INCREASING HEALTH PROFESSIONALS' ABILITY TO RECOGNIZE, DIAGNOSE, AND INTERVENE IN AUTISM SPECTRUM DISORDER CASES IN AFRICA: EXAMPLES FROM SPECIFIC DEVELOPMENTAL STAGES - A LONGITUDINAL CASE STUDY.

Nicola Wannenburg[a,*], Roelf Van Niekerk[b]

[a]*Department of Psychology, Rhodes University, Makhanda, South Africa*
[b]*Department of Industrial and Organisational Psychology, Mandela University, Gqeberha, South Africa*

Abstract

Background:

As awareness surrounding autism spectrum disorder (ASD) in Africa has increased, the high rate of non-verbal autism on the continent has come to the fore. Late diagnosis and access to viable interventions are continued concerns. Due to the greater focus on the communicable disease in healthcare curriculums, healthcare professionals frequently do not possess the required knowledge and experience to diagnose cases of neurodevelopmental disorders. Nurses are often the first healthcare professionals to encounter autistic individuals or their families because of being the first professionals whose advice is sought about worrisome symptoms, either by high-functioning individuals with autism or by a worried parent of a newborn or toddler.

Methods:

A narrative review of healthcare professionals' knowledge of ASD in Africa provided context for the research and highlighted areas needing focus. A qualitative mixed-method case study was used to highlight symptoms and potential behaviors of autism that healthcare practitioners may face in practice.

Findings:

A lack of focus on neurodevelopmental disorders in healthcare curriculums has led to an inability to recognize, diagnose, and intervene in ASD cases across Africa, which places a greater burden on families, especially in low-resource settings. Nurses are central in both clinics and communities. Nurses' ability to discern neurodevelopmental and autistic behavior from typical childhood development is crucial to timely diagnosis and intervention as well as accurate treatment of presenting communicable diseases or co-morbidities. Increasing health professionals' awareness and understanding of autism spectrum disorder should aid in the reduction of undiagnosed and untreated cases.

Conclusions:

Healthcare professionals' ability to diagnose developmental disorders at a younger age, may increase the chances of intervention and autonomy in children with neurodevelopmental disorders and support for families.

Recommendation:

In order to facilitate early diagnoses and intervention of neurodevelopmental disorders, greater emphasis needs to be placed on non-communicable diseases in health care curriculums.

Keywords: Autism, neurodevelopmental disorders, nurses, diagnosis, Africa, Submitted: 2023-02-23 Accepted: 2023-03-21

1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that presents with severe impairment in communication and relational skills, restricted interests as well as stereotypical and repetitive behaviors.[1,2]The existence of ASD in Africa is no longer disputed.[3,4] However, the lengthy denial of the presentation of this particular neurodevelopmental disorder in Africa as well as the urgency and focus required by many infectious diseases on the continent, has led to ASD not receiving the necessary attention.[3,5] This has resulted in a lack of awareness and knowledge among healthcare workers and educators, as well as late diagnosis and intervention.[4,6] These factors all contribute to impeded development and language delay in individuals with ASD.[7,8] Many African countries may be classified as low-income and low-resource settings. Individuals with ASD who are unable to be autonomous increase the economic burden on their families and countries. This results from undeveloped individuals with ASD not being able to contribute to the workforce as adults as well as often requiring a family member to remain at home as a permanent caregiver.

Early diagnosis and intervention are important to individuals with ASD in developing communication and relational skills and as much autonomy as possible.[8–10] Not all individuals with ASD that receive the intervention will develop the necessary autonomy to hold a full-time job or study at the post-secondary level. Nevertheless, any increase in autonomy and communication will assist both individuals with the disorder as well as their caregivers. Greater knowledge about ASD is required by healthcare workers generally in order for symptoms of ASD to be discernable from other disorders as well as any comorbidities that may be present.[6,10]

While this paper provides information for all healthcare workers, social workers, and educators, it is aimed at increasing ASD knowledge among nurses in Africa. Nurses are often the first professionals whose advice is sought about worrisome symptoms, either by high-functioning individuals with autism or by a worried parent of a newborn or toddler. Nurses may also encounter undiagnosed babies and children while consulting or treating a physical disease or injury that was initially the primary concern. It is important to note that symptoms of ASD may present as physical as well as relational, communication, and psychological symptoms. Nurses being able to recognize symptoms of ASD will lead to more diagnoses as well as an increase in the possibility of intervention and assistance for families. Lack of awareness of this neurodevelopmental disorder often leads to the stigma associated with the presenting symptoms.[10,11] Nurses are also in prime positions in hospitals and communities to increase awareness about ASD and decrease stigma.

While research on ASD in Africa is generally limited, research from both South Africa[12] and Nigeria[13–17] reveals that healthcare professionals such as nurses, doctors, and psychologists, as well as students of these disciplines, lack accurate knowledge to recognize, diagnose, and inform parents of their child's disorder. This greatly influences prognosis. Lack of knowledge about ASD among healthcare professionals is not isolated to Africa but is an international concern.[18]

Much of the research on ASD in African countries has stemmed from South Africa and Nigeria.[5] While both countries have far fewer resources to manage ASD (and other neurodevelopmental) cases than western countries, these two African countries' resources still greatly outweigh many other African countries' financial, medical, and practical resources. It is, therefore, possible to presume that if ASD knowledge is lacking in South Africa and Nigeria, nurses in African countries where there is less awareness about ASD will be in a similar if the not worse position to handle an ASD case. Bakare et al. designed the knowledge about childhood autism among health workers (KCAHW) questionnaire to assess healthcare professionals' knowledge of ASD in African countries.13 Despite this tool initially being designed for use in Africa, it has also been employed in

*Corresponding author.
Email address: n.wannenburg@ru.ac.za (Nicola Wannenburg)

the United States of America where it has been found to be useful.[18] Cultural and linguistic relevance are always important in designing and implementing such tools. However, the applicability of the KCAHW in Africa as well as the USA supports the notion, that as a neurodevelopmental disorder, ASD contains elements that traverse cultural, racial, and linguistic bounds.

Research employing the KCAHW has revealed that psychiatric followed by pediatric nurses have shown the greatest knowledge and ability to diagnose autism as well as nurses who have extensive experience working with children.[15,16] However, this knowledge is still limited. Both lack of exposure to children and an absence of neurodevelopmental information in the healthcare curriculum relates to the lack of knowledge among healthcare professionals, both in Africa and internationally.[16,18,19]

Textbook knowledge about ASD is necessary and valuable. However, merely knowing broad terms used in the diagnostic and statistical manual of mental disorders (DSM) to describe individuals on the autism spectrum does not provide healthcare professionals with knowledge of how the symptoms may present in a patient and discern what parents may relay to nurses about their child's behavior. While each case will present differently to varying degrees, illustrating presenting symptoms through a case study will provide healthcare workers with examples of what they may encounter in practice.

The case that follows focuses on aspects of the life of Temple Grandin who had classical nonverbal autism as a child, but through intensive intervention developed to live as an autonomous and productive adult. Despite Grandin being born in the USA and growing up in an earlier historical period, a case study focusing on her life has valuable information for healthcare professionals in Africa. Grandin grew up during a time when little was known about autism, stigma was rife in relation to any 'odd' or unexplainable behaviors exhibited by children, and few, if any, established ASD interventions existed. This is still contextually relevant to many parts of South Africa, as well as Africa. Secondly, the information that may be derived from Grandin's life has international significance. This is because she is one of the few people with autism that has been able to provide a longitudinal history and reflection of what it is like to live with autism (from the autistic person's perspective), the struggles of misdiagnoses, and lack of information, and her family and teachers needing to make use of what was available in order to help her develop. Oshodi et al.20 as well as Durkin et al.21 stress how important the global flow of autism knowledge is and that children and adults from any part of the world should be able and allowed to benefit from such information. At this point in time, there are no such studies in Africa that may provide in-depth longitudinal knowledge about autism. However, as autism is a neurobiological disorder, researchers/health professionals from South Africa, as well as other parts of Africa) acknowledge that while culture, language, and context should always be considered, the similarities in autistic behavior can be observed across continents.[20,22–24] This makes the information from Grandin's childhood that illustrate autistic behaviors and 'red flags' valuable and relevant to healthcare professionals in Africa. The aspects of Grandin's life that are relayed are not necessarily descriptions in medical settings, but also portrayals of everyday life in order for nurses to gain a holistic sense of how an individual with ASD may behave and experience the world.

Aims of the study

The primary aim of this study is to increase healthcare workers' ability to recognize and intervene in ASD cases. Further aims of this study are:

- To raise awareness about ASD amongst healthcare professionals, especially nurses.
- To increase healthcare professionals' knowledge about ASD and potential 'red flags'.
- To provide an informational platform to highlight the need for further research on ASD in Africa.

2. Methods

An interpretive qualitative paradigm that incorporated a mixed method approach was em-

ployed for the conduction of this research.[25] While the mixed method approach often combines quantitative and qualitative methodologies, it may also denote an integration of qualitative approaches.[26,27] A preliminary literature review was conducted on peer-reviewed articles on healthcare workers' knowledge and experiences of ASD on the African continent to provide context and ascertain areas requiring further research and to inform the focus of the psychobiographical case study. Three databases (Google Scholar, African Journals Online, and PubMed) were searched using the terms "autism" AND "autistic" AND "Africa" AND "healthcare professionals" AND "knowledge". Reference lists of selected articles were reviewed for further information on the topic. According to Ponterotto the mixed method approach, such as that used for this study, is particularly relevant to facilitating the complex nature of psychobiographical research.[26,27]In terms of psychobiographical studies where there may be a vast amount of data, an integrated methodological approach may assist with 'sorting', focusing on pertinent information, and increasing the depth of analysis.

2.1. ***Participant and sampling method***

Grandin was purposively sampled as the subject of this psychobiographical case study.[28] She was purposively sampled as she is an individual who had non-verbal autism as a child but who through intensive intervention acquired the ability to speak and give comprehensive accounts of her experiences.

2.2. ***Data collection***

The data triangulation principle was employed to guide the data collection regarding Grandin's life and development.[29] Therefore, data was sought from a variety of sources and judiciously sorted through for valid and pertinent information.[29] A preview of this research occurred in 2020 to access where notable gaps in the current neurodevelopmental research in Africa were. A more comprehensive data collection followed between January 2022 and September 2022. As the data was ascertained it was screened for its impartiality or lack thereof toward the subject of the study.[30] Regarding this research, data collection concerns, relating to the subject's childhood, such as reductionism were also considered. Reductionism is addressed through the employment of Erikson's stages of psychosocial development.[31] This staged approach considers events in Grandin's life across her lifespan and incorporates the social, environmental, and biological, as well as healthy and unhealthy aspects of the subject's life. For the purposes of this paper, further data reduction of the psychobiographical case study compromising Grandin's entire lifespan was required. This is elaborated on in the following section.

2.3. ***Data processing and analysis***

Data processing and analysis guidelines for this study were based on Miles and Hubermans' three-step interwoven process that involves data reduction, data display, as well as conclusion drawing, and verification.[32]The conduction of the processing and analysis of data was further facilitated by the incorporation of Erikson's triple bookkeeping approach with Yin's time series analysis.[29,31] Diagnostic symptoms and possible presentations of ASD mentioned in the DSM-5 and KCAHW further aided data reduction. The relevance of the selected data to presentations of autism observed by health professionals in Africa is supported by the use of the KCAHW for data reduction. Due to limited space, the case study will focus on aspects of Grandin's childhood that reveal markers of ASD.

2.4. ***Validity and Bias concerns***

A potential downfall of the case study method in particular, and more generally qualitative research, is the lack of rigour in the research process that can be confounded by bias[25,29]. Research that is conducted in a rigourous manner pays particular attention to the validity and reliability of the study in order for it to be credible or 'trustworthy'[25,26]. Yin[29] stresses the importance of an appropriate research design, data collection method, as well as analytic process that are aligned with the research objectives. These

specifics related to this study have been outlined. Further validity and reliability concerns were credibility, transferability, and construct validity. In order to ensure credibility or internal validity all possible reasons for an outcome were explored as well as ensuring that all data collected was factual. In order to deal with potential researcher bias, the data triangulation method was employed as well as journaling and discussions with peers and colleagues surrounding emotions and assumptions that may have been made during the data collection and interpretation[25,26,29]. Construct validity or the defining of parameters to be studied also aided in the reduction of bias as it increased the possibility of there being a reasonable alignment between the research question or aims and the methodological approach that the researchers employed.

2.5. ***Ethical considerations***

Informed consent was obtained from the subject, Temple Grandin, for the conduction of the psychobiographical case study. This consent included the presentation of data in journal articles. Ethical clearance was obtained from the Rhodes University Psychology Department Research Projects and Ethics Review Committee. Because of the nature of psychobiographical studies, the subject's identity does not remain anonymous. Nevertheless, caution was taken to ensure all documents and information were handled with respect and that the subject's privacy was not invaded. Through obtaining consent from the subject of the study construct validity was increased. Caution was taken not to harm or embarrass the subject or the subject's family. The trustworthiness of the data was increased through the corroboration of various sources.

2.6. ***Findings***

For the sake of categorization, the data follows Eriksonian age groups.[31] The findings of each age group will be followed by salient points as opposed to a lengthy discussion after the findings. The findings and salient points are written in such a way that they can be a reference point for practical purposes.

Birth to 18 months: Unless otherwise specified, the data for this stage is obtained from Cutler (Grandin's mother).[33]

Temple Grandin's birth and first few weeks in the world seemed fairly usual for her socio-historical period. Eustacia, Grandin's mother, was young and inexperienced with babies. However, Grandin's parents had been advised by a nurse at the hospital about general infant care. They also had a nurse consult with them at home. No healthcare professional had noticed anything amiss with Grandin at this point. Nevertheless, when Eustacia was alone with Grandin she felt that she did not know "how to win her over" (p. 5) as Grandin did not seem to care.[33] Eustacia questioned whether Grandin was too quiet and sleeping too much. However, she felt ashamed that she had wondered if Grandin was behaving strangely and so rather ignored her concerns. As the months proceeded Eustacia noticed that while other babies in her community grabbed their mothers' hair, necklaces, or earrings, Grandin did not interact at all. By the time Grandin was six months old she did not want to be held and would stiffen and pull away. A few months later it became almost impossible for anyone to hold Grandin as she would scream, claw at the person, and struggle to get away from them. Grandin's withdrawal hurt Eustacia and affirmed her choice to keep her distance from Grandin and ignore that something was potentially wrong with her child.

When Grandin turned one, Eustacia took her to the beach to swim. A swell carried Grandin, who was wearing a life jacket, away from Eustacia. Grandin floated further into the ocean out of Eustacia's reach. Eustacia screamed frantically and a man heard her, saw the situation, and rescued Grandin. All the while Grandin was silent and non-responsive. Eustacia thought that Grandin "seemed neither happy nor unhappy" (p. 7) at being pulled out to sea or to being handled by a stranger.33 At this point Eustacia began to feel that Grandin had been taken from her "to somewhere quite far off" (p. 8).[33]

Salient points relating to ASD presentation and diagnosis

- Symptoms of ASD such as not making eye contact, not interacting with caregivers in any way, or not wanting to be held/touched may be present before the infant is 12 months.

- A pregnancy or birth trauma is not related to the onset of ASD. It is not preventable, but treatable.

- Caregivers may have no knowledge of ASD and may merely be aware that their baby is different from other babies in some way. Parents ignoring the initial signs of ASD is not uncommon.

- Lack of emotional responsiveness or awareness (merely seeming detached, absent, or "far off") in relation to a crisis, such as Grandin was when being swept out to sea, may be present in the first year. The converse may apply to physical contact, by which the infant may seem severely distressed.

18 months to 3 years: Unless otherwise specified, the data for this stage is obtained from Cutler.[33]

Eustacia first voiced her fears about Grandin's development when Grandin was 21 months old. Veevee and her daughter came to visit. Ceelie, who was only a few months older than Grandin, played in the sand, making objects with her molds and spade. Ceelie would look to the adults for approval and be encouraged by their praise. Grandin did not interact with anyone. Nor did she play the way Ceelie did, even when Eustacia and Veevee tried to involve her. Grandin sat lost in her own world, merely picking up sand and watching it slip through her fingers, over and over again. When Eustacia could no longer handle her child's oddness she blurted out "Why isn't Temple doing what Ceelie's doing?" (p. 14).[33]Veevee was a pediatric nurse and took Eustacia's question as an opportunity to express her own concerns that Grandin was not playing or learning to speak. Veevee believed that Grandin could be taught to speak and suggested that Eustacia make an appointment for Grandin at the clinic. The doctor who saw them at the clinic thought that Grandin was "very odd" (p. 15).[33] The doctor suggested that Eustacia get some plastic cups to try to play with Grandin.

Slowly Grandin learned how to take the cups and give them back to her mother. However, she would never look at her mother and remain mute and lost in her own world. She still preferred to be alone and desisted from being touched.[34] While Grandin was often lost in her own world she would react suddenly and sometimes aggressively to sounds, smells, textures, and sudden movements from other people.[35] Grandin remained mute until she was almost three years old. At this time, she started to laugh. However, the laughter was filled with spitting and became "uncontrollable spasms" (p. 16) that she would struggle with throughout childhood. Dick, Grandin's father, was disgusted with his daughter and could not tolerate the disorder she created.[33] He was adamant that she was retarded and belonged in an institution. Grandin's behavior became more tumultuous and disruptive to the family. Tension and disharmony between her parents grew. Eustacia's mother was also disappointed with Eustacia for bearing such an impolite, odd child with a "distasteful malfunction" (p. 21) as it was having a negative impact on the family's standing in their community.[33]

Grandin's tantrums increased. They involved her ripping things off walls, ripping her mattress, and pulling out the stuffing until she reached the springs and then eating bits of the mattress.[36] This would be followed by fits of spitting and laughing.[34] One day Grandin ran out of the house and into the road. She proceeded to take her clothes off and defecate. Eustacia grabbed Grandin and took her back inside where she broke and threw any object that she could find. After throwing toys, bedding, and the bin into one pile Grandin once again defecated, picked it up, and smeared it onto the walls. Grandin would also urinate on the carpets or on curtains that she had pulled and placed between her legs.[37] This behavior was repeated on many occasions.

Slowly, Grandin became more responsive to her family. However, she did not learn to speak.

Grandin remembers that she began to understand what people were saying, but could not respond.[37] With encouragement from her aunt and continued support from Veevee, Eustacia took Grandin back to the clinic where she was held for observation. When placed in a room with other children Grandin sat in a corner and ignored them. Following this observation, the doctor suggested that an ear specialist test Grandin's hearing to check if it was not interfering with her learning to speak and socialise. However, Grandin's hearing was found to be normal. Like Eustacia's friend Veevee the pediatric nurse, the doctor believed that Grandin could learn to speak and suggested a speech therapist despite her initial diagnosis of "brain damage" (p. 3).[38]

2.7. ***S alient points relating to ASD presentation and diagnosis***

- A lack of interest in others or surroundings may be more obvious during this stage.
- A disinterest in playing more generally and playing with other children may be apparent. Age-appropriate friendships do not begin to form.
- An absence or delay in speech, as well as an inability to communicate, is one of the most obvious symptoms of ASD and more difficult for parents to ignore. Young children may seem to not understand anything that their caregivers are saying. With intervention, many individuals with ASD can learn to communicate and speak. As was evident with Grandin, some individuals will learn to understand words and find other ways to communicate before they are able to speak. It is important to note, in some ASD cases children may be able to speak or recite passages of text but have no understanding of what they or anyone else is saying.
- ASD symptoms may be mistaken for deafness. It is, nevertheless, important to make sure.
- Obsessive or repetitive actions, like for example Grandin repeatedly picking up sand and letting it slip through her fingers, may be seen.
- The need for consistency may be more apparent and various sounds, tastes, and textures may cause an outburst or violent reaction. A child may eat strange things such as Grandin did when eating her mattress.
- Intellectual disability is a potential comorbidity (as well as epilepsy). However, the child's inability to communicate and display age-appropriate behavior, such as Grandin urinating and defecating on the floor and curtains, may disguise intellectual ability. The child may for no apparent reason oscillate between absence and tumultuous behavior.
- Families may experience shame, as well as increased tension between caregivers. Supportive elders in the family, like an aunt, was to Eustacia, and knowledgeable friends such as pediatric nurse Veevee, can encourage a positive turning point in a family with a member who has ASD.

Age 4 to 5 years: Unless otherwise specified, the data for this stage is obtained from Cutler.[33]

Grandin could hear, but she found it difficult to distinguish the sounds of vowels and consonants, especially when people spoke quickly.[37] The speech therapist helped Grandin to learn the consonants and to stretch them out.[38] Grandin remembers that this is what she particularly struggled with because to her ears all she heard were vowels.[38] Reaching desperation with Grandin's slow progress Eustacia took her to a psychiatrist. The psychiatrist did not understand Grandin's condition and told Eustacia that Grandin had infantile schizophrenia/psychosis.

When Grandin was four years old, she still could still not speak or interact except through her tantrums. Grandin's tantrums and destructive behavior grew worse later in the day when she became tired.[34] Grandin had stopped playing with her feces but still lived in her "private land of enchantment" (p. 38).[33] When Grandin

was five years old Eustacia noticed that the work with the speech therapist began to reveal results. She had started to speak, even though her words were not clear. Grandin also began to behave herself in a group and, for example, wait her turn for a cup of juice. Grandin's development of social skills and more socially acceptable behavior was aided by her language development, strict rules at family meals, as well as playing games that had particular instructions.[37] Grandin's development was more apparent in controlled or familiar environments. Throughout her childhood, she would overreact when there were many people and loud noises.[34] Invariably Grandin would hit another child or throw something at someone. Grandin's voice was flat and had no rhythm or inflection.[37] Whenever she did speak it highlighted her differentness from other children. This was also aggravated by her not being able to make eye contact.

Grandin struggled with many tasks because she still needed to connect meaning to the words she heard and how to distinguish various objects or creatures from one another. This point was illustrated by Grandin being able to distinguish their big dog from their two cats by size.[35] Grandin applied this same logic to the animals in the neighborhood.36 However, when her next-door neighbor got a dachshund she could not understand why it was not a cat because it was also small. She needed to identify another distinguishing feature between cats and dogs other than their size, and this was their noses.[36] As a result of Grandin's improvements, she was able to attend the small preschool in their community. This did, however, include many days of being sent home for unacceptable behavior.

2.8. Salient points relating to ASD presentation and diagnosis

- Children's inability to make eye contact may be more apparent during this stage. A child's withdrawn state and inability to make friends will be noticeable. A child with ASD will seem 'different' from other children of a similar age.

- ASD is sometimes misdiagnosed as infantile schizophrenia or psychosis.

- Early intervention with speech therapy is particularly useful in teaching children with ASD to speak/communicate. More affordable interventions such as joining an art or drama group in the community may also be beneficial.

- Despite ASD being a neurodevelopmental disorder unruly behavior should not be condoned. As was the case for Grandin, rules/boundaries, and instructions for daily living, as well as those incorporated into games, can be beneficial reference points for individuals with ASD well into adulthood.

- The behavior of a child with ASD will become more predictable to caregivers when the child is in a familiar environment. Strange behavior or screaming in crowded or unfamiliar environments, such as a hospital, is not unusual.

- Children with ASD process the world and interactions with people differently than neurotypicals. Inappropriate behavior or responses to another person is not necessarily due to the child lacking intelligence or trying to be difficult. An example of this is Grandin not being able to understand why the next-door neighbor's dog was not a cat as it was small. Knowing that individuals with ASD have a different way of understanding and relating to the world may aid patience in healthcare professionals and parents when trying to connect with children with ASD.

6 to 12 years: Unless otherwise specified, the data for this stage is obtained from Grandin and Scariano.[37]

During this stage, Grandin went on to attend the small local country school. Grandin struggled to learn to read. Not wanting Grandin to fall behind, her teacher asked her mother if she would help at home. Grandin's tantrums continued and she developed a discomfort with the texture of some clothes which would continue into adulthood.[38]However, she did begin to learn that there were certain social conventions, such

as wearing her scratchy petticoat to church, that she had to adhere to.[33] She also learnt to keep quiet during Sunday dinners. Grandin's explanation to her mother that her being able to cope with this particularly uncomfortable situation was that "Sunday dinner is quiet. It's noise and confusion I hate" (p. 44).[33] Despite Grandin's erratic and disruptive behavior at school, she liked to play double solitaire at home with her father.[33] During the game she was quick and focused.

During grade two, Grandin started daydreaming about a "magical device" (p. 36) that would be physically comforting.[37] She still could not tolerate any physical contact, whether a pat on the back or a hug. She flinched if anyone touched her.[34] Even though Grandin did not have such a magical contraption she self-soothed by wrapping herself with blankets and hiding under the couch. Alternatively, she 'clothed' herself in cardboard as she found the pressure comforting.[34]

Eustacia noticed that Grandin's relationship with her next-door neighbor Lyman was significant. While other children merely tolerated or accepted Grandin on the basis of her living in the community, Lyman was fond of her.[33] Both children were imaginative and enjoyed mischief and making/creating things to play with.[33] During her schooling Grandin made another friend, Eleanor, who also had similar interests. Grandin's fixating or obsessing extended to areas other than her "magical device". In the fourth grade, Grandin had a fixation with wanting to know everything about the upcoming election.[34] Grandin and Eleanor went as far as to take the election posters off of the telephone poles in order to hang them in their bedrooms. When someone teased Grandin and mimicked her awkward speech and "jerky movements" (p. 44)[37] in the assembly hall, she threw a tantrum and lay on the floor, and kicked anyone who came near her.[35] Even though Eleanor was appalled she defended Grandin.

Grandin's younger sister had become very aware of the tension between their parents and kept asking Grandin if she thought that their parents were going to get divorced. Unaware, Grandin thought her sister was being silly.

2.9. ***Salient points relating to ASD presentation and diagnosis***

- The child may begin to exhibit the need for routine. This may be extreme in some cases, especially as the child gets older.

- Attending a school with smaller classes may be a possibility for some children. It would be imperative that the child's teacher has some knowledge of ASD. Healthcare professionals in communities could provide educators with vital information to identify and understand cases of ASD.

- Like Grandin, children with ASD may still find it difficult to speak and communicate effectively during this stage. Some children may not be able to speak or communicate at all. This may make obtaining information about an illness or physical injury complicated for parents and healthcare professionals.

- Despite the child with ASD having difficulty learning various subjects at school or learning at all, isolated abilities may be present, such as Grandin's ability to play card games and be creative. While these abilities may present as obsessions or seem odd, such as Grandin's attempts to make her magical device, they can potentially be used to aid the child's academic learning as well as learning to make friends with children who have similar interests as Grandin did with Lyman and Eleanor.

- Even children of school-going age with ASD may find physical contact extremely difficult. It is imperative for nurses to recognize this as a potential symptom of ASD and understand that examining such a patient may be difficult (or even impossible if the child becomes violent).

- Children with ASD are often not aware of the 'bigger picture' but focus on parts of a whole or what is directly in front of them. This could be seen with Grandin obsessing

over election posters (and wanting to take them down) and not understanding their relation to the actual election. Healthcare professionals should be aware that a sick child with ASD may obsessively focus on a minor symptom or injury, such as a tiny cut, instead of mentioning something serious or life-threatening. In terms of relationships, because Grandin's parents were married and living together, in her mind that was all there was to know. She could not 'read' or comprehend the tension between them nor fathom or fear an event such as a divorce. As with other individuals with ASD, the intricacies of relationships, especially romantic relationships, eluded Grandin. It is important for healthcare professionals to be aware of this lack of relational awareness among children with ASD as they may be particularly vulnerable to abuse as a result.

Adolescence: Unless otherwise specified, the data for this stage is obtained from Grandin and Scariano.[37]

Grandin graduated from primary school and entered the seventh grade at a new school. This was a particularly unhappy time in her life. She struggled with most subjects, particularly mathematics, and languages. She also continued to misbehave, but in a childish way that was frowned upon by the other students.[35] Despite Grandin's efforts to fit in at school, she did not make any friends. She still struggled to speak in a way that sounded normal and had difficulty communicating her thoughts. This led to her being teased and humiliated for being different. She regularly got into fights. Grandin was warned that tantrums and violence were not accepted at the school. However, when a girl passing Grandin in the corridor called out; "Retard! You're nothing but a retard!" (p. 68), she threw her history book at the girl's face. This episode resulted in Grandin being expelled from school. [37]

Grandin's mother was out of options in terms of conventional schooling, so she enrolled Grandin at a small farm school for special needs children. Grandin was passionate about the farm animals and worked hard on duties around the farm. She began to settle but still had outbursts. When Grandin tripped over a wire and punched the child who had laughed at her, her teacher took away the privilege of riding the horses and working with the various animals for a week. This was particularly difficult for Grandin as she had fallen "in love with animals" (p. 1).[36] Grandin was also not allowed to do any other farm work for the week. While Grandin still got up to mischief and behaved badly at times, she never used her fists to settle an argument again.

Mr. Carlock, a teacher at the school who became Grandin's mentor well into her adulthood, was not judgmental and tried to understand how Grandin experienced the world. Mr. Carlock encouraged her to use her interest in animals and how mechanical things worked on the farm to focus her attention on science classes. By focusing on her interests and obsessions, Grandin managed to complete high school and go on to study animal/agricultural science at university.

2.10. ***Salient points relating to ASD presentation and diagnosis***

- A disruption in routine or change of familiar environment, such as changing schools or hospitalisation, can cause adolescents with ASD to regress and trigger outbursts.

- Physical contact, making eye contact, and communicating may still be difficult or even impossible for adolescents with ASD.

- Adolescents with ASD may seem childish in relation to their peers. Communication skills may be underdeveloped and interests very specific or obsessive. They may suffer from depression due to bullying and the isolation of not fitting in and not understanding the nature of teenage friendships or romantic relationships.

- Distinguishing depression from the withdrawn state often associated with ASD may be difficult for caregivers and medical professionals.

- Mentors as well as channeling interests/obsessions into potential scholarly or vocational pursuits may encourage development.

3. Limitations of the study

As with all case studies, the transferability of the findings is a limitation due to the limited pool of participants. Nevertheless, owing to symptoms of ASD being similar across cases, the necessity of a descriptive case in order to highlight behaviour associated with neurodevelopmental disorders and aid diagnosis remained. Future studies may build on such a study to include more participants' experiences or experiences of various caregivers, which at this point this study does not do.

A further limitation was that while the researchers had Grandin's consent for the research and the necessary information is available in the public domain, the researchers reached an ethical quandary when needing to sort, choose, and analyse data that related to other peoples' lives being included in the analyses. A more in-depth focus and analysis of such people may have portrayed them in a psychologically unhealthy light, as a result of their sometimes cruel or hurtful actions toward Grandin. This was often due to misunderstanding her diagnosis and may have provided much insight into the misunderstandings that can occur with the symptoms of neurodevelopmental disorders. However, such inclusion may be considered defamatory. As this manuscript will also be in the public domain, the researchers questioned how ethical such analysis would be without the specific individuals' consent and therefore did not include them in the findings. This may have limited the inclusion of pertinent data or a more in-depth analysis of certain data. The researchers did, however, attempt to retain the context and environment of Grandin's development while being aware of such ethical considerations.

4. Conclusion and future recommendations

In 2023 there is still a lack of autism knowledge, research, and skilled professionals to diagnose and manage ASD cases. This statement has international relevance.16,18-20 However, the burden of not having a diagnosis or treatment plan for individuals with ASD and their families is often greater in low-resourced and economic settings such as in many African countries.20,24 This has created an urgency to minimize the ASD knowledge gap in Africa, especially among healthcare professionals and educators.20 As previously mentioned, nurses are critical healthcare professionals in addressing the lack of diagnosis, misdiagnosis, and need for intervention of ASD in African countries. With this in mind, this paper has aimed to raise awareness and knowledge about ASD among nurses by highlighting symptoms and salient points through a case study. While access to interventions for ASD is problematic in low-economic settings, diagnosis is nevertheless a critical starting point in the treatment process and for families to understand their child's situation. Nurses will always be vital in this regard.

The valuable use of the KCAHW (developed in Africa), to aid the data reduction of salient points on an individual from the USA, both supports the international relevance of the KCAHW18, as well as the growing understanding that symptoms of ASD are exhibited similarly across continents, cultures, and languages.22-24 This does not negate the necessity for factors such as the individual's context, culture, and language to be considered when diagnosing and treating ASD. However, this finding supports the value and necessity of the global flow of autism knowledge from international sources into Africa, and from Africa to other parts of the world.

Not many screening measures have been adapted linguistically or culturally for African countries. However, measures such as the 23Q are available to aid healthcare professionals in making a diagnosis. It is recommended that more tools for various aspects of ASD, either be adapted for different regions in Africa or such as the KCAHW questionnaire, be developed in Africa.39 It is suggested that such tools be made more readily available to nurses. Further research into healthcare professionals, and more specifically, nurses' knowledge of ASD such as that conducted by Matenge12 in South Africa

and Bakare et al.13 in Nigeria should also be supported. Further research on ASD in Africa, as well as the design of screening measures by African researchers/practitioners, may begin to assist individuals with ASD, their families, and the healthcare professionals treating them, as well as encourage the development of Africa as an international ASD resource.

5. List of abbreviations

ASD: Autism spectrum disorder

DSM: Diagnostic and statistical manual of mental disorders

KCAHW: Knowledge about childhood autism among health workers questionnaire

6. Acknowledgments and funding

Nicola Wannenburg acknowledges the financial assistance from the Rhodes University postdoctoral fellowship that made the initial exploration into neurodevelopmental disorders and neurodiversity possible. Opinions expressed and conclusions arrived at, are those of the authors and not necessarily to be attributed to Rhodes University or the donor.

7. Disclosure statement

We have no conflicts of interest.

8. Publisher details:

Publisher: Student's Journal of Health Research (SJHR)
(ISSN 2709-9997) Online
Category: Non-Governmental & Non-profit Organization
Email: studentsjournal2020@gmail.com
WhatsApp: +256775434261
Location: Wisdom Centre, P.O.BOX. 148, Uganda, East Africa.

9. References:

1. APA. Diagnostic and Statistical Manual of Mental Disorders (5th ed). American Psychiatric Association. 2013.https://doi.org/10.1176/appi.books.9780890425596

2. Rejeb A, Namouchi I. Genetic and socio-anthropological regards in infantile autism. Int J Mod Anthrop. 2010; 3: 98-114.https://doi.org/10.4314/ijma.v1i3.60337

3. Bakare MO, Munir KM, Bello-Mojeed MA. Public health and research funding for childhood neurodevelopmental disorders in sub-Saharan Africa: a time to balance priorities. Healthc Low Resour Settings. 2014; 2(1): 1-9.https://doi.org/10.4081/hls.2014.1559PMid:25309887 PMCid:PMC4190054

4. Ruparelia K, Abubakar A, Badoe E, et al. Autism spectrum disorders in Africa: current challenges in identification, assessment, and treatment: a report on the international child neurology association meeting on ASD in Africa, Ghana, April 3-5, 2014. J Child Neurol. 2016; 31(8): 1018-1026.https://doi.org/10.1177/0883073816635748PMid:26979098 PMCid:PMC6858866

5. Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. Autism spectrum disorder in

Sub-Saharan Africa: A comprehensive scoping review. Autism Res. 2017; 10(5): 723-749.https://doi.org/10.1002/aur.1766PMid:28266791 PMCid:PMC5512111

6. Malcom-Smith S, Hoogenhout, M, Ing N, Thomas KGF. Autism spectrum disorders-global challenges and local opportunities. J Child Adolesc Ment Health. 2013;25(1):1-5.https://doi.org/10.2989/17280583.2013.767804PMid:25860302

7. Abubakar A, Ssewanyana D, Newton, CR. A systematic review of research on autism spectrum disorders in Sub-Saharan Africa. Behv Neurol. 2016; 14: 1-14.https://doi.org/10.1155/2016/3501910PMid:27872512 PMCid:PMC5107214

8. Bakare MO, Munir, KM. Excess of nonverbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa- a trend possibly resulting from late diagnosis and intervention. SAJP. 2011; 17(4): 118-120.https://doi.org/10.4102/sajpsychiatry.v17i4.295PMid:22229024

9. Alli A, Mupawose A. Parents' journey into the world of autism. SAJCH. 2015; 9(3): 81-84.https://doi.org/10.7196/SAJCH.7942

10. Chinawa JM, Manyike PC, Aniwada EC, et al. Prevalence and socioeconomic correlates of autism among children attending primary and secondary schools in South East Nigeria. Afri Health Sci. 2016; 16(4): 936-942.https://doi.org/10.4314/ahs.v16i4.8PMid:28479884 PMCid:PMC5398438

11. Kleintjies S, Lund C, Flisher AJ. A situational analysis of child and adolescent mental health services in Ghana, Uganda, South Africa and Zambia. Afr J Psychiatr. 2010; 13: 132-139.https://doi.org/10.4314/ajpsy.v13i2.54360PMid:20473475

12. Matenge, B. An exploration of nursing professionals' understanding of autism spectrum disorder. [Unpublished Masters dissertation, University of Cape Town]. 2014.

13. Bakare, M. O., Ebigbo, P. O., Agomoh, A., & Menkiti, N. C. Knowledge about Childhood Autism among Health Workers (KCAHW) questionnaire: Description, reliability and internal consistency. Clin Prac and Epid in Ment Health. 2008; 4(17). doi:10.1186/1745-0179-4-https://doi.org/10.1186/1745-0179-4-17PMid:18538020 PMCid:PMC2430959

14. Bakare, M. O., Agomoh, A. O., Ebigbo, P. O., Eaton, J., Okonkwo, K. O., Onwukwe, J. U., & Onyeama., G. M. Etiological explanation, treatability and preventability of childhood autism: A survey of Nigerian healthcare workers' opinion. Ann Gen Psychiatr. 2009; 8(6). doi:10.1186/1744-859X-8-6https://doi.org/10.1186/1744-859X-8-6PMid:19216745 PMCid:PMC2646731

15. Bakare, M. O., Ebigbo, P. O., Agomoh, A., Eaton, J., Onyeama, G. M., Okonkwo, K. O., Onwukwe, J. U., Igwe, M. N. Orovwigho, A., & Aguocha, C. Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. BMC Pediatrics. 2009; 9(12). doi:10.1186/1471-2431/9/12https://doi.org/10.1186/1471-2431-9-12PMid:19216754 PMCid:PMC2650693

16. Igwe, M. N., Bakare, M. O., Agomoh, A., Onyeama,G. M., & Okonkwo, K. O. Factors influencing knowledge about childhood autism among final year undergraduate medical, nursing and psychology students of university of Nigeria, Enugu State, Nigeria. Italian J Pediatr. 2010; 36(44). doi:10.1186/1824-7288-36-44https://doi.org/10.1186/1824-7288-36-44PMid:20540799 PMCid:PMC2894024

17. Igwe, M. N., Ahanotu, A. C., Bakare, M. O., Achor,J. U., & Igwe, C. Assessment of knowledge about childhood autism among pediatric and psychiatric nurses in Ebonyi State, Nigeria. Child and Adolescent Psychiatr and Ment Health. 2011; 5(1). doi:10.1186/1753-2000-5-1https://doi.org/10.1186/1753-2000-5-1PMid:21214953 PMCid:PMC3022827

18. Queisser, C. (2016). Assessing nurses' knowledge about autism spectrum disorders. [Doctoral dissertation, Capella University]. 2016.

19. Hartley-McAndrew, M., Doody, K., & Mertz, J. Knowledge of autism spectrum disorders in potential first-contact professionals. North American J Med Science. 2014; 7(3): 97-102.

20. Oshodi, Y. O., Campbell, E. A., & Les,

F. E. A. (2019). Strategies for autism diagnosis and care in resource deprived settings in Africa: An overview. Adolescent Psychiatry. 2019; 9: 58-56.https://doi.org/10.2174/2210676609666181220125513

21. Durkin MS, Elsabbagh M, Barbaro J, et al. Autism screening and diagnosis in low resource settings: challenges and opportunities to enhance research and services worldwide. Autism Res. 2015; 8: 473-476.https://doi.org/10.1002/aur.1575PMid:26437907 PMCid:PMC4901137

22. Akande, A. Autism - A case in early childhood: A South African investigation. Early Child Dev and Care. 1999. 155(1): 71-78.https://doi.org/10.1080/0030443991550107

23. Chambers, NJ, Wetherby AM, Stronach ST, Njongwe N, Kauchali S, Grrinker RR. Early detection of autism spectrum disorder in young isiZulu-speaking children in South Africa. Autism. 2017; 21(5): 518-526.https://doi.org/10.1177/1362361316651196PMid:27335105

24. Onaolapo, A. Y., & Onaolapo, O. J. Global data on autism spectrum disorders prevalence: A review of facts, fallacies and limitations. Univ J Clin Med. 2017. 5(2), 14-23.https://doi.org/10.13189/ujcm.2017.050202

25. Yin R K. Mixed methods research: are the methods genuinely integrated or merely parallel? Research in Schools. 2006; 13(1): 41-47.

26. Ponterotto JG. Qualitative research in counseling psychology: a primer on research paradigms and philosophy of science. J Couns Psych. 2005; 35: 1-21.https://doi.org/10.1037/0022-0167.52.2.126

27. Ponterotto JG. Case study in psychobiographical ethics: Bobby Fischer, world chess champion. Journal of Empirical Research on Human Research Ethics. 2013; 8(4): 19-27.https://doi.org/10.1525/jer.2013.8.4.19PMid:24169418

28. Durrheim K, Painter D. Collecting quantitative data: Sampling and measuring. In: M. Terreblanche M, Durrheim K, Painter D (editors). Research in practice: Applied methods for the social sciences. 2nd ed. Cape Town: University of Cape Town Press, 2006; 131-159.

29. Yin RK. Case study research: Design and methods. 5th ed. Thousand Oaks, CA: Sage; 2014.

30. Kelly K. Calling it a day: Reaching conclusions in qualitative research. In: Terre Blanche M, Durrheim K, Painter D (editors). Research in practice: Applied methods for the social sciences. 2nd ed. Cape Town: University of Cape Town Press; 2006: 370-387.

31. Erikson EH. Childhood and society. Harmondsworth, Middlesex: Penguin; 1950/1973.

32. Miles MB, Huberman AM. Qualitative data analysis: An expanded sourcebook. Thousand Oaks, CA: Sage; 1994.

33. Cutler E. A thorn in my pocket. Arlington, Texas: Future Horizons; 2004.

34. Grandin T. My experiences as an autistic child. Journal of Ortho Mol Psychiatr. 1984; 13: 144-174.

35. Montgomery S. Temple Grandin: How the girl who loved cows embraced autism and changed the world. New York, NY: Haughton Mifflin Harcourt; 2012.

36. Grandin, T, Johnson C. Animals in translation: Using the mysteries of autism to decode animal behavior. New York, NY: Scribner; 2005.

37. Grandin T, Scariano M. Emergence: Labeled autistic. New York, NY: Warner books; 1986/2005. 38. Grandin T, Panek R. The autistic brain: Helping different kinds of minds succeed. New York, NY: Mariner Books; 2013.

39. Kakooza-Mwesige A, Ssebyala K, Karamagi C, et al. Adaptation of the "ten questions" to screen for autism and other neurodevelopmental disorders in Uganda. Autism. 2014; 18(4): 447-457.https://doi.org/10.1177/1362361313475848PMid:23536263

Author biography

Nicola Wannenburg is a research associate in the department of psychology at Rhodes University and has been continuing her education in the Faculty of Science.

Roelf Van Niekerk is registered clinical and industrial psychologist and has been lecturing at Nelson Mandela University in the Industrial and Organisational Psychology department.