{28,38,39}

Text message response rates in this study were similar to prior trials investigating text message interventions for urban adolescents.

Dowshen and colleagues investigated text-messaging intervention for minority HIV-positive adolescents taking antiretroviral therapy.^{30,31} Participants in this study responded to 61% (SD=30%) of all self-care text messages on average, and the correlation between text-reported and self-reported medication adherence was moderate ($R=0.52$).³¹ The slightly higher average response rate and correlation in this study might be due to the older age (23-years *vs.* 18-years) and the chronic and socially impactful nature of HIV infection, which requires close interaction with health care providers. Participants also chose the time of day that they wanted to receive text messages and personalized their reminders, which suggest that message personalization may increase text-messaging adherence.



Finally, attenuation in text message response rates overtime suggests that text fatigue may occur. A meta-analysis on text messaging systems for health found that health related text messages delivered at reduced frequency show higher patient compliance than daily text messaging.³² Comparing TECH-N results to our previous DepoText Trial supports this finding. DepoText participants received family planning appointment messages once per month and were on average 23% more responsive (76%) to automated text messages²⁹ than TECH-N participants (53%), despite similar age, race and background. “Habituation”—human’s tendency to ignore a stimulus delivered frequently—may explain patient’s differed response to daily *vs.* weekly text message reminders.⁴⁰ However, the acute need for PID medication reminder support occurs daily over the 14-days after diagnosis rather than family planning injection behaviors occur every 3-months. Future research investigating patient responsiveness to adherence monitoring messages delivered at shorter *vs.* longer intervals will enhance our understanding of its effect on response rates.

LIMITATIONS

A notable limitation of our study is the subjective assessment of medication adherence using self-report and its associated risk for reporting bias.⁴¹ Pill counts were attempted, but participants often did not have pill bottles at follow-up with the outreach staff member. Patients in the intervention arm received a clinical visit from TECH-N nurses three to five-days following PID diagnosis. The influence of nursing visits on medication adherence or study retention were not assessed in this study. Additionally, a few patients were taking medications in addition to doxycycline (i.e., metronidazole) and complex drug regimens have been known to affect adherence.⁴² However, this is the standard of care for PID, and the pill burden of this disorder cannot be overcome. TECH-N reminder messages would still be useful for the twice daily dosing of metronidazole along with doxycycline. .

The problem of handling missing text reported data for correlation analysis was discussed extensively. Single imputation using each participant’s average daily text reported adherence was considered. However, the proportion of missing data (given average response rate of 53%) was too large to employ these methods. We chose to use observed data and present baseline scenarios (all participants no matter their response rate) and best-case scenario (high responders). A 75% response rate or greater was the cut off for near perfect responders as this was a conservative level of text engagement needed to provide a reasonable amount of intervention. Prior research investigating the adherence monitoring capacity of automated text messaging systems for urban youth have evaluated correlation without perfect response rates.³¹ Ultimately, participant non-responsiveness may be an inherent problem with text message interventions in clinical practice.

Finally, this research was conducted at a single urban academic center enrolling primarily low-income African American youth and may have limited generalizability to the general population of PID patient. However, the TECH-N study was executed in a community with significant STI disparities and effectively offered self-care support to vulnerable youth, who are disproportionately

affected by PID and often difficult to reach in outpatient settings.

CONCLUSION

This study takes an important step towards understanding the role of text messaging in supporting adolescents and young adults with PID in outpatient settings and assessing antibiotic adherence for clinical and research purposes. Our findings are in line with prior research demonstrating that adolescents with sexual health concerns are open to additional clinical support *via* text messaging.^{28-30,33,39} It demonstrates that health-related text messaging is a feasible strategy for reaching adolescent and young adult (AYA) patients with PID in outpatient settings. However, baseline response rates to automated text messaging systems make text messaging insufficient as the sole means of monitoring adherence clinical management or research studies in this population.

Future research designed to optimize patient responsiveness to automated text messaging systems may improve automated text messaging systems’ role in antibiotic adherence monitoring. Given the demonstrated attenuation in text message responsiveness overtime and incomplete text reported adherence data, use of additional means to monitor adherence and to support urban youth enrolled in sexual and reproductive health interventions are needed.

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CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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APPENDICES

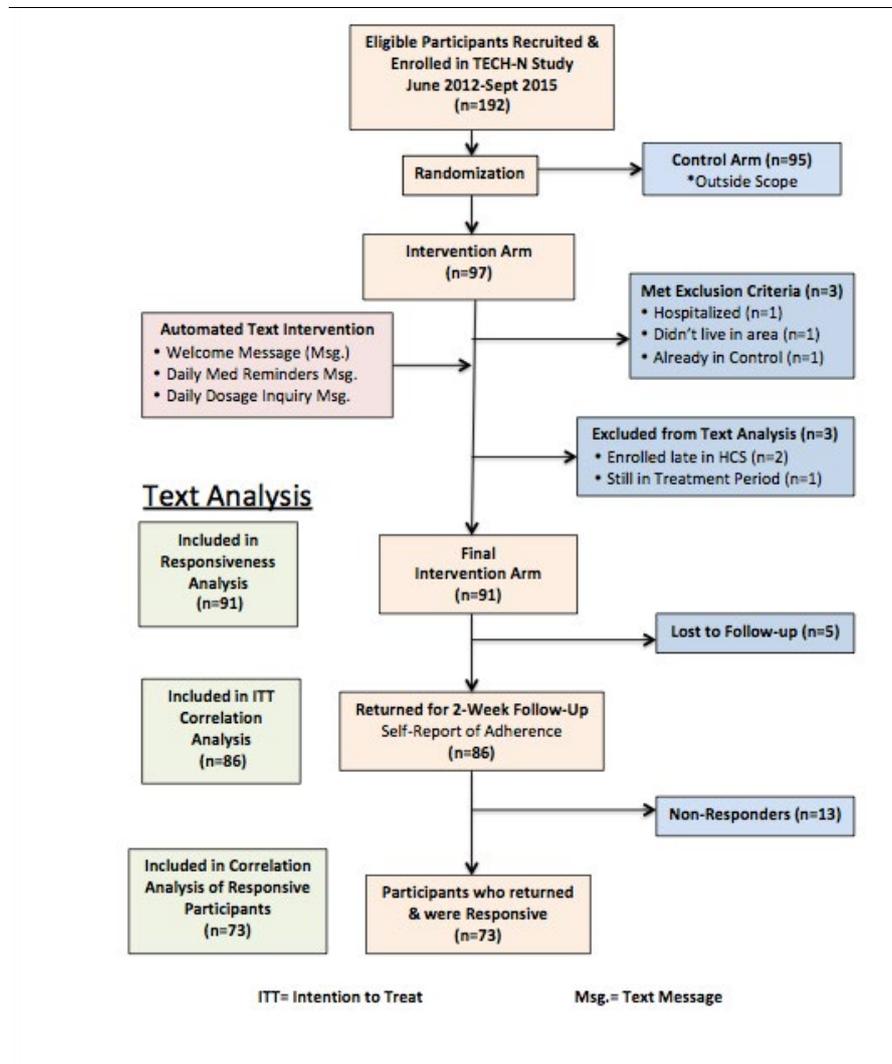
Appendix A

Pt. ID	Enrollment Date	Day	Message	Direction	Time
5	10/11/12	0	Welcome to the TECH-N study. Call us at 410-302-3103 if you do not receive a call in 24 hours. Text 1 if you got this message. TECH-N Team	outbound	10/11/12 3:55 PM
5	10/11/12	0	1	inbound	10/11/12 5:48 PM
5	10/11/12	0	Thanks!	outbound	10/11/12 5:48 PM
5	10/11/12	1	Good morning! Don't forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses	outbound	10/12/12 9:00 AM
5	10/11/12	1	Good Evening! How many doses did you take today? Text 0, 1, or 2 Betty & Jennette, TECH-N Nurses	outbound	10/12/12 7:00 PM
5	10/11/12	1	1	inbound	10/12/12 7:02 PM
5	10/11/12	1	Please respond with how many doses you took: 0, 1, or 2.	outbound	10/12/12 7:02 PM
5	10/11/12	1	One dose is good, but you need to take both doses every day to make sure your body heals properly.	outbound	10/12/12 7:02 PM
5	10/11/12	2	Good morning! Don't forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses	outbound	10/12/12 9:00 AM
5	10/11/12	2	Okay	inbound	10/12/12 9:52 AM
5	10/11/12	2	Good Evening! How many doses did you take today? Text 0, 1, or 2 Betty & Jennette, TECH-N Nurses	outbound	10/12/12 7:00 PM
5	10/11/12	2	2	inbound	10/12/12 7:02 PM
5	10/11/12	2	Please respond with how many doses you took: 0, 1, or 2	outbound	10/12/12 7:02 PM
5	10/11/12	2	That's great! You're on your way to recovering completely.	outbound	10/12/12 7:02 PM
5	10/11/12	3	Good morning! Don't forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses	outbound	10/12/12 9:00 AM
5	10/11/12	3	Good Evening! How many doses did you take today? Text 0, 1, or 2 Betty & Jennette, TECH-N Nurses	outbound	10/12/12 7:00 PM
5	10/11/12	3	2	inbound	10/14/12 7:16 PM
5	10/11/12	3	Please respond with how many doses you took: 0, 1, or 2.	outbound	10/14/12 7:16 PM
5	10/11/12	3	That's outstanding! Stick with it and you'll give your body the best chance to heal.	outbound	10/14/12 7:16 PM
5	10/11/12	4	Good morning! Don't forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses	outbound	10/12/12 9:00 AM
5	10/11/12	4	Good Evening! How many doses did you take today? Text 0, 1, or 2 Betty & Jennette, TECH-N Nurses	outbound	10/12/12 7:00 PM
5	10/11/12	4	2	inbound	10/15/12 7:03 PM
5	10/11/12	4	Please respond with how many doses you took: 0, 1, or 2.	outbound	10/15/12 7:03 PM
5	10/11/12	4	That's awesome. Keep up the good work. Taking both doses every day is very important for you to heal completely.	outbound	10/15/12 7:03 PM
5	10/11/12	5	Good morning! Don't forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses	outbound	10/12/12 9:00 AM
5	10/11/12	5	Good Evening! How many doses did you take today? Text 0, 1, or 2 Betty & Jennette, TECH-N Nurses	outbound	10/12/12 7:00 PM
5	10/11/12	5	2	inbound	10/16/12 7:18 PM
5	10/11/12	5	Please respond with how many doses you took: 0, 1, or 2.	outbound	10/16/12 7:18 PM
5	10/11/12	5	Great to hear! You're well on your way to getting better.	outbound	10/16/12 7:18 PM
5	10/11/12	6	Good morning! Don't forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses	outbound	10/12/12 9:00 AM
5	10/11/12	6	Good Evening! How many doses did you take today? Text 0, 1, or 2 Betty & Jennette, TECH-N Nurses	outbound	10/12/12 7:00 PM
5	10/11/12	6	2	inbound	10/12/12 7:00 PM
5	10/11/12	6	Please respond with how many doses you took: 0, 1, or 2.	outbound	10/12/12 7:00 PM
5	10/11/12	6	Awesome job. You're almost halfway done with the medication. Let's finish week one tomorrow by taking both doses.	outbound	10/12/12 7:00 PM
5	10/11/12	7	Good morning! Don't forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses	outbound	10/12/12 9:00 AM

Appendix B

A	B	C
Good Evening! How many doses did you take today? Text 0, 1, or 27 Betty & Jennette, TECH-N Nurses		Color Legend
Please respond wit how many doses you took: 0. 1. or 2.		Dose Inquiry
Good morning! Dort forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses		Dose Response
Good Evening! How many doses did you take today? Text 0, 1, or 27 Betty & Jennette, TECH-N Nurses		Duplicate Dose Responses
2		Encourgement
Please respond wit how many doses you took: 0. 1. or 2.		Patient comments
That's awesome. Keep up the good work. Taking both doses every clay is very important for you to heal completely.		Prompt to respond numerically
Thanks		Welcome, Retention
Good morning! Dort forget to take your medication twice today with a BIG glass of water. Betty & Jennette, TECH-N Nurses		Patient Responses to Welcome, Retention
Good Evening! How many doses did you take today? Text 0, 1, or 27 Betty & Jen nette, TECH-N Nurses		
2		
	Result	Value Calculated
Functions		
COUNTIF(A1:A12,"Good Evening!")	3	# Dosage Inquiry Msg.
CountColour (A1:A12, C3)	2	# DosageResponses
sumbycolor(A1:A12, C3)	4	Text-Reported Dosage
=B16/BIS*100(%)	66.67%	Individual Response Rate

Appendix C



Review

Early Identification, Assessment and Interventions in Children with Developmental Disabilities: A Review on Autism

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ABSTRACT

Developmental disabilities are a set of disorders which occur during the child's developmental stages affecting his or her language, physical and mental abilities or behavior. These include autism and other related disorders which all negatively influence the way the child achieves normal developmental milestones. Nurses are expected to work in collaboration with parents and other health care professionals to monitor each child's growth and development during each well-child visit or Infant Welfare Clinics (IWC) as well as during illness episodes. Generally, parents' concerns regarding developmental delays are discussed and the child is followed-up accordingly through developmental screening. A brief test is conducted on the child while the parent/caregiver completes a questionnaire or checklist regarding the child's developmental history. The American Academy of Pediatrics (AAP) recommends that developmental and behavioral screening be conducted for all children during regular IWC or well-child visits at nine, 18 and 30-months. Early diagnosis together with early treatment can make a major difference in a child's life and also decrease the possibility for costly interventions in future. Several programs have been designed to deal with the variety of social and behavioral difficulties associated with autism, focusing on reducing problem behaviors in children with autism. Once an individual is given a confirmed autism diagnosis by a qualified professional, the parents need to seek further information immediately on how to support their child. Early intervention treatment services have been shown to greatly improve a child's development. Thus, diagnosing autism early and instituting treatment and support promptly is mandatory for better prognosis.

Keywords

Developmental disabilities; Children with autism; Early assessment, Diagnosis and interventions.

INTRODUCTION

Developmental disabilities are a set of conditions which occur during human development as a result of atypical development that influence typical development affecting the child's language, physical and mental abilities or behavior.¹ Examples include autism and other related disorders which affect the way children are attaining normal developmental milestones. Health care professionals particularly nurses in collaboration with parents have the responsibility to monitor and discuss the child's growth and development. This is expected to be done during each well-child visit or Infant Welfare Clinics (IWC) and during illness episodes. Issues regarding developmental delays and any other concerns the parents might have are discussed and the child is followed-up accordingly through developmental screening. This brief examination tells whether the child is developing normally or if she/he is lagging behind peers with respect to acquiring basic skills as expected for age.

Thus, during growth and development children are supposed to be monitored and then screened to find out whether they are meeting the typical developmental milestones as expected.² That is, smiling, babbling, pointing, waving and sharing interests as well as playing, sitting, speaking, and moving among others. During the developmental screening a nurse practitioner (NP) or a physician looks closely at how the child is moving from one stage of development to another. Usually, the child and parents are involved; whereby a brief test is conducted on the child while the parent/caregiver completes a questionnaire or checklist regarding the child's developmental history.

These questionnaires and checklists are standardized tools designed in line with research evidence about developmental and behavioral screening.³ That is, they take into consideration questions about a child's development with respect to language,

movement, thinking, behavior, and emotions. Developmental screening can also be done by other experts in the healthcare settings as well as in early childhood education, school or community settings. It is worth stating that developmental monitoring is done on a regular basis during the IWC while developmental screening is more formal and is usually performed whenever the child's parents or the physician has a concern (Appendix A).

However, the American Academy of Pediatrics (AAP) recommends that developmental and behavioral screening be conducted for all children during regular IWC or well-child visits at nine, 18 and 30-months. Again, AAP recommends that screening specifically for autism spectrum disorders (ASD) be done for all children at 18 and 24-months during regular well-child visits.⁴ If after the screening an area of concern is identified, an official developmental evaluation may be required. This further assessment is conducted in collaboration with other experts to take an in-depth look to identify any deficits or delays so that diagnosis can be made as early as possible and treatment instituted immediately.

Early diagnosis together with early treatment can make a major difference in a child's life and also decrease the possibility for costly interventions in future. It is worth saying that in this paper evaluation and assessment are used interchangeably. This paper sought to:

1. Evaluate and diagnose young children with developmental disabilities particularly autism from an interdisciplinary perspective.
2. Identify and critically examine risk factors and early warning signs of atypical development.
3. Critically examine common assessments and diagnostic approaches such as the diagnostic and statistical manual of mental disorders fourth edition (DSM-IV), International Classification of Diseases-10 (ICD-10), used to identify developmental delays in various fields.
4. Examine different modalities of interventions typical of individuals with developmental disabilities, particularly autism.
5. Explore advances in intervention for children with developmental disabilities.
6. Critically examine factors that contribute to treatment success.

AN INTERDISCIPLINARY PERSPECTIVE IN THE EVALUATION AND DIAGNOSIS OF YOUNG CHILDREN WITH DEVELOPMENTAL DISABILITIES PARTICULARLY AUTISM

It is worthy of note that a brief screening test does not usually provide a diagnosis of developmental disabilities. However, it tells whether a child is developing normally or if a specialist should conduct a detailed assessment.⁵ A formal developmental evaluation is then required, if the screening test suggests an atypical development. This formal assessment gives a critical look at the child's development, typically conducted by a team of well-trained experts. That is, a pediatrician, developmental pediatrician, pathologist, speech-language pathologist, occupational therapist and child psychologist among others (Appendix B). The experts are expected to observe the child, administer a structured test, pose questions to the parents/caregivers and/or request them to complete a check-

list or questionnaire.⁶ The outcomes of this formal assessment will tell if the child requires special therapies or early intervention services or both.

It is very important for developmental evaluation to be carried out because many children with developmental delays or behavior concerns are not identified early as required. Thus, by the time they are diagnosed in school, significant delays might have occurred and they must have missed opportunities for treatment. Hence, assessing children for the diagnosis of autism and other related disorders is very vital if these children are expected to do well in educational and other social settings.⁴ The following section explains how assessment and diagnosis for autism is made.

Evaluation and Diagnosis of Autism

As mentioned earlier regular developmental monitoring and screening are very necessary for all children during well-child visits, and if there are concerns regarding the child's development an evaluation is done to diagnose the condition as soon as possible. Therefore, it is mandatory to discuss how a child can be evaluated and diagnosed with autism. Developmental and behavioral screening are performed to identify and establish the need for a specific intervention and further standardized testing. If the screening indicates the need, the evaluation is conducted by different specialists using a number of specialized assessment tools to assess a mixture of specific behaviors.⁵ Physicians, pediatricians, developmental pediatricians, NPs and psychiatrists who diagnosis autism are usually well trained specifically for this purpose. This combination of experts helps to provide multi-disciplinary diagnostic assessments fast enough and suggests appropriate services.⁶ The subsequent subsections highlight what is done before, during and after an autism diagnostic assessment.

Before the Assessment

Before commencing the evaluation one of the experts, usually the physician asks a few questions regarding the child's development and behavior. He/she may want to know how often the child behaves in a certain way and when this behavior was first manifested. Also, when and how the child reached certain developmental milestones should be made known, the family's medical history and why the parents decided to seek help or whether they were referred is also needed and all documented.⁵ Generally,⁵ the number of professionals to participate in the assessment is determined based on the child's unique needs and reason(s) for referral (that is whether speech, medical and/or behavioral challenges among others).

During the Assessment

Generally, diagnostic testing for autism includes a variety of developmental assessments, physical and neuro-developmental examinations and parent interview. During the diagnostic assessment, the child's parents/caregivers will be required to give information to the clinician regarding their child, including his/her medical history. Also, the child will be observed then reports and previous assessments findings about the child as well as information from school or childcare provider (if available) will be reviewed.⁶ Again,

laboratory tests and X-rays may be requested. Furthermore, formal professional assessment tools and criteria is used by qualified and trained professionals to establish a diagnosis. Finally, the diagnostic criteria for ASD as stated in the fifth edition of the DSM will be used to confirm diagnosis and level of severity.

It should be noted that in most countries, only physicians or psychologists are certified to diagnose autism.⁷ However, in some societies, NPs who are properly trained may also make autism diagnosis.

In order to diagnose autism early, the NP evaluates all children during well-child visits to identify children at risk for ASD. For every child he/she is expected to:

1. Review the developmental history for risk factors such as polyhydramnios, prematurity, low birth weight, prenatal infections with fever, advanced maternal and paternal age, large discrepancy between maternal and paternal age, among others. and less than 18-months between deliveries.
2. Review family history to find out if there are siblings with ASD or close relatives with developmental or psychiatric diagnoses.
3. Interview parents/caregivers about developmental concerns, observe the child and conduct standardized developmental screening⁸ using recommended screening tools.
4. Refer children who screen positive for atypical or delayed development for a more detailed evaluation.

In addition, the NP should assess each child and determine whether they are achieving developmental milestones as required, particularly “joint attention” which the child should start displaying by the age of nine months.⁹ Joint attention is the ability of the child to share another person’s interest, usually the mother or draws the mother’s attention to his/her focus/object of interest. That is, the child follows the mother’s gaze to look at the object she is looking at, and looks back at her with shared effect, or looks at an object and then gaze at his or her mother and the object repeatedly to draw her attention to his/her object of interest. The lack of joint attention is a major Red Flag for autism. Other milestones to look for include social smile, response to name and gesture to request needs at two, nine and fifteen months respectively (see the next major section for details). During each well-child visit the NP elicits and assesses how well the child is attaining developmental milestones. For instance, the NP smiles at a two months old child, looks whether the child smiles back and calls the name of a nine months old child from behind and observes if the child will respond, as well as giving an 18-months old child a doll and a comb to comb the doll’s hair while observing the child’s action, among others.

Generally, a team-based approach led by a primary care provider, paediatric specialist, or clinical child psychologist trained to diagnose ASD is recommended to confirm an autism diagnosis.

After the Assessment

At the end of the assessment a written diagnostic report containing the full name of the child, date of birth, date of the assessment and a statement clearly stating the conclusion of the evaluation is

signed by the professional (including name and credentials) and handed to the parents. The conclusion should spell out clearly whether or not the child meets the diagnostic criteria for ASD. In addition, the report may contain the name of the clinic and location, the kinds of diagnostic tools used during the assessment, any other diagnoses made and the child’s level of capability and performance. Furthermore, suggestions concerning treatment and other possible steps to take in future are given.⁵ It is important to note that this information summarizes the child’s assessment findings and diagnosis which is very vital in planning the child’s treatment program. Again, the report may also include referrals to other specialists for cognitive or academic testing if needed.

Once an individual is given a confirmed autism diagnosis by a qualified professional, the parents/caregivers need to seek further information immediately on how to support their child. Early intervention treatment services have been shown to greatly improve a child’s development as these therapies help children from birth through three-years of age (36-months) to learn important skills. Also, special education services may be required for children age three years and older diagnosed with developmental delay or disability.⁶ The services vary and depend on the unique needs of the child. These could either be a therapy to assist the child develop speech, or walk, interact with others, and learn effectively. Such support or special education services are supposed to be provided by the school systems and made available to all children diagnosed with a disability as stipulated by the Individuals with Disabilities Education Act (IDEA).

The IDEA also recommends that children who are younger than three years and are predisposed to developmental delays could qualify for early intervention treatment services whether they have received a formal diagnosis or not. Also, interventions such as speech therapy required for specific signs such as language delays might not need an official diagnosis. It is important to note that though it is extremely important to diagnose a child early and start treatment immediately, intervention started at any age once the individual is identified can still be of help. When parents become worried about their child’s development it can be pretty difficult for them to make the right decision on what to do.⁶

Thus, it is very necessary for parents to be informed of possible centers where they can get help when they have concerns about their child’s development. These centers provide information to parents on where to have their children assessed and locate support services.⁵ If available, families are expected to be connected to community-based medical, educational, social and financial resources. To ensure that each individual diagnosed with autism receives best treatment options a comprehensive approach to care is provided by a multidisciplinary team. This is usually made-up of a psychiatrist, NP, developmental-behavioral pediatrician, psychologist, clinical social worker, and clinical counselor.

RISK FACTORS AND EARLY WARNING SIGNS OF ATYPICAL DEVELOPMENT

Children normally develop following a known and predictable pattern which can be described using a continuum of development and most children’s development would appear midway in

the continuum. A child is said to be developing normally if he/she is achieving developmental milestones that is, yardsticks used to monitor each child's development.⁷ Developmental milestones are skills such as smiling, laughing, cooing, babbling, saying single words, making phrases and then sentences, sitting, crawling, walking, jumping and following instructions among others. The manner and period during which children acquire certain skills and abilities in the course of development differ from one child to another. Some reach developmental milestones faster than others; some are just on time while others lag behind their peers.

Since there is an expected time-frame to achieve these milestones for normal development it is important to identify risk factors and warning signs of abnormal development. This can go a long way to prevent developmental delays and enhance typical development. It is important to note that there is a difference between developmental delays (when the child achieves skills slowly) and developmental disorders (when the child manifests skills that are abnormal in terms of quality, form and function).⁸ However, it is important to identify both early and treatment instituted promptly. Early intervention is known to be effective in helping children with special needs to either catch up or assist them study effectively.

Hence, it is important for parents, teachers and health care providers, especially nurses to know and understand the early warning signs and risk factors for childhood disabilities and delays which can impact normal development. This will enhance normal development and in turn curb the incidence and prevalence of developmental disorders. The following sub-sections present the risk factors and early warning signs of atypical development.

Risk Factors of Atypical Development

The rates and ways of development differ for different children; little children learn to crawl, talk, or use the toilet at different speeds. But sometimes a child may reach those milestones much later than other kids. There are many reasons why some children may have delays in reaching some developmental milestones or have developmental disabilities. These include prematurity or low birth weight, genetic disorders such as Down syndrome or muscular dystrophy, poor vision, hearing impairment and malnutrition. Also, factors such as personality, health status, life experiences and/or temperament could be the cause of these variances. In addition, physical abuse or neglect,⁹ the use of drugs and/or consumption of alcohol during pregnancy and fetal hypoxia during delivery could predispose to developmental delays and disabilities. Again, most developmental disabilities are thought to be associated with a combination of factors such as low birth weight, environmental exposure to drugs or tobacco and high-levels of environmental toxins (that is, lead). Furthermore, maternal infections during pregnancy, stress or neonatal infections, trauma and deficiency in iron, vitamins and proteins are all associated. These are explained in the next paragraph.

Stressful and negative life experiences may actually affect how children's brains develop. Specific, emotionally traumatic life events such as early medical complications which result in medical

interventions, pain, long hospital admissions and discrimination among others may lead to lifelong mental health disorders. Also, numerous stressful life events have been known to affect the shape and size of a child's brain and the connections between the brain cells negatively affecting development, behavior and learning. Furthermore, social and emotional delays are usually associated with cognitive delays and refrigerator mothers or neglectful parenting or early institutional neglect.¹⁰ Cognitive delays are generally associated with serious medical conditions in the prenatal period, genetic problems, exposure to alcohol and lead as well as neglect. Such delays are commonly connected to ASD and related disorders.

Early Warning Signs of Atypical Development

As earlier mentioned during development some children display behaviors that tend to deviate from the normal range of development. An example is when children display a series of behaviors that are significantly different from their peers. Such abnormal behaviors should be carefully noted and the dates and times at which they emerged, their sequence and quality and how they affect the child's functioning should be recorded.⁷ Also, the duration and frequency of behavior(s), type of activity (language, fine motor), the settings and activities in which they occur, interactions with peers and others should all be noted and recorded. Furthermore, areas of weakness and concern should be noted and distinguished from the child's personality.

Some of these abnormal manifestations could be early warning signs of later and more significant disorders which could be resolved and prevent future disorders. Thus, it is necessary to identify children who present signs of atypical development that is those who achieve developmental milestones earlier than expected or attains developmental milestones later than their peers. Particular attention should be placed on children whose development is just a little bit different from the normal that is the "gray area" children because most often they seem to have a typical development.¹¹ As a result, they may not receive support services early enough to assist them in the areas of development in which they require assistance. Therefore, it is very necessary to closely monitor "gray area" children and pay particular attention to those areas in which they may be developing typically, but lagging a bit behind their peers.

This is very necessary especially in the first five-years of development which are crucial as early identification and prompt intervention will best support growth and development. The following sections explain some warning signs of abnormal development for different types of delays/disabilities at different periods. The early warning signs of speech/language and motor skills development, social and emotional delays, and cognitive delays are presented.

Early Warning Signs of Atypical Development at Six Months

Children with developmental delays and disabilities manifest differently during development. Hence, every child should be observed for the following early warning signs or "Red Flag":

Concerning speech and language delays it is important to note if the child does not coo or smile, does not try to reproduce sounds and does not respond to loud noises or turn to follow sounds and voices as well as cannot follow objects or people with his/her eyes.¹² For motor skills development, take note if the child has trouble holding head up by age three-months, is unable to reach for and grasp with fingers, or hold objects and bring them to his/her mouth by four months. In addition, note should be taken if by five months the child does not roll over in either direction and cannot sit up without assistance by six-months.

Early Warning Signs of Atypical Development at Six-Months to One-Year

During this stage of development note should be taken of the following warning signs; the child lacks simple problem solving skills that is, cannot find his/her toy even though the child saw the toy actually being hidden.¹³ Also, whether a child has difficulties to respond when called to come over and see something interesting, and if she/he keeps on inflicting pain on self for example, by biting the toe or hitting the head against the wall. Again, early warning signs of cognitive developmental delays include inability to wave bye-bye and point to objects or pictures by one year.

Concerning motor skills delays, note when the child has problems with sitting, standing up, reaching for objects, or picking up objects, and does not play games like peek-a-boo. Additionally, is the child unable to crawl or walk, push down with legs when feet are placed on a firm surface/does not bear weight when pulled up to a standing position? Furthermore, the child should be observed to determine whether arms or legs are stiff, or posture is floppy or limp by seven months, and can still not stand even when supported or cannot crawl at one-year.¹³ For speech and language delays, if a child at this stage cannot produce any single words such as “mama or dada”, or does not understand words like “bye-bye” or “no”.

Also, it is important to note and report the warning signs related to vision such as the child does not follow moving and falling objects (whether close or far) with both eyes and does not observe movement of the hands. Again, difficulties moving one or both eyes in different directions, crosses eyes frequently, with one or both eyes turning in or out all the time as well as tearing constantly.

Early Warning Signs of Atypical Development at Two-Years

Talking about speech and language delays, the child does not speak up to 15 words, cannot use two-word phrases without repetition and can only imitate speech. Also, the child can only use speech to communicate immediate needs.¹² Other concerns are if the child has a wide vocabulary, but still have problems with articulation or pragmatics. For motor skill developmental delays, the child does not walk by 18-months and can only walk on toes, does not develop a heel-to-toe walking pattern or unable to push a wheeled toy around by two-years. Again, the child may take much longer time than expected to walk and get to his/her destination.

Children having social and emotional developmental de-

lays may display difficulties interacting with other children and/or with adults, this is noticeable before the child begins school. Usually, by three months the child does not smile at people and pays no attention to strangers or seems frightened by strange faces. Also, by seven-months, the child shows no emotional attachment to parents or caregivers, does not derive satisfaction being with people, does not smile unless prompted, and refuses hug. Again, at nine the child does not display back-and-forth sharing of sounds, smiles, or facial expressions as well as does not wave back at people, and cannot point or reach for his/her toy.¹⁰

Early warning signs of cognitive developmental delays include inability to imitate how common objects such as a pencil, hairbrush, telephone, or spoon are used, by two years the child cannot understand simple instructions such as come, go, give me that pen. Also, the child is unable to imitate words frequently used such as mama, food, eat, drink and so on.⁷ In addition, to the early warning signs mentioned above it is important to watch for any loss of skills that the child has already learned.

Furthermore, it is worth noting that the child’s brain is at its most flexible from birth to age five, thus it is very mandatory to get the required assistance and resources early enough if any of the above signs are noticed. This is in order to enable the child learn to his/her maximum potential during this very important phase of development. Earlier intervention on any of the area of disability may certainly result in better outcomes for the child.

COMMON ASSESSMENTS AND DIAGNOSTIC APPROACHES USED TO IDENTIFY DEVELOPMENTAL DELAYS AND DISABILITIES IN VARIOUS FIELDS

Various methods are available for use in assessing and diagnosing developmental delays and disabilities. Also, several instruments are available specifically designed to evaluate and diagnose autism spectrum disorders. Again, it is important to note that several items are needed to evaluate speech and language in children with autism. These include behavioral observation, preverbal language skills or early communicative skills, receptive and expressive language skills, and oromotor functions.¹⁴

In addition, the assessment could be done officially by the use of norm-referenced or criterion-referenced tests such as preschool language scale—fourth edition (PLS-4) and clinical evaluation of language fundamental-revised (CELF-R). However, educators in settings where there are no resources for a formal assessment could adapt tests or checklists locally and use to assess the related skills. The instruments available for the diagnosis of autism include interview, checklists and observation schedules among others which cover the entire lifespan.¹⁵ For the purpose of this paper the following sub sections describe some of the instruments used for diagnosing autism. The instruments presented in this paper are believed to be the most widely used and can be easily adapted by NPs for use in the assessment and diagnosis of autism in different settings.

Interview

This includes the Autism Diagnostic Interview-Revised (ADI-R)

tool which is one of the most widely used diagnostic algorithms and a diagnostic tool of choice for many public school systems and psychologists assessing children suspected of being on the spectrum. It involves a comprehensive, structured interview conducted by a trained clinician or psychologist with the child's parents or other caregivers, familiar with the child's developmental history and current behavior of the child. The interview can be used to assess both children and adults, as long as their mental age is above 2-years, 0-months. This comprehensive interview provides a thorough assessment of persons suspected of having autism or other autism spectrum disorders. The ADI-R has proven highly useful for formal diagnosis as well as treatment and educational planning.

It is a semi-structured interview that focuses on the three key symptom domains used to diagnose ASD. These domains are communication, social interaction, and repetitive or stereotyped patterns of behavior.¹⁶ The interview is made up of 93 items and takes about two-hours or more to administer. The items are scored on a scale from 0 (typical behavior or development) to 2 (abnormal behavior/development, or impairment).

The ADI-R uses DSM-IV Revised and ICD-10 criteria for autism, incorporated in its diagnostic scoring algorithm. Overall, ADI-R has good psychometric properties with inter-rater reliability in the range of 0.62 to 0.89, adequate convergent validity with other scales such as the childhood autism rating scale (CARS) and autism diagnostic observation schedule (ADOS-G) and good construct validity with DSM-IV and ICD-10 criteria.¹⁷ Key weaknesses of the ADI-R are that, it does not directly involve the child, it relies solely on parent report (the memory of the child's caregivers), it is quite long which needs much time to administer, and by an experienced autism clinician. Also, it was realised that ADI-R could not be used to reliably diagnose Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or Asperger's Syndrome (AS), however, DSM-5 now diagnose autism as a single disorder with three levels of severity.¹⁸

Checklists

Described below are some of the checklists used for diagnosing autism:

Autism spectrum disorders battery: The ASD Battery was devised to assist in the diagnosis of the different types of ASD that is autism, PDD-NOS and AS. The ASD Battery is exceptional in that in addition to the diagnostic component, it also has aspects of comorbid psychopathology and challenging behaviors. Again, it contains versions for toddlers that is, baby and infant screen for children with autism traits (BISCUIT); and children, adolescents and adults with intellectual disability.¹⁴ The toddler and adult versions used to diagnose both autism and PDD-NOS, while the child version is employed for the diagnosis of PDD-NOS, and AS. The key drawback of the ASD battery is that it depends only on parent or caregiver's report and therefore, subject to rater biases.

Modified Checklist for Autism in Toddlers

The modified checklist for autism in toddlers (M-CHAT) is an

example of a diagnostic tool that has been developed to identify autism at an early age. This instrument is the first revision of the checklist for autism in toddlers (CHAT). The M-CHAT is an expanded 23-item version of the CHAT.¹⁷ Like CHAT, M-CHAT is administered to parents and answered as either yes or no and the child is scored as "pass" or "fail". The M-CHAT is used for children in the age range 18-24-months and the test is composed of indicators that indicate signs of severe autism. Examples include "is your child curious about other children?" "Does he/she ever bring objects over to show you something?" It is important to note that a child "fails" the test if two or more of the six critical items are endorsed.

However, if a child "fails" it does not mean the child has an ASD because the M-CHAT was developed as a screening and not a diagnostic instrument. The CHAT and M-CHAT are some of the methodologically sound measures that have correctly detected ASD (either autism or PDD-NOS) at a rate of 83%. The CHAT however, was unable to differentiate between the two levels ASD. Also, the CHAT and M-CHAT have low sensitivity for the original scale and limited follow-up data available for the two revisions.²⁰ Again, it requires expertise knowledge of ASD and training in order to accurately use the two instruments and may not accurately diagnose before the age of three-years.

Observation Schedules

These comprise the following:

Childhood autism rating scale: The childhood autism rating scale (CARS) was developed in North Carolina to support the adequate screening of children for the treatment and education of autistic and related communication handicapped children (TEACCH) program.²¹ The TEACCH program was instituted in the early 1970s by Eric Schopler and colleagues and has been used by many with ASD and their families. This measure is completed by incorporating information from parent or teacher interviews together with direct observation of the child performed by experienced experts.

The CARS consists of 15 independent subscales rated on a scale from 1-4; 1) Relationship with people 2) Copying others 3) Emotional response 4) Gestures 5) Object use 6) Adaptation to change 7) Visual response 8) Listening response 9) Taste, smell, and touch response and use 10) Fear or nervousness 11) Speech 12) Nonverbal communication 13) Activity level 14) Level and consistency of intellectual response 15) General impressions. A score of 1 signifies the behavior of a normally developing child and a score of 4 reveals a "severely abnormal" behavior. A score in the range of 30-35.5 suggests mild autism, while a score of 37-60 reflects severe autism.¹⁷

A key drawback of the CARS is that it was developed based on DSM-III criteria for autism, and the symptoms it measures do not directly match up with those of the diagnostic and statistical manual of mental health disorders, fourth edition, revised-text (DSM-IV-TR) or DSM-V. Also, the CARS usually exaggerate the number of autistic symptoms in children with severe to profound intellectual disability. Finally, the CARS equally do not differentiate the symptoms of autism from those of the other forms of ASDs.¹⁷

Autism diagnostic observation schedule-generic: The ADOS-G is a semi-structured observation schedule designed to assist in the diagnosis of autism and appraise current functioning.²¹ The ADOS-G is employed in the diagnosis of children and adults at different stages of development and language ability levels. It is made up of four modules namely: 1) preverbal/single words, 2) flex phrase speech, 3) fluent speech child/adolescent, and 4) fluent speech adolescent/adult. To assess the child using these modules, he/she is subjected to circumstances that require him/her to do such things as requesting help for example, with dressing; engage in symbolic play; take turns in conversation; perform simple tasks such as brushing the teeth; story telling; discussing tasks that occurred earlier in the assessment, and discussing social and emotional situations.

Each module can be completed in approximately 30-minutes. The ADOS-G has advantage over CARS, because it includes a diagnostic algorithm for diagnosing PDD-NOS which according to DSM-V diagnostic criteria is level two ASD. However, it cannot diagnose AS, level one ASD. Items are scored on a 3-point scale from 0 (typical development) to 2 (explicit evidence of abnormality). It has adequate inter-rater, test-retest and internal reliabilities, and it has been shown to have good construct validity with DSM-IV criteria and good convergent validity with the ADI-R.¹² Research has revealed that employing multiple assessment methods; official assessment, observation and parent report will produce a more valid language profile for a child with an ASD as opposed to utilizing a single assessment technique. Other diagnostic criteria for ASD include:

i. Diagnostic and statistical manual of mental health disorders: The DSM is the acronym for diagnostic and statistical manual of mental health disorders which is an official diagnostic guide for diagnosing mental health disorders such as ASD.²² It is a reference book developed and published by the American Psychiatry Association (APA) as a guide to the various types of mental illnesses and is being revised and updated to new visions. The entry for each disorder includes a definition and a list of signs and symptoms used as diagnostic criteria. The DSM-IV-TR was used as a diagnostic reference that describes and categorizes all known mental illnesses and emotional disorders including ASD. Recently, the DSM-IV-TR has been revised to the DSM-V.

The DSM-V has made major changes in categorizing ASD as neurodevelopmental disorders. This categorization defines ASD as a set of disorders which begins in childhood manifesting as impairments in development resulting in deficits in personal, social and academic functioning. According to APA¹⁶ the DSM-V ASD refers to:

Persistent deficits in social communication and interaction in different contexts, manifesting currently or had manifested in the past as impairments in: 1. Social-emotional reciprocity evident by atypical social approach and back-and-forth conversation or decreased sharing of interests, emotions/affect or failure to initiate/respond to social interactions. 2. Nonverbal communicative behaviors used for social interaction, evident by poorly integrated verbal and nonverbal communication or abnormalities

in eye contact and body language or deficits in understanding and use of gestures or the absence of facial expressions and nonverbal communication.²² 3. Building up, sustaining, and understand relationships, displayed as difficulties adjusting behavior to suit various social contexts or in sharing imaginative play or in making friends or total lack of interest in peers.

Restricted, repetitive patterns of behavior, interests, or activities presenting as or had presented at least two of the following in the past: 1. Stereotyped or recurring motor movements, use of objects, or speech (for instance, simple motor stereotypes, arranging toys in a row, or flipping objects, echolalia, idiosyncratic phrases); 2. Resistance to change, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior. For example, the child manifests floppy thinking patterns, ritualistic greetings, is strongly attached to same objects or meal every day, or is greatly distressed with minimal changes in activities or in moving from simple to complex activities; 3. Highly limited and fixated interests with unusual intensity or focus; that is, the child is strongly and abnormally attached to strange objects and extremely displays restricted interests.¹⁹

In addition: The impairment prevents the child from communicating effectively, build and sustain relationships, achieve their maximum potential. Also, the symptoms manifest early during development and are not linked to another medical or neurological condition or mental disorder.

ii. Leiter international performance scale – revised: The Leiter international performance scale–revised (Leiter-R) is developed specifically for persons having problems with communication and hearing or other types of impairments that involve language. It is a valid measure used to reliably determine non-verbal cognitive, memory and intentional abilities. The non-verbal cognitive abilities do not necessitate the ability to identify, operate, and understand words and numbers, and the scale needs no verbal response from the person being assessed.¹⁴ Hence, it can be completely administered without the use of verbal language and instructions. The Leiter-R subtests are formulated with respect to the child's age and used to determine scores for fluid reasoning and intelligent quotient.

iii. Intention condition of behavioral enhancement procedures: The intention condition of behavioral enhancement procedures (UOI) is used to assess the child's ability to understand the intentions of others. During the evaluation the child is made to observe how an experimenter attempts to perform a target action (for example, fitting a key into a lock which the child has never seen being done rightly until completion. After three failed attempts without succeeding, the child is then told come over "*now it's your turn*". The child is expected to understand what the examiner intention was and as a result perform the intended action correctly without repeating the failed action performed by the experimenter.¹⁰

The child is given a score of zero if he/she is unable to pay attention to the stimulus presented; displays stereotyped and/or sensory manipulation of the object and repeats the failed attempt performed by the examiner among others. The UOI requires the least amount of attention by the child, is easy and quick

to administer, and is also recommended for children presenting with severe symptoms.¹¹

iv. Emotional contagion test: The emotional contagion test (TCE) is used to assess the emotional contagion, from a quantitative and qualitative perspective, that is the existence or lack of sentimental attunement in the child. This is done by observing the child's behavioral and emotional response with respect to a structured stimulus. The child is presented with four video recordings of a typical individual expressing basic emotions such as happiness, sadness, fear and anger through non-verbal gestures.²³ Each response is given a score of 0 if the child cannot repeat emotional gesture (it is considered absent). On the other hand, if the child repeats the motor pattern of the emotion and behavior the response is considered present and the child may be given a score of 1, 2 or 3.

v. Behavior rating inventory of executive function – preschool version: The behavior rating inventory of executive function–preschool version (BRIEF-P) is a questionnaire consisting of 63 distinct items used to measure various areas of executive functions in preschool children from two-years and zero-months to five-years and 11-months in everyday environments.²⁴ The BRIEF-P is made up of five scales; inhibit, shift, emotion control, Working memory and plan/organize. These five clinical scales are merged to create three large indicators, which are inhibitory self-control (ISCI), flexibility (FI) and emergent metacognition (EMI), one composite score/GEC and two validity scales (inconsistency and negativity). The scores reflect the child's level of functioning as demonstrated by his/her parents' report.

vi. Short sensory profile: The short sensory profile (SSP) is a questionnaire derived from the Sensory Profile and is completed by caregivers. The questionnaire comprised 38 items which can be completed in about 10-minutes. The items are divided into domains corresponding to seven different areas, which help to determine how a child with ASD modulates sensory input through sensory systems. Also, these determine which behavioral and emotional responses are associated with sensory processing.²⁵ The domains assessed include sensitivity to touch, taste, smell, movement, under-responsiveness or seeks sensation, auditory filtering, low energy or weakness and visual or auditory.

vii. Repetitive behavior scale-revised: The repetitive behavior scale-revised (RBS-R) is a questionnaire that determines the extent of repetitive behaviors in children with ASD. It is composed of 44 items, on a four-point Likert scale ranging from “absent behavior” to “*ever-present behavior*” and high scores signify regular dysfunctional behaviors.²⁶ Also it has six behavior subscales that is, stereotyped, self-injurious, compulsive, routine, sameness and restricted.

DIFFERENT MODALITIES OF INTERVENTION EMPLOYED IN THE MANAGEMENT OF CHALLENGING BEHAVIORS IN INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES, PARTICULARLY AUTISM

Many programs have been designed to deal with the variety of social and behavioral difficulties associated with autism. The main focus of these programs is to decrease problem behaviors in children with autism and teach them new skills.²⁴ These individuals are

taught how to act in social situations and/or how to communicate better with other people. Even though autism is a lifelong condition, children with autism may be supported and taught how to become less dependent.

Behavior can be defined as the different kinds of actions and skills (both normal and abnormal) displayed by individuals. It is important to note that behavior can be influenced by one's environment hence, behavior analysts using a scientific approach seeks to understand behavior and how it is affected by the environment. The science of behavior analysis provides guidelines about how behavior works, or how learning occurs. Examples are positive and negative reinforcement which help to maintain and increase the acceptable behavior by respectively using a reward or taking away something unpleasant in response to a stimulus.²⁷ For example, negative reinforcement can be used to stop tantrums in children with autism.

Another technique is punishment that helps to decrease and extinct poor or abnormal behavior. Over the years, many techniques for increasing good behaviors and decreasing abnormal behaviors have been developed by the field of behavior analysis.²⁷ The use of these methods and principles to deal with socially important problems and to enhance acceptable behavior change is referred to as applied behavior analysis (ABA). The following paragraphs explains how the ABA has been used in managing children with autism.

The ABA has been used over the years to build useful skills such as looking, listening and imitating, reading, taking the perspective of others and conversing in learners with autism of all ages. Therefore, the ABA principles and techniques assist individuals with autism to learn appropriate behavior and live contented and fruitful lives. The ABA is known widely as a safe and efficient management strategy for autism.¹¹ Some ABA techniques have proven their effectiveness in enhancing communication and social interaction skills as well as support individuals with autism to care for themselves, succeed at work and fully participate in family and community activities.

Also, ABA techniques are employed in managing some of the challenging behaviors exhibit by children with autism. Again, ABA techniques have been incorporated in to different programs resulting in comprehensive treatment programs for youths and adults with autism helping each individual to learn, achieve and live successfully in their communities.²⁷ It is important to note that a comprehensive ABA program for learners with autism should:

- Be designed and administered directly by qualified, well-trained professional behavior analysts.
- Determine initial treatment goals through detailed evaluation of each learner's skills as well as learner and family preferences.
- Choose unique goals which are meaningful for the learner and his/her family.
- Make provision for continuing objective measurement of the learner's progress.²⁸
- Make provision for the behavior analyst to frequently evaluate the progress data in order to adjust the goals and procedures as

required.

- Provide instruction on developmentally suitable goals in skill areas such as communication, social, self-care, motor, academics, play and leisure.
- Have skills broken down into small parts and/or steps according to the learner's ability and taught from simple such as listening and imitating single sounds to complex such as taking turns in conversations.
- Employ various behavior analytic procedures that is, both adult-directed and learner-initiated in order to enhance learning in different ways.
- Expose the learner to many opportunities both naturally occurring and planned specifically to allow for the acquisition and the daily practice of skills in structure and unstructured situations.
- Make provision for the intervention to be administered consistently for a reasonable number of hours per week.²⁹
- Make provision to abundantly reinforce useful skills and socially accepted behaviors using rewards.
- Emphasize on the need for positive social interactions and making learning fun.
- Not reinforce behaviors that are harmful or prevent learning.
- Employ methods to teach varieties of skills in order to enable learners to attain novel skills to use in a variety of settings.
- Emphasize on skills that will permit the individual to gain independence and lead a successful life.
- Train the parents of the learner in order permit them to teach and support skills during routine family activities.
- Organize meetings between family and program staff regularly in order to review progress, plan and make adjustments.²⁸

ADVANCES IN INTERVENTION FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

Recently, educationists have advocated for an inclusive education for children with developmental disabilities. That is, all regular schools should be modified to accommodate and support children with disabilities in such a way to provide a barrier-free learning environment which will permit all children to achieve their maximum potentials. Also, because no one solution fits all children with disabilities different strategies and interventions should be developed and tried out in order to determine the ones that work best for us and for each learner in our various classrooms. Since it is clear that a child's academic potential cannot be developed in isolation, the social, emotional and physical aspects of development must be considered.³⁰

Hence, an ideal and comprehensive support system will include special educators, community-based specialists, and assistive devices at affordable costs, medical assessments and services. In addition, the institution of intervention early enough for successful outcomes have been emphasized.⁹ Furthermore, involvement of the parents/family of children with developmental disabilities in the treatment plan has contributed enormously to better treatment outcomes. The following section presents advances that have taken place in the area of early intervention for children with developmental disabilities or delays in the last ten-years.

Advances in Early Intervention for Children with Developmental Disabilities

Providing comprehensive early intervention services and support for children with developmental disabilities/delays remains a global priority.³¹ The early years of every child's life are very vital because during this period children grow very fast and have so much to learn. Children with disabilities and families face special challenges requiring extra help early enough to make a difference in their lives.

The early intervention program (EIP) is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. Generally, there exists support for early intervention services in different countries especially in high income nations. According to research parental benefits for participating in early treatment programs are enormous.³¹ Parents are able to confidently perform their roles and contribute to their child's development with optimism about the future. A comprehensive early intervention program can at least prevent the significant negative effect in intellectual development that usually happens during early childhood for children with developmental disabilities/delays.

The EIP was first created in New York by Congress in 1986 under the IDEA. The EIP for infants and toddlers with disabilities and their families is made available through the Bureau of Early Intervention and is administered by the New York State Department of Health. The EIP in New York State is found in Article 25 of the Public Health Law and has been in effect since July 1, 1993. According to the State only infants and toddlers who are under three years of age and have a confirmed disability in at least one of the following areas of development that is, physical, cognitive, communication, social-emotional and adaptive are eligible for EIP services.³² The subsequent subsection describes the EIP services.

Early Intervention Services

The EIP provides a range of therapeutic and support services to infants and toddlers with confirmed disability or established developmental delay and their families.³³

These include:

- Family education and counseling, home visits, and parent support groups.
- Special instruction and vision services.
- Speech pathology and audiology services.
- Occupational and physical therapists services.
- Psychological and social work services.
- Service coordination.
- Nursing and nutrition services.
- Assistive technology devices and services.
- Vision services.

The EIP also consists of the child's individual records which include all written materials gathered or incorporated in the EIP. These include all information collected for the child's refer-

ral to the EIP, screening, assessment reports and summaries, parent assessment and other records concerning the child and family. In addition, it composed of progress notes about the child's and family's services prepared by early intervention service providers and any complaints filed by the family among others.³⁴ It is worthy of note that all information collected is kept confidential by the Early Intervention Official and evaluators, service providers and coordinators. Parents must give their written consent before any information collected about their child can be released.

Furthermore, varieties of home-based and school-based treatments and interventions for children with autism have been developed over the years. These include behavior and communication therapies which have been developed to handle the range of language, social and behavioral difficulties related to autism. Some of these programs are designed to decrease challenging behaviors and to teach new skills while others are used to teach children how to behave in social situations and communicate better with others. These therapies allow children with autism to function well in life.³²

Successful educational therapies designed for children with autism usually composed of a team of specialists including special educators and a range of activities to enhance behavior, social and communication skills.¹¹ Intensive and well-structured, individualized behavioral interventions administered to preschool children produce good results. It has been revealed that no medication can treat the major signs of autism; however, some medications can assist in managing them. Examples are antidepressants used to control anxiety, and antipsychotic drugs used occasionally to manage severe behavioral crisis.

FACTORS THAT CONTRIBUTE TO TREATMENT SUCCESS FOR CHILDREN WITH AUTISM

Different types of therapies have been shown to improve the lives of children with developmental disabilities especially autism.³⁵ Some interventions help to modify behavior such as ABA, some assist in developing thought processes and creativity for example Floortime, while others help the child to express thoughts and ideas either using speech or non-verbally. However, it is important to note that no single intervention works for all children and children's needs change over time which necessitates the incorporation of other treatment options.³² Therefore, most children improve best when different therapies are combined or used in a sequence. Several factors can be associated with the successful outcomes for autism treatment and this is usually determined by the degree of improvement in quality of life.

The associated factors which include early diagnosis and treatment, the severity of presenting symptoms, parental involvement and proper determination of individual goals by well-trained experts,²⁸ among others are both child- and therapy- centered. It is worth noting that treatment, therapy and intervention are used interchangeably in this write up. The subsequent paragraphs explain some of the reasons why an autism therapy is more likely to be successful.

Talking about the factors related to the individual, an in-

tervention would be successful if the child has mild traits at the time of diagnosis and treatment is instituted early that is, between the ages of two and three.²⁸ This is the period when children are beginning to interact more with others and learn from their environment. An effective therapy and high-level of support especially from family members and the school authorities at this stage will enhance skills development and reduce autistic symptoms. For instance, early interventions and other supports can lead to improved social communication and interaction with others, joint attention and play skills which in turn enhance the child's language and cognition.

To talk of therapy centered-factors ABA programs for learners with autism that are designed and supervised by qualified behavior analysts who are experienced in providing ABA treatment for autism are most likely to be successful.³⁴

Other factors include:

- The collective effort of all stake holders; educationists, pediatricians, psychologists and NPs among others.
- Frequent evaluation of treatment plan and client's progress by well-trained experts.

CONCLUSION

Diagnosing autism early and instituting treatment and support promptly is mandatory for better prognosis. The diagnosis and treatment of autism and related developmental disabilities require a multidimensional approach and a collaborative effort of all stake holders. Generally, nurses and other health professionals with the aid of parent reports are expected to identify children with autism during routine well-child visits that is, before they begin school. Different standardized diagnostic tools are available and should not be used in isolation but in combination with other tests. In addition, each child's behavior should be carefully observed in a clinical setting by well-trained experts in order to better comprehend the child's unique communicative and social interaction difficulties. This should clearly define the child's development profile, and directs individualized interventions and support. Furthermore, it is recommended that interventions should be designed, implemented and supervised by qualified and experienced professionals in order to guarantee the success of treatments.

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APPENDICES

Appendix A

<i>Differences between Developmental Monitoring and Screening</i>		
Indicator	Developmental Monitoring	Developmental Screening
Who monitors?	Parents/other caregivers/nurse	Healthcare provider/ early childhood teacher/other trained provider
Looking for what?	Developmental milestones	Developmental milestones
When?	From birth to 5 years	Developmental Screening at 9, 18, 30-months of age Autism Screening at 18 and 24-months of age
Why?	To help you: <ul style="list-style-type: none"> • Understand changes occurring in your child • Talk about your child's progress with doctors and childcare providers • Learn what to expect next • Identify any delay early 	To find out: If your child needs more help with development, which is not always apparent to doctors, childcare providers, or parents If more developmental evaluation are necessary
How will this be done?	With ease, with the use free checklists	Using an official, validated screening tool
<i>Source: Adapted From National Center on Birth Defects and Developmental Disabilities^a</i>		

Appendix B

<i>Developmental Evaluation</i>	
What is it?	A more in-depth evaluation of a child's development
Why performed?	To identify and diagnose developmental delays and conditions To find out if your child needs specific treatment and whether he/she
Who evaluates?	A developmental pediatrician, child psychologist, nurse practitioner or other trained provider
When?	Whenever there is a concern during development
How?	By conducting a detailed examination using formal assessment tools, observation, and checklists completed by parents and other caregivers.
<i>Source: Adapted From National Center on Birth Defects and Developmental Disabilities^a</i>	

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