Record: 1

Title: Mothers of children with autism spectrum disorder: Their views on their children's hospital experiences, expectations from nurses, and a hospital environment sensitive to differences – A qualitative study

Authors: Kolukisa, Tugce a, b, ∗
Cinar, Nursan c

Affiliation: a Department of Nursing, Institute of Health Sciences, Sakarya University, Sakarya, Türkiye
b Karabuk University Safranbolu Şefik Yılmaz Dizdar Vocational School, Karabuk, Türkiye
c Department of Nursing, School of Health Sciences, Sakarya University, Sakarya, Türkiye

Source: In Archives of Psychiatric Nursing August 2025 57

Publisher: Elsevier Inc.

Keywords: Autism spectrum disorder
Mothers' experiences
A hospital sensitive to differences
Pediatric nurse

Abstract: Purpose Children with Autism Spectrum Disorder (ASD) tend to require healthcare services more frequently than their neurotypical peers. With the increasing prevalence and high rates of medical comorbidities, it has become increasingly important for healthcare providers and care systems to meet the healthcare requirements of children with ASD. This study aims to examine the hospital experiences of mothers raising children with ASD, their expectations from nurses, and their views on a hospital environment sensitive to differences.

Results After analyzing the obtained data during the interviews, three themes and 36 codes were identified. The themes are as follows: Evaluations of Autism Spectrum Disorder, Evaluations of Nursing Care, and Recommendations.

Conclusion Given the high prevalence of ASD and the documented challenges that children with ASD encounter in accessing healthcare services, this research aims to enhance the quality of hospital care for children with ASD, offering valuable insights.

@@@@Highlights •Hospitalization rates of individuals with ASD are reported to be twice as high compared to individuals without ASD.•Hospitals are an important healthcare environment where accessibility for ASD should be improved.•Mothers are the primary caregivers who interact most with healthcare professionals in early childhood•Nurses need to have good knowledge, understanding and awareness of ASD to provide autism-friendly care

Document Type: Article

ISSN: 0883-9417

DOI: 10.1016/j.apnu.2025.151912

Accession Number: S0883941725000834

Database: ScienceDirect

Record: 2

Title: Challenges hindering family involvement in the hospital nursing care of a child with autism

Authors: Neil A. Williams
Dudu G. Sokhela
Thembelihle S.P. Ngxongo

Source: Health SA Gesondheid: Journal of Interdisciplinary Health Sciences, Vol 30, Iss 0, Pp e1-e9 (2025)

Publisher Information: AOSIS, 2025.

Publication Year: 2025

Collection: LCC:Public aspects of medicine

Subject Terms: autism
autism spectrum disorder
barriers
challenges
hindering
family involvement
nursing care.
Public aspects of medicine
RA1-1270

Description: Background: Family involvement is crucial in a child’s treatment; however, many professional nurses still neglect to involve families in their child’s care. Studies have indicated that the perceived lack of family involvement in hospitalised children with autism spectrum disorder (ASD) is a problem in many countries. Few studies have been conducted in Africa with none relating to family involvement, highlighting the need for further research. Aim: To develop in-depth insights into the challenges regarding family involvement in hospital nursing care of children with ASD, in the South African context. Setting: Paediatric wards at selected private hospitals and family homes in the eThekwini District of KwaZulu-Natal. Methods: An interpretative phenomenological analysis method was used. A sample of 10 professional nurses and

10 family members was achieved by purposive sampling. Data were collected from participants using semi-structured in-depth interviews. Results: The following challenges were identified by the participants: the lack of knowledge of nurses regarding ASD, nurses not listening to family, uncaring attitude of nurses, nurses' lack of time and shortage of nursing staff. Conclusion: Nurses play a pivotal role in overcoming the challenges to family involvement, in the hospital nursing care, of a child with ASD. Making nurses aware of the challenges will help improve family involvement in hospitals nursing for the child with ASD. Contribution: This study added to the body of knowledge by identifying the challenges to the involvement of families in the hospital nursing care of a child with ASD.

Document Type: article

File Description: electronic resource

Language: Afrikaans
English

ISSN: 1025-9848
2071-9736

Relation: https://hsag.co.za/index.php/hsag/article/view/2731; https://doaj.org/toc/1025-9848; https://doaj.org/toc/2071-9736

DOI: 10.4102/hsag.v30i0.2731

Access URL: https://doaj.org/article/d599708b675a4180a2272a308923831f

Accession Number: edsdoj.599708b675a4180a2272a308923831f

Database: Directory of Open Access Journals

Record: 3

Title: Inpatient Hospitalization of Adolescents Diagnosed with Autism Spectrum Disorder: An Ethical Analysis.

Authors: Hrycko, Andrew J.[1] (AUTHOR) *ahrycko@mcw.edu*
Sinderbrand, Molly[2] (AUTHOR)

Source: American Journal of Bioethics. Apr2025, p1-7. 7p.

Publication Model: Ahead of Print

Document Type: Article

Subject Terms: *AUTISM spectrum disorders
*BIOETHICS
*HOSPITAL care
*TREATMENT effectiveness

*NORMATIVITY (Ethics)
*OUTPATIENT medical care
*COMMUNITY health services
*TEENAGERS

Author-Supplied Keywords: Autism spectrum disorder
behavioral interventions
healthcare equity
inpatient hospitalization
respite care

NAICS/Industry Codes: 621494 Community health centres
621498 All Other Outpatient Care Centers
621499 All other out-patient care centres
541712 Research and Development in the Physical, Engineering, and Life Sciences (except Biotechnology)
913910 Other local, municipal and regional public administration
623220 Residential Mental Health and Substance Abuse Facilities
624190 Other Individual and Family Services

Abstract: AbstractAdolescents with Autism Spectrum Disorder (ASD) are admitted to inpatient psychiatric hospitalization (IPH) at an alarmingly high rate. IPH is often intended for the immediate benefit and betterment of the individual, however, the result often incurs a degree of harm on the adolescent. With the rising prevalence of ASD and lack of physicians with ASD care experience, the adolescent is left with inadequate treatment, causing heightened anxiety and behavioral regression. While IPH may offer temporary relief and behavior management, it lacks sustainable long-term benefits while conflicting with the bioethical principle of beneficence. Here, we argue for a paradigm shift toward outpatient preventative resources (OPR), providing individualized, community-based care aimed at preventing the need of IPH, using it as mainly a last resort. By reallocating funding from IPH to OPR, the overall patient outcomes and support for caregivers will improve and effectively will reduce the harm on the ASD adolescent. [ABSTRACT FROM AUTHOR]

Author Affiliations: [1]Medical College of Wisconsin
[2]University of Pennsylvania

ISSN: 1526-5161

DOI: 10.1080/15265161.2025.2497989

Accession Number: 184823935

Database: Academic Search Index

Record: 4

Title: Exploring the communication access and participation of a young adult with autism spectrum disorder with limited speech and inpatient nursing staff.

Authors: Gormley, Jessica
Brittlebank, Savanna
Light, Janice

Source: Disability & Rehabilitation: Assistive Technology; May2025, Vol. 20 Issue 4, p939-947, 9p

Publication Year: 2025

Subject Terms: MEDICAL personnel
RESEARCH funding
AUTISM
SCIENTIFIC observation
CHILDREN'S hospitals
JUDGMENT sampling
DESCRIPTIVE statistics
REHABILITATION centers
PATIENT-professional relations
COMMUNICATION
ASPERGER'S syndrome
SPEECH disorders
CASE studies
DATA analysis software
PEOPLE with disabilities
PSYCHOSOCIAL factors
VIDEO recording

DISEASE complications
ADULTS

Geographic Terms: UNITED States

Author-Supplied Keywords: Augmentative and alternative communication systems
autism
communication
inpatient

NAICS/Industry Codes: NAICS/Industry Codes 622110 General Medical and Surgical Hospitals
622112 Paediatric hospitals
622310 Specialty (except Psychiatric and Substance Abuse) Hospitals
624190 Other Individual and Family Services
623220 Residential Mental Health and Substance Abuse Facilities
622210 Psychiatric and Substance Abuse Hospitals

Document Type: Article

Abstract: This study aimed to describe the nature of interactions between health care professionals and a young adult with autism spectrum disorder with limited speech during an inpatient stay. An observational study was conducted to describe the interactions between a young adult on the autism spectrum and 14 of his inpatient health care providers. Naturalistic video-recordings were taken, and behavioral coding was completed to measure the frequency and type of communication turns taken. The providers took 93% of conversational turns. Most provider turns (76%) were non-obligatory in nature and did not invite the young adult to engage in turn-taking. The young adult only had access to his communication system during one of the 27 interactions (4%); however, when he had access to his system, he demonstrated higher levels of turn-taking. Health care providers should offer patients with limited speech more communicative turns, provide adequate wait time, and ensure communication systems are available during all inpatient interactions. IMPLICATION FOR REHABILITATION: Inpatient health care providers dominated interactions with a young adult with autism and limited speech. Most inpatient health care provider turns did not present an opportunity for the patient to respond. The young adultcould not access his communication system for most interactions. [ABSTRACT FROM AUTHOR]

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DOI: 10.1080/17483107.2024.2420179

Accession Number: 185198473

Database: Complementary Index

Record: 5

Title: Challenges in managing children with autism spectrum disorder in emergency and hospital settings: strategies for effective care

Authors: Shafiqa M. Al Sharif

Source: Emergency Care Journal (2025)

Publisher Information: PAGEPress Publications, 2025.

Publication Year: 2025

Collection: LCC:Medicine (General)

Subject Terms: Autism
emergency
hospitalization
challenging behavior
strategies
Medicine (General)
R5-920

Description: Children with autism spectrum disorder (ASD) face unique challenges when receiving emergency and inpatient care, including sensory sensitivities, communication barriers, and anxiety-inducing changes in routine. In Saudi Arabia, these challenges are compounded by factors such as limited public awareness, delayed diagnoses, and limited resources. This review explores the prevalence of ASD in Saudi Arabia, the primary obstacles to effective healthcare, and strategies for improving emergency care and hospitalization experiences for children with ASD. The article highlights the importance of individualized care plans, sensory adaptations, and culturally informed staff training to support ASD patients and their families in emergency and hospital settings.

Document Type: article

File Description: electronic resource

Language: English

ISSN: 2282-2054

Relation: https://www.pagepressjournals.org/ecj/article/view/13366; https://doaj.org/toc/2282-2054

DOI: 10.4081/ecj.2025.13366

Access URL: https://doaj.org/article/43dd42c49fc44fdd98a8809f06a5caf1

Accession Number: edsdoj.43dd42c49fc44fdd98a8809f06a5caf1

Database: Directory of Open Access Journals

Record: 6

Title: Individualizing Hospital Care for Children and Young People With Learning Disabilities: It's the Little Things That Make the Difference

Authors: Oulton, Kate
Sell, Debbie
Kerry, Sam
Gibson, Faith

Affiliation: a Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID). Great Ormond Street Hospital NHS Foundation Trust, Greater London, England
b London South Bank University, Greater London, England

Source: In Journal of Pediatric Nursing January-February 2015 30(1):78-86

Publisher: Elsevier Inc.

Document Type: Article

ISSN: 0882-5963

DOI: 10.1016/j.pedn.2014.10.006

Accession Number: S0882596314002735

Database: ScienceDirect

Record: 7

Title: Emergency department visits by children with and without autism spectrum disorder: An initial comparison evaluating multiple outcome measures at one urban children's hospital

Authors: Casey, Laura Baylot
Williamson, Robert L.
Miller, Sarah

Smith, J. Brian
Frame, Kimberly N.
Langford, Elisabeth C.
Coleman, J. Brittain
Gilmore, Barry
McVicar, Kathryn A.

Affiliation: a University of Memphis, United States
b Le Bonheur Children's Hospital, University of Tennessee Health Science Center, United States

Source: In Research in Autism Spectrum Disorders January 2015 9:144-150

Publisher: Elsevier Ltd

Document Type: Article

ISSN: 1750-9467

DOI: 10.1016/j.rasd.2014.10.005

Accession Number: S1750946714002360

Database: ScienceDirect

Record: 8

Title: Individualized Care Delivery for Children With Autism and Related Disabilities Undergoing Overnight Video Electroencephalography (EEG): One Hospital's Experience With a Coordinated Team Approach.

Authors: Nix, Kalyn[1,2] (AUTHOR)
Siegel, Atara[1] (AUTHOR) *siegelat@kennedykrieger.org*
Smith, Jessica V.[1] (AUTHOR)
Wells, Elizabeth M.[1] (AUTHOR)
Atmore, Kathleen[1] (AUTHOR)

Source: Journal of Child Neurology. May2024, Vol. 39 Issue 5/6, p201-208. 8p.

Document Type: Article

Subject Terms: *AUTISTIC children
*CHILDREN with developmental disabilities

*AUTISM in children
*CHILD care
*ELECTROENCEPHALOGRAPHY
*GENERAL anesthesia
*DISABILITIES

Author-Supplied Keywords: autism
barriers to care
behavioral difficulty
compliance
individualized care plan
neurology
pediatric
vEEG

Abstract: Background and Purpose: Children with developmental disabilities have increased risk of epilepsy and need for overnight video electroencephalographic (EEG) monitoring. However, video EEGs have historically been considered difficult to complete for this population. An autism support service at a pediatric tertiary care hospital implemented a coordinated team approach to help children with developmental disability tolerate overnight video EEGs. The project included completion of a caregiver-report preprocedure questionnaire that then was shared with the multidisciplinary team and used to create individualized care plans. The current study aims to describe rates of video EEG completion and need for lead placement under general anesthesia among children with autism and related disabilities who received these supports. Methods: Rates of video EEG completion and general anesthesia use were analyzed for children referred to the support service between April 2019 and November 2021. Results: A total of 182 children with developmental disability (mean age = 10.3 years, 54.9% diagnosed with autism) met inclusion criteria. 92.9% (n = 169) of children successfully completed EEG (leads on ≥12 hours). Only 19.2% (n = 35) required general anesthesia for video EEG lead placement. The majority (80.2%) of parents (n = 146) completed the preprocedure questionnaire. Video EEG outcomes did not differ based on completion of the questionnaire. Parent-reported challenges with communication and cooperation were associated with shorter video EEG duration and greater use of general anesthesia. Conclusions: These findings suggest that most children with developmental disability can complete video EEG with sufficient support. Preprocedure planning can identify children who would benefit from additional accommodations. Further research is necessary to clarify which supports are most helpful. [ABSTRACT FROM AUTHOR]

Author Affiliations: [1]Center for Neuroscience and Behavioral Medicine, 8404Children's National Hospital, Washington, DC, USA
[2]12321Warren Alpert Medical School of Brown University, Providence, RI, USA

Full Text Word Count: 5844

ISSN: 0883-0738

DOI: 10.1177/08830738241252849

Accession Number: 177899832

Database: Academic Search Index

Record: 9

Title: Expanding upon Best Practice Approaches to Caring for Children with Autism Spectrum Disorder Who Engage in Challenging Behavior in Hospital Settings Using Behavior Analytic Principles: A Scoping Review.

Authors: Call, Nathan A.; [1,2,3]Bernstein, Alec M.; [4]Bottini, Summer; [5,6]Kalia, Megha; [7]Pattishall, Amy E.; [8,9]Muething, Colin S.[5,10]

Affiliation: [1]Professor, Emory University School of Medicine, Atlanta, GA
[2]Associate Chief for Clinical Affairs, Division of Autism and Related Disorders, Department of Pediatrics, Emory University School of Medicine, Atlanta, GA
[3]Vice-President, Marcus Autism Center, Children's Healthcare of Atlanta, Atlanta, GA
[4]Senior Behavior Analyst, Division of Developmental and Behavioral Health, Children's Mercy Kansas City, Kansas City, MO
[5]Assistant Professor, Department of Pediatrics, Emory University School of Medicine, Atlanta, GA
[6]Psychologist, Marcus Autism Center, Atlanta, GA
[7]Medical Student, Medical College of Georgia, Augusta University, Augusta, GA
[8]Associate Professor, Department of Pediatrics, Emory University School of Medicine, Atlanta, GA
[9]Emergency Medicine Physician, Children's Healthcare of Atlanta, Atlanta, GA
[10]Program Manager, Severe Behavior Program, Marcus Autism Center, Children's Healthcare of Atlanta, Atlanta, GA

Source: Pediatric Nursing (PEDIATR NURS), Nov/Dec2022; 48(6): 283-295. (13p)

Publication Type: Journal Article - CEU, research, systematic review, tables/charts

Language: English

Major Subjects:

Autism Spectrum Disorder -- Therapy -- In Infancy and Childhood
Disruptive Behavior
Hospitals
Applied Behavior Analysis

Minor Subjects: Human; Scoping Review; PubMed; Cochrane Library; Descriptive Statistics; Data Analysis Software; Centers for Disease Control and Prevention (U.S.); Child; Pediatric Nursing; Education, Continuing (Credit)

Abstract: Children with autism often engage in challenging behavior, such as physical aggression or restrictive and repetitive behavior, which interferes with the delivery of medical procedures. Although researchers have described best practices for providing services to individuals with autism within medical settings, many of these recommendations lack empirical support, mainly because it relates to overcoming challenging behavior. In contrast, applied behavior analysis offers evidence of best practices, but translation of these findings to medical settings is limited. We conducted a scoping review of the existing medical literature on best practices for treating children with autism who engage in challenging behavior within hospital settings. We also discussed how the behavior-analytic literature might contribute to best practice recommendations.

Journal Subset: Core Nursing; Nursing; Peer Reviewed; USA

Special Interest: Evidence-Based Practice

ISSN: 0097-9805

MEDLINE Info: *NLM UID:* 7505804

Entry Date: 20230119

Revision Date: 20241008

DOI: 10.62116/pnj.2022.48.6.283

Accession Number: 161225432

Database: CINAHL Plus with Full Text

Record: 10

Title: Parental experiences of caring for children who have learning disabilities and procedural anxiety in hospital: An interpretive phenomenological study.

Authors: Murdoch, Lauren; [1]Chang, Yan-Shing[1]

Affiliation: [1]Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, UK

Source: Child: Care, Health & Development (CHILD CARE HEALTH DEV), Sep2022; 48(5): 809-819. (11p)

Publication Type: Journal Article - research, tables/charts

Language: English

Major Subjects: Parental Attitudes
Parents of Children with Disabilities -- Psychosocial Factors
Learning Disorders -- In Infancy and Childhood
Anxiety -- In Infancy and Childhood
Hospitals
Parental Role

Minor Subjects: Human; Purposive Sample; Facebook; Semi-Structured Interview; Telephone; Phenomenological Research; Thematic Analysis; Patient Advocacy; Child

Abstract: Background: Children with learning disabilities (LD) are more likely to have health conditions that require hospital attendance than children without LD. Like all children, they can experience fear and distress related to procedural anxiety. Parents play a key role in managing procedural anxiety in children with LD. No previous published qualitative studies have explored parental experiences of caring for a child with LD and procedural anxiety in hospital. Objectives: To explore how parents experienced caring for their child with LD and procedural anxiety in hospital. Methods: A purposive sample of six participants were recruited through a Facebook group for parents of children with LD. Remote semi-structured interviews were conducted via telephone, Microsoft Teams or Whatsapp. Interviews were transcribed verbatim and analysed using interpretative phenomenological analysis. Results: Five key themes were generated: (1) Emotional toll: parents characterized their experiences as highly emotional; reporting feeling stressed, anxious and worried. (2) Restraint and holding: parents spoke of their experiences of restraint which was largely viewed as negative and sometimes inappropriate. (3) Advocacy: parents articulated their responsibility as advocates for their children. (4) Going it alone: parents were extremely proactive in managing their child's anxieties but some also felt highly-pressurized and isolated. (5) Inconsistency and uncertainty: parents experienced inconsistency and uncertainty in their children's care from healthcare professionals which led to anxiety and frustration. Conclusion: Parents of children with both LD and procedural anxiety experienced many challenges. Parents' expertise must be utilized by clinicians when caring for children with LD and procedural anxiety whilst ensuring appropriate support for parents. Nurses require specific training in psychosocial interventions to enhance care for children with LD and procedural anxiety. Further research identifying effective nursing strategies to enhance parental experiences would be beneficial to improve care to this patient group.

Journal Subset: Biomedical; Europe; Peer Reviewed; UK & Ireland

ISSN: 0305-1862

MEDLINE Info: *NLM UID:* 7602632

Entry Date: 20220818

Revision Date: 20230901

DOI: 10.1111/cch.12990

Accession Number: 158428402

Database: CINAHL Plus with Full Text

Parental experiences of caring for children who have learning disabilities and procedural anxiety in hospital: An interpretive phenomenological study

Background: Children with learning disabilities (LD) are more likely to have health conditions that require hospital attendance than children without LD. Like all children, they can experience fear and distress related to procedural anxiety. Parents play a key role in managing procedural anxiety in children with LD. No previous published qualitative studies have explored parental experiences of caring for a child with LD and procedural anxiety in hospital. Objectives: To explore how parents experienced caring for their child with LD and procedural anxiety in hospital. Methods: A purposive sample of six participants were recruited through a Facebook group for parents of children with LD. Remote semi-structured interviews were conducted via telephone, Microsoft Teams or Whatsapp. Interviews were transcribed verbatim and analysed using interpretative phenomenological analysis. Results: Five key themes were generated: (1) Emotional toll: parents characterized their experiences as highly emotional; reporting feeling stressed, anxious and worried. (2) Restraint and holding: parents spoke of their experiences of restraint which was largely viewed as negative and sometimes inappropriate. (3) Advocacy: parents articulated their responsibility as advocates for their children. (4) Going it alone: parents were extremely proactive in managing their child's anxieties but some also felt highly-pressurized and isolated. (5) Inconsistency and uncertainty: parents experienced inconsistency and uncertainty in their children's care from healthcare professionals which led to anxiety and frustration. Conclusion: Parents of children with both LD and procedural anxiety experienced many challenges. Parents' expertise must be utilized by clinicians when caring for children with LD and procedural anxiety whilst ensuring appropriate support for parents. Nurses require specific training in psychosocial interventions to enhance care for children with LD and procedural anxiety. Further research identifying effective nursing strategies to enhance parental experiences would be beneficial to improve care to this patient group.

Keywords: complex needs; learning disability; paediatrics; parents; procedural anxiety; qualitative research methods

Key messages

- Caring for a child with LD and procedural anxiety in hospital is a challenging experience for their parents.
- Parents were extremely proactive in supporting of their children, yet some felt over-relied upon by healthcare professionals. Nurses need to recognize and value parents' expertise whilst ensuring adequate support for parents themselves.
- Specific guidance is needed in relation to holding and restraint of children with LD who have procedural anxiety to ensure safe and compassionate care.
- That staff lack skills required to care for children with LD and procedural anxiety is congruent with wider criticisms of healthcare inequalities affecting children with LD.

INTRODUCTION

Learning disabilities (LD) is the preferred term used by the UK National Health Service (Department of Health, 2001) to describe reduced intellectual ability and difficulty with everyday activities. Internationally, the term 'intellectual disability' is used with the same purpose. Approximately 2.5% of the children aged 0–17 years in the United Kingdom are living with a LD. This represents over 351,000 children, 118,000 of which are aged 0–5 years (Office for National Statistics, 2019). Causes of LD in children are diverse, encompassing congenital conditions, genetic causes, and acquired brain injury from accident or epilepsy; approximately 43% of children with LD have unexplained causes (Courtman & Mumby, 2008). The number of children with complex needs (including LD) is growing due to advancements in healthcare technology increasing survival from acute and chronic childhood illness (Pinney, 2017). Compared with children without LD, children with LD are more likely to require healthcare interventions due to coexisting health problems, ranging from dental procedures to neurosurgery (Courtman & Mumby, 2008). They may also find it more difficult to tolerate the sensory stimulation, regimes and unfamiliar social contact associated with hospital settings (Short & Calder, 2013).

Procedural anxiety refers to fear, anxiety and worry experienced when undergoing a medical or surgical procedure. Often this can be linked to previous negative experiences (e.g., needle-phobia) whereby negative cycles of fear and pain lead to heightened distress (Noel et al., 2012). Anxiety is known to exacerbate perceptions of pain and is associated with prolonged recovery periods, increased need for analgesia, nausea and vomiting (McCann & Kain, 2001), as well as dysfunctional behaviour changes post-operatively, for example, tantrums and bed-wetting (Kain et al., 1996).

Procedural anxiety may cause such distress that procedures are postponed, abandoned or necessitate sedation or restraint (Short & Calder, 2013). This poses additional risks to the child including side effects from medication, accidental injury or delayed treatment. These interventions can be traumatic and may further entrench procedural anxiety. All children have the right to healthcare under the United Nation's *Convention on the Rights of the Child* (United Nations, 1989), and children with LD are rightfully entitled to equity in their healthcare outcomes (Government Equalities Office, 2010). Children with LD are already susceptible to poorer quality of care than their peers (Mimmo et al., 2020), and poor care for procedural anxiety may further entrench existing health inequities for these children.

The study is underpinned by the family-centred care model, which is widely accepted as the paediatric standard-of-care by clinicians across healthcare settings (Kuo et al., 2012). This model acknowledges parents as experts in their children and emphasizes the need to engage with them collaboratively, in partnership with healthcare professionals (HCPs). Family-centred care also recognizes that a child exists within the family unit and that children's well-being is inherently linked to that of their immediate family (Gilson et al., 2018). Therefore, it is important to consider parental experiences in nursing practice. This is increasingly highlighted in contemporary literature, which calls for the need for healthcare services to partner with parents and carers and enable children with LD to voice their experiences of care (Mimmo et al., 2020). Although limited previous published qualitative studies have investigated the topic of parental experiences of caring for a child with LD in hospital (Avis & Reardon, 2008; Bates et al., 2019; Brown & Guvenir, 2009; Taghizadeh et al., 2019), none have yet addressed parental experiences of caring for a child with both LD and procedural anxiety in hospital. This study addresses this gap.

METHODS

This study utilized interpretative phenomenological analysis (IPA). The essence of IPA is to capture the complexity of an individual's lived experience (Pietkiewicz & Smith, 2014), which is appropriate for this study exploring the lived experiences of parents who cared for their child with LD and procedural anxiety in hospital. The research question was: how do parents experience caring for their child with learning disabilities and procedural anxiety in hospital?

Participant recruitment and sampling

Potential participants were approached on a Facebook group for parents of children with LD via a recruitment advert. All initial correspondence between the researcher and potential participants was by email. The study design targeted six participants who were sampled via purposive sampling (see Table 1). The sample size was typically small in line

with IPA methodology, favouring depth over breadth (Moser & Korstjens, 2017). This is intrinsic to IPA's main concern of giving each participant's discourse full appreciation while acknowledging its limitations for generalizability (Pietkiewicz & Smith, 2014).

1 TABLEInclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
A parent of a child with LD and procedural anxiety aged 0–18 whom they have prior experience of caring for during a hospital visit in the United Kingdom	Parents with learning disabilities.
Competent and willing to either have a telephone call, use Whatsapp (to instant messaging, video or voice call), or use Microsoft teams (to voice or video call) for interviews.	Parents whose hospital experience have occurred outside the United Kingdom
Willing to talk about their experiences of caring for their child during an episode of procedural anxiety	

Data collection

Remote one-to-one semi-structured interviews were conducted between August 2020 and September 2020 at a time chosen by participants and conducted via their choice of Whatsapp (instant messaging), telephone or Microsoft Teams. The participants were encouraged to find a quiet, private space of their choosing. The author interviewed the participants from home. No non-participants were visibly present with the exception of the husband and child of one participant (it is unknown if other household members were present for Whatsapp or telephone interviews).

The interviews followed a schedule (see Appendix A) designed and piloted for this research. No modifications were made to the schedule following the pilot. For telephone and Microsoft Teams interviews, audio recordings were taken via dictaphone and transcribed verbatim. Some field notes were made immediately after the interviews.

Data analysis

Data were analysed as per the IPA process described by Smith and Osborn (2003), generating the key themes and subthemes of the interviews through a cyclical process incorporating multiple readings and making notes, transforming notes into emerging subthemes, seeking relationships and clustering themes (see Table 5). Both authors analysed the data and agreed on the final themes and subthemes. Data saturation is not a conventional goal of IPA (Smith, 2004); instead, data adequacy (Vasileiou et al., 2018) is considered a more suitable concept in IPA as individual experiences are so unique and complex that data can never be truly saturated. As analysis of interview data generated consistent themes across transcripts, the sample size ($n = 6$) and data collected from this study were judged to be adequate. Findings were returned to participants for comment; no participants provided feedback.

Ethics

Ethical approval was granted by the King's College London research ethics committee (LRU-19/20-19986). Informed consent was received from all participants. Participants were assured of confidentiality and anonymity, but were also aware that confidentiality could not be maintained if a disclosure was made that could raise concerns regarding the well-being and safety of themselves or their child.

Reflexivity

The first author is a paediatric nurse working full-time clinically in a large tertiary paediatric hospital in central London and is experienced in caring for children with complex needs and disabilities from an acute medical and surgical setting and in the community. Being familiar with the patient group, the researcher's background may have affected her expectations of the experiences participants would report. The first author conducted interviews and identified herself to participants as a nurse which may have affected the

dynamic of their interaction. Participants were not known to the authors prior to study commencement. The second author is a health service researcher with expertise in qualitative research and provided objective views during the research project including the data analysis and interpretation process.

FINDINGS

Participants' characteristics

Of a total of 21 individuals who expressed an interest in participating, six participants provided informed consent. No reasons were specified by those who chose not to participate. The participant demographic information is displayed in Table 2. All the participants were female although the participant requirement aimed at both female and male. There might be a range of reasons for this. For example mothers typically assume primary caregiver roles due to a varied range of complex social factors, not limited to social norms and additional financial burden associated with caring for a child with LD in the United Kingdom (Buckner & Yeandle, 2017), or an overrepresentation of women recruited via Facebook for healthcare research (Whittaker et al., 2017).

2 TABLEParticipants' demographics

	Number of participants (total n = 6)
Gender	
Female	6
Male	-
Age of participant (years)	
35–40	2
41–45	3
46–50	-
51–55	-
56–60	1
Region (UK)	
South East England	4
North East England	2
Age of child with LD (years)	
>3	-
3–6	2
7–9	1
10–12	-
13–15	2
16–18	1

	Number of participants (total n = 6)
Number of siblings	
Only child	1
1	1
2	2
3	2

Table 3 displays each child's primary diagnosis, procedures associated with anxiety and interview format. Children in this demographic are typically complex with multiple co-morbidities but only primary diagnoses have been displayed in Table 3 to avoid compromising participant anonymity.

3 TABLEChild's primary diagnosis, procedural anxiety and interview format

	Participant (pseudonym)					
Jane	**Suzie**	**Heidi**	**Lydia**	**Maxine**	**Sophie**	
Child's primary diagnoses disclosed in interview	Epilepsy, autism spectrum disorder	Undisclosed	Trisomy 21	Noonan's syndrome, autism spectrum disorder	Trisomy 21	Trisomy 21
Procedures described in interview	Nasogastric tube placement, blood test	Blood test	Blood test	Echocardiogram, impedance study, imaging, blood tests	Blood test, dental treatment	Blood test
Interview format	Whatsapp instant messaging	Whatsapp instant messaging	Whatsapp instant messaging	Microsoft teams	Telephone	Telephone

Interview characteristics

The average duration and transcript word count for each format of interview are shown in Table 4. Telephone interviews had the shortest average duration (32 minutes), while interviews via Whatsapp instant messaging yielded the shortest average transcript word count (2338 words). In the context of IPA, this is a shorter duration than expected for an interview and could be due to participants' conflicting demands on their time; several participants mentioned their time was limited by caring for their child. Parents spoke remarkably concisely regarding their experiences and perhaps had prepared what they wanted to share. Whatsapp's credibility as an interview tool remains mixed in methodological literature, although it should be acknowledged that some academics argue nonverbal communication typically emerges in different forms in instant messaging scenarios (emoticons, capitalization, phatic statements, etc.) and does not necessarily lack the complexity of spoken words (Lijadi & Schalkwyk, 2015).

4 TABLEInterview characteristics

Type of interview	Number of interviews conducted	Average duration of interview (minutes)	Average word count of transcript (total number of words)	
Mean	**Range**	**Mean**	**Range**	
Whatsapp (instant messaging)	3	81	63–91	23381812–3310
Telephone	2	32	33–31	42273170–5283
Microsoft Teams	1	41	41	35503550

Themes

Five key themes were generated from the data. Table 5 presents themes and examples of additional supporting quotations.

5 TABLEThemes, subthemes, notes and quotations

Theme	Example of emerging subthemes	Notes	Example of supporting quotations
Emotional toll	Dread and anticipation	Frequency of appointments; child's behaviour can be challenging; strong negative emotions; anxiety-inducing for parents.	We do actually dread every single hospital appointment, just because you do not know how he's going to be [...] We dread even taking him to the GP- and, you know, he has nearly every aspect of his medical and developmental side being monitored, so the appointments are endless. (Lydia)
Burden of maintaining a 'brave-face'	Hiding emotions from child; aware that child will be affected by parental distress; emotionally challenging.	I was feeling emotional but trying not to show that emotion because I did not want my child to get more distressed ... so it's really hard ... (Maxine)	
Restraint and holding	Awareness of long-term impact on child	Concerns for the future; fear; negative view of restraint.	I know it scares me that if it continues and he gets bigger and stronger that they will have to restrain him manually and I'm extremely against that and it will cause his fears to become so much worse. (Heidi)
Fears child will feel betrayed by parent	Afraid to damage child's trust in parent; concerned for	It's about our relationship as well is not it? You do not want to damage your relationship with	

Theme	Example of emerging subthemes	Notes	Example of supporting quotations
	relationship; feeling conflicted; challenging.	your child, but they are thinking 'my mum knows and she's still putting me through this procedure', so it's really hard. (Lydia)	
Undermined trust in clinicians	Following clinician's instructions; regret; parent education; perceived lack of clinician expertise regarding autism; feeling guilty for child's prior bad experiences.	I feel responsible as well because we physically done that [sic], not the doctors, not the nurses, that was us holding him down because we thought that was what we had to do and now obviously we have done courses and stuff on autism and that's the worst thing to do ... And I thought they would have known that. (Lydia)	
Advocacy	Parents acutely aware of their role as child's advocate	Be the advocate. Be helpful.	I like to be the advocate for my son and to tell staff he's a superhero. It helps him, and we all like to be helpful. (Heidi)
Feelings from being child's advocate	Intense emotions; fear; hysteria; feeling out of control; not being listened to; frustrated; guilt.	I was near on hysterical at one point. I was so frightened for her. The trauma I knew she was going through, no one would listen to me, no one would help her, that's how it felt- that I am her voice and I am being silenced. I felt like, and still do, that I let her down. (Jane)	
Going it alone	Parents independently and proactively initiating interventions for their child	Parents travelling weekly to take child to hospital; parents initiating intervention; time and energy consuming; highly committed to child's well-being.	We did it on a Wednesday because we did not go to nursery on a Wednesday [...] getting the train from here to [the hospital] and back again takes most of the day really [...] but it is quite tiring, it is your whole day which is then gone, but if it helps him- being in hospital- it also helps us I suppose, it's worth it in the long run. (Lydia)
Feeling let down by healthcare professionals unable to	Seeking help; feeling isolated; healthcare professionals unable to help child; let down	It's awful, you turn to people for help and guidance and they are meant to be the experts. It makes you feel very alone. (Jane)	

Theme	Example of emerging subthemes	Notes	Example of supporting quotations
meet highly complex and specific needs of child	by the 'experts'; expectation that the healthcare professionals will be able to help.		
Inconsistency and uncertainty	Availability of staff inconsistent	Routine appointments varied in staffing; specialist staff not reliably available.	We always go to the same hospital, the same unit, the same place, but one year you'll go and get a play specialist, two extra staff and the nurse, type-thing, other years I've been and they only have the one nurse in there. (Sophie)
Uncertainty during the COVID-19 pandemic	Concerned about visiting arrangement during COVID; impact of COVID	I've had many sleepless nights worrying about this over COVID if he was admitted and me not being allowed, or me then presenting with symptoms. (Suzie)	

Emotional toll

When asked to characterize their experiences of caring for their child in hospitals, all participants spoke explicitly and unambiguously about the emotional toll of caring for their child when they were acutely distressed. Five parents expressed acute feelings of regret or guilt, when describing a traumatic incident that had happened to their child during a procedure.

For me it's exhausting, worrying, guilt over Harry. And stressful. The build up to going is stressful too [...] overall it is very very upsetting. (Suzie)

We just felt like we were torturing him. (Lydia)

Three parents spoke of disguising their emotions, choosing to put on a 'brave-face' for their children, and the difficulty of maintaining this at a time when they themselves were upset. The emotions identified by parents were almost always negative. However, one parent also reported a more hopeful feeling of anticipation that her son might tolerate the procedure well, which would ultimately be of benefit to him.

Restraint and holding

All parents talked about being asked to hold or restrain their child. Parents' experiences ranged from therapeutic holding to unplanned restraint. They described doing both with great reluctance and discomfort and cited this as one of the most distressing aspects of caring for a child during a procedure.

I laid on the bed with her on top of me, screaming her heart out whilst I held her head, other nurses held her arms and legs whilst the tube was put in. (Jane)

Parents were also highly aware of the long-term effects of negative experiences on their child.

Several participants referred to feelings of betrayal when restraining their children for procedures. They were concerned that their child could not understand the necessity of the treatment and were afraid of damaging their child's trust in them. Three parents disclosed conflicting emotions as they felt restraint was the kindest approach to take with their children, even though this was distressing for them both, as their anxiety was so severe that there was no other way the procedure could be performed. Suzie described feeling cautious of how this would be received by staff, even though she felt this was in her son's best interest as multiple attempts to elicit cooperation from him were futile and ultimately ended in further distress.

My son [...] usually takes up to 5 people including myself to hold him. I'm always worried they will not agree to continue due to his distress, which would mean going back again (Suzie)

Lydia described feeling pressured to restrain her child, and her subsequent regret, as retrospectively she believed the restraint was an unhelpful and inappropriate intervention for her son. This experience appears to have damaged her trust in their healthcare providers.

Advocacy

Parents reported mixed experiences of advocating for their child. Often the circumstances of advocating was to request different HCPs be allocated, or to challenge care plans.

From that point onwards I've insisted that someone who takes blood is someone who's really proficient [...] and can do it quickly, in and out, one attempt. (Maxine)

Parents' reported advocating for their child was met with mixed reactions. Two parents felt their concerns were dismissed and had to 'prove' their child could not tolerate a procedure before alternatives were considered; they felt they were pressured into attempting an intervention they anticipated would not be successful, which was upsetting and frustrating.

Three parents also acknowledged that their child was likely to remain under the care of specialists for some time and seemed to feel conflicted about advocating for their child. Although they were mindful of being perceived as 'obstructive', their child's well-being was their upmost priority. They were also aware of the overarching financial aspects of their child's care.

It's hard because they have got a job to do, you know Simon needs the procedures and the scans and stuff, and it is so frequent as well, so we understand. And we understand there's financial implications and stuff like that as well. (Lydia)

Two parents reported that they felt HCPs were quick to assume their child's level of ability, based on their initial presentation, which was often misinterpreted and caused upset and frustration for parents. In these circumstances, parents were quick to correct HCPs.

Just because a child is twelve with Down syndrome does not mean she likes Tinky-Winky from the Teletubbies. (Sophie)

Two parents discussed gaining confidence advocating for their child over time, particularly after experiencing poor care from HCPs, and 'learning the hard way'. Parents recognized the limitations of doctor's expertise within the context of rare and complex diseases and the individual needs of their child.

I've found with my daughters' care you kind of have to be an expert in everything because things change so much and new research comes out [...] so you kind of have to be an advocate and do that, and of course every child is different. (Maxine)

Going it alone

Participants described feeling isolated, unsupported or left to 'fend for themselves' in several aspects of the lived experience while independently taking the lead on their child's care. Parents were considered 'alone' in the sense that they had taken on the roles, unique to their child's needs, that HCPs would not expect of parents of other, less complex, children. The notion of 'alone' was also conceptualized in the sense that parents of children with unique and highly specific needs were often the only people able to provide care for their child, to the extent that two mothers reported not feeling supported by fathers in this respect. Participants acknowledged an added weight of responsibility that they could not simply hand over care to nurses or friends and family.

I'm not sure how he would cope if I had to leave him. (Suzie)

Parents reported instances where it seemed they had been exceptionally proactive and independent in trying new strategies to ease their child's distress. For example, Lydia described taking her child into hospital on a weekly basis to de-sensitize them to the hospital environment. She spoke positively of this experience as it allowed her son to begin to tolerate being inside the hospital entrance without casing distress, despite being a very time-consuming process. Parents referenced information they had read about in academic literature, discussed specialist courses they had taken, recommended books, shared petitions and discussed contemporary hot-topics. Heidi described how her decisions around restraint were influenced by other parents' experiences she had observed on online forums, rather than clinicians' advice.

I always told them not to restrain him, so they never did. I know of other parents on the forums who write things like 'I cannot hold him down because he's too strong now' and I did not want to be in that position. (Heidi)

Jane described how she was told by a HCP that they had 'never met a child like [daughter] before'. She described her disappointment and frustration when being told that they did not know how to help her child. These experiences appeared to be inherent to the nature of parenting a child with rare, complex or highly specific needs.

Inconsistency and uncertainty

Inconsistency and uncertainty were demonstrated in parents' discussions about HCPs, parents' decision-making, and the ongoing COVID-19 pandemic. All parents spoke of inconsistency in relation to their interactions with HCPs in terms of skills, competencies and availability of specialist staff. Some parents expressed having reservations leaving their child in the care of nurses, based on their child's specific needs associated with their LD which staff were unable to meet.

As he's non-verbal, staff would have to know Makaton and even knowing it they would struggle to understand the way he signs. (Suzie)

Though parents reported negative experiences throughout the majority of the interviews, all parents described at least one positive interaction they had had with HCPs. They spoke highly of these interactions and highlighted how valuable these experiences were.

The first time, when there was a specialist, the nurse went so far as to draw blood out of their own arm to demonstrate what was going to happen. (Heidi)

Parents also experienced uncertainty fundamentally linked to the complex nature of their child's needs. One parent reported her child's behaviour was typically unpredictable, which itself was anxiety-inducing. Another mother reported her child's additional needs made decision-making more challenging. Two parents spoke of their anxieties surrounding the current COVID-19 pandemic disrupting their routine care which added to the burden of uncertainty.

It's [COVID-19] just setting us back I think. The little progress we have made it just feels like we are having to go back to square one and try all over again. (Lydia)

DISCUSSION

To the best of our knowledge, this is the first qualitative study to explore parental experiences of caring for a child with both LD and procedural anxiety in a hospital setting. A key finding from this study was the theme of 'going it alone'. This theme is partially reflected in the existing literature on the topic of parental experiences of caring for children with LD in hospital. For example, Avis and Reardon (2008) identified the pressure put on parents caring for their child with LD in hospital in terms of the delegation and delivery of care with parents reporting often feeling over-relied upon by HCPs. However, their evidence did not demonstrate the full extent to which parents can feel isolated as the sole providers of their child's care. Neither did it identify the extent to which parents proactively and independently initiated interventions to improve their child's experience when their child also had procedural anxiety, for example, bringing their child to hospital regularly to desensitize them. This has implications for family-centred care as HCPs need to utilize parents' invaluable expertise, whilst also recognizing the need to provide support and optimize parental well-being.

The findings highlighted the emotional toll experienced by participants in the study. Participants cited intense emotions associated with their child's procedural anxiety characterizing their feelings as stress, anxiety and guilt. These parents may benefit from additional emotional support. This could be delivered in many forms, such as incorporating parents' needs in care planning on admission, or a formal referral to psychological services. However, there are minimal studies on the effectiveness of nursing interventions to support parents' mental health in parents of children with LD, and many nurses report lacking confidence and skills discussing mental health with parents (Gilson et al., 2018).

Although important, provision of extra emotional support alone could be viewed as treating the symptom not the cause. Parents will inevitably experience many stresses and anxieties which are specific to caring for children with LD and exacerbated by procedural anxiety; these may be alleviated simply from improved patient care. Findings from Oulton et al. (2020) suggest 'getting it right' from the onset is vital in establishing parent trust in the healthcare system. Various types of psychosocial intervention have been found to be successful in reducing child anxiety and pain and improves procedural success but are often overlooked by clinicians (Chrisler et al., 2021). Many of these interventions could be carried out within the scope of nurses' roles, for example preparing patients with video, social story or medical play, teaching patients coping strategies such as breathing techniques or procedural support such as distraction. However, these interventions have not been fully evaluated from a cost–benefit perspective (Chrisler et al., 2021) and may not be feasible for widespread implementation considering workforce pressures such as nursing shortages.

One of the most concerning findings from this study was of the use of restraint and holding, which was a major concern for participants. Bates et al. (2019) also reported similar findings from parents of children with cleft palette and LD. The improper restraint of people with LD is an enduring issue attracting widespread attention in recent years with the Whorlton Hall (2019) and Winterbourne View (2011) hospitals scandals in England. These bought mainstream attention to systemic abuse towards adults with LD within NHS institutions. Some academics continued to criticize an inadequate response from the government (Richards, 2020). Similarly, the forthcoming Oliver McGowan mandatory training (Department of Health and Social Care [DHSC], 2019) highlights enduring concerns of staff not valuing parent's knowledge and expertise.

There remains a distinct lack of clarity and unity with regard to clinical guidelines for children with LD (Bray et al., 2019). While recent guidelines, *Reducing the Need for Restraint and Restrictive Intervention*, (DHSC & Department of Education, 2019) have been published, they are not specific to healthcare settings. Although other guidelines exist for holding in paediatrics (Royal College of Nursing, 2019), these do not address the needs of children with LD. National evidence-based guidelines for restraint in children with LD in healthcare settings, with consideration to procedural anxiety, are essential to the safety and well-being of child patients. However, this would require a strong, comprehensive evidence base which is not yet available. Further research in this area is highly desirable.

Parents were concerned about the skills and knowledge of HCPs caring for their child with LD. This has also been highlighted in previous studies (Avis & Reardon, 2008; Brown & Guvenir, 2009; Sharkey et al., 2014), with many parents reporting feeling unable to leave their children with ward staff. This sentiment is mirrored by nurses themselves in a recent study in which nurses reported feeling less confident and capable caring for children with LD than those without (Oulton et al., 2018). Although Mencap's *Getting It Right* charter (2010) calls for all paediatric units to have access to a dedicated LD nurse to support staff, Oulton et al. (2019) suggest they are not effectively or efficiently used. Similarly,

parents have reported inconsistent access to specialist staff including specialist liaison nurses (Brown & Guvenir, 2009) and play specialists (Taghizadeh et al., 2019). The value of play specialists in preparation and distraction of children is well-evidenced, although provision is not reliably available or utilized effectively (Gulyurtlu et al., 2020).

The Equality Act (Government Equalities Office, 2010) sets out the legal duty of all healthcare services to consider the needs of all children, young people and adults with LD, who are entitled to expect quality in the outcomes of their healthcare provision. This involves making reasonable adjustments to prevent disadvantage arising from any disability that could negatively impact a child. More recently, *The Learning Disability Improvements Standards for NHS Trusts* (NHS, 2018) outlines the rights of patients to receive safe and personalized care with the same quality and outcomes of their peers. Given the numerous concerns reported by parents, it seems HCPs are missing opportunities to make reasonable adjustments and failing to meet these standards. This is similar to recent findings from Oulton et al. (2015) that young people with LD reported the 'little things' which comprised individualized care were of upmost importance to patients. Oulton et al. (2015) asserted that developing partnerships with parents was pivotal in the delivery of care.

A seminal 2017 review by the National Council for Disabled Children which asserted that 'at a fundamental level the skills needed for working with our group of children did not seem to be fully recognised, articulated or appropriately valued' (Lenehan, 2017, p. 28). These inequalities are further intersected by other factors, for example, social-economic status (Public Health England, 2015). The issue is complex and warrants further enquiry and engagement with children, families and the wider community to improve the experiences of children with LD across all sectors. Lenehan noted that services were reliant on the 'particular skills, interests and determination of the clinicians involved' (Lenehan, 2017, p. 18). This resonates with the 'ad hoc' positive experiences of participants reported in this study. Given the extent of wider workforce challenges, such as COVID-19 and the global nursing shortage which is an urgent and multifactorial issue in contemporary nursing (Marufu et al., 2021), implementing widespread training may be challenging. Nonetheless, this is vital to ensuring equitable health outcomes for all children.

This study is limited by the IPA methodology as data are restricted to experiences of few individual participants and lacks generalizability. Further research is required to substantiate the findings of this research. It would also be desirable to capture the experiences of fathers and ethnic minority groups, given that healthcare inequalities are intersected by many demographic factors (Public Health England, 2015). Using Whatsapp for conducting interviews also potentially limits the findings as current methodological literature is mixed on the credibility of its use. Using digital technologies ensured the transmission of viruses was minimized during the COVID-19 pandemic while it was important that participants were familiar with the interface. Due to the limitations of these platforms, children with LD were not included as participants as these platforms typically have age-restrictions which posed additional ethical concerns and may not be an appropriate or effective form of communication for individuals with communication barriers. This would affect the quality of the data collected. However, further research to capture children with LD's experiences using accessible methods is needed as Oulton et al. (2017) assert it is vital to challenge the notion that it is acceptable to exclude this population of patients from research on the basis of their inability to participate.

CONCLUSION

Parents characterized their experiences as highly emotional reporting stress, anxiety and worry. Appropriate support should be offered to parents, ranging from informal support provided by nursing staff as part of their care plan to comprehensive, formal support from specialist clinicians. Parents articulated their responsibility as an advocate for their child and were extremely proactive in managing their child's anxieties, but some also felt highly-pressurized and isolated. Parents' expertise must be utilized when caring for their child with LD and procedural anxiety; but they must not be over-relied upon and provided with appropriate support as per family-centred care.

Parents discussed their experiences of restraint which was largely viewed as negative and sometimes inappropriate. Given the lack of guidance relating to holding and restraint in children with LD and procedural anxiety, further high quality research in this area is needed to build clinical guidance to support safer care for parents. Parents experienced inconsistency and uncertainty in their care, even when visiting the same ward, which was a source of anxiety and frustration. Nurses require more specific training in the care of children with LD and procedural anxiety, this could include a range of psychosocial interventions such as preparation, procedural support and coping strategies. Further

methodological research relating to use of Whatsapp instant messaging as a platform for interviews would be beneficial, as well as strategies to recruit fathers and those from diverse backgrounds to future research on this topic.

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CONFLICT OF INTEREST

The authors declared no conflict of interest.

DATA AVAILABILITY STATEMENT

Full transcripts of the data are not available as participants in this study did not agree for their transcripts to be shared publicly.

ETHICS STATEMENT

Ethical approval was granted by the King's College London research ethics committee (reference: LRU-19/20-19986).

PATIENT CONSENT STATEMENT

Written informed consent was received from all participants prior to all data collection.

A APPENDIX INTERVIEW SCHEDULE

Semi-Structured Interview Guide

Beginning of Interview:

Welcome and introduce myself.

Reiterate the aims of the project. Confirm what is meant by procedural anxiety.

Remind people of key issues- data will be kept confidential and anonymous, unless there is a reason researcher needs to act, participants can feel free to withdraw at any time.

Demographic questions:

What is the participant's age?

What is the participants gender?

What is the age of child with learning disability?

Do they have any other children, and their ages if applicable?

What region of the country does the family lives in?

Interview Guide

- What has been your experience of caring for your child with a learning disability, whilst they are having procedural anxiety?
- Can you describe how this experience made you feel?
- What stands out to you the most about being with your child during a procedure?
- What support have you received from staff? Do you feel this is the right level of support?
- How do you think your child's experience have affected your experiences, if at all?

Interview expected to last approx. 45–60 minutes via video or voice call.

End of Interview

Thank participants for time.

Offer Support Services sheet.

Ensure they have researcher's details if they have any further questions.

Remind of deadline to withdraw consent.

Confirm whether they would like a copy of the finished report when it is available and how they would be happy for researchers to contact them with this.

Footnotes

1 Funding information Royal College of Nurses Foundation Bursary was awarded to Lauren Murdoch.

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By Lauren Murdoch and Yan-Shing Chang

Reported by Author; Author
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Source: Archives of Psychiatric Nursing

Record: 11

Title: Development of a Novel Multi-Disciplinary Specialized Care Service for Children and Adolescents with Autism Spectrum Disorder and/or Intellectual/Developmental Disability in a Tertiary Children's Hospital Setting

Authors: Joelene F. Huber
Alvin Loh
Suneeta Monga
Jessica Esufali
Michelle Shouldice

Source: Children, Vol 10, Iss 1, p 57 (2022)

Publisher Information: MDPI AG, 2022.

Publication Year: 2022

Collection: LCC:Pediatrics

Subject Terms: autism spectrum disorder
Intellectual/Developmental Disability
mental health
developmental pediatrics
behavior-medicine
tertiary care
Pediatrics
RJ1-570

Description: Children and adolescents with autism spectrum disorder (ASD) and/or Intellectual/Developmental Disability (IDD) are at greater risk of developing comorbid medical conditions, mental health diagnoses, behavioral challenges, and having overall poorer physical and mental health outcomes. Hospital environments present unique stressors and challenges for children and adolescents with ASD/IDD including a change in familiar environment, unpredictable routines, and exposure to sensory stimuli that may be overwhelming. While many school boards have specialized multi-disciplinary special needs support teams and services made up of professionals with expertise in supporting students with ASD/IDD, most hospitals do not have a formal multi-disciplinary ASD/IDD support team in place to support patients, families, and health care staff across the hospital. There is an emerging recognition of the need for specialized multi-disciplinary developmental-

behavioral and mental health expertise in hospital inpatient settings. This paper describes the framework for the development of an innovative multi-disciplinary program to better support children and adolescents with ASD/IDD within a tertiary children's hospital setting.

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Language: English

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Accession Number: edsdoj.476654e22b31447aaf34f00d93775c72

Database: Directory of Open Access Journals

Record: 12

Title: Many Hands Working Together: Adapting Hospital Care to Support Autistic Children's Mental Health.

Authors: Mahoney, Wanda J.[1] *wmahoney@wustl.edu*
Abraham, Gifty[2]
Villacrusis, Minerva[3]

Source: American Journal of Occupational Therapy. Mar/Apr2023, Vol. 77 Issue 2, p1-10. 10p. 3 Charts, 1 Graph.

Document Type: Article

Subject Terms: Competency assessment (Law)
Nursing audit
Treatment of autism
Statistics
Psychology of children with disabilities
Social support
Confidence
Nurses' attitudes
Evaluation of human services programs
Health facilities

Clinical trials
Research methodology
Children's hospitals
Effect sizes (Statistics)
Mann Whitney U Test
Patient satisfaction
Self-efficacy
Human services programs
Pre-tests & post-tests
Social context
Experience
Hospital nursing staff
Health care teams
Quality assurance
Pediatric nursing
Autism
Descriptive statistics
Interdisciplinary education
Integrated health care delivery
Occupational adaptation
Data analysis software
Data analysis
Medical needs assessment
Children

Geographic Terms: Midwest (U.S.)

NAICS/Industry Codes: 622110 General Medical and Surgical Hospitals
622112 Paediatric hospitals
622310 Specialty (except Psychiatric and Substance Abuse) Hospitals
541712 Research and Development in the Physical, Engineering, and Life Sciences (except Biotechnology)
621498 All Other Outpatient Care Centers

621330 Offices of Mental Health Practitioners (except Physicians)
624190 Other Individual and Family Services

Abstract: Importance: Hospitals pose a threat to autistic children's mental health. Adapting hospitals to meet children's needs can address this issue. Objective: To determine the impact of an interprofessional program (Adaptive Care) to support autistic children's mental health on nursing staff's knowledge, efficacy, and confidence. Design: Pretest–posttest, quasi-experimental design. Setting: Large pediatric hospital. Participants: Nursing staff were the first participants in the program implementation. Approximately 300 nursing staff received training through the program, and 107 completed program evaluation surveys. Of these, 18 nursing staff completed both the pretest and posttest surveys approximately 1 yr apart. Intervention: Occupational therapy practitioners and other professionals developed and implemented the program, which consists of staff training and resources to adapt hospital physical and social environments and to ultimately improve patients' hospital experiences. Outcomes and Measures: Researcher-developed, pilot-tested, online survey to assess knowledge, perceived effectiveness, confidence, and strategies that staff used while caring for autistic children in the hospital. Results: Respondents had increased effectiveness and confidence working with autistic children in the hospital after program implementation. Respondents reported significantly more strategies to care for autistic children. Conclusions and Relevance: Interprofessional collaboration and programming can positively affect social environments in the hospital by enhancing nursing staff's self-efficacy, confidence, and strategies to support mental health and to enhance health care for autistic children. What This Article Adds: The Adaptive Care program is an example of occupational therapy practitioners and other interprofessional team members adapting physical and social health care environments to support autistic children's mental health. This program was effective at increasing nursing staff's self-efficacy, confidence, and strategies while caring for autistic children in the hospital. Positionality Statement: This article uses the identity-first language autistic people. This nonableist language describes their strengths and abilities and is a conscious decision. This language is favored by autistic communities and self-advocates and has been adopted by health care professionals and researchers (Bottema-Beutel et al., 2021; Kenny et al., 2016). The Adaptive Care program is an example of occupational therapy practitioners and other interprofessional team members adapting physical and social health care environments to support the mental health needs of autistic children. [ABSTRACT FROM AUTHOR]

Author Affiliations: [1]Wanda J. Mahoney, PhD, OTR/L, is Associate Professor of Occupational Therapy and Medicine, Program in Occupational Therapy, School of Medicine, Washington University in St. Louis, St. Louis, MO
[2]Gifty Abraham, OTD, OTR/L, is Associate Professor, Department of Occupational Therapy, Midwestern University, Downers Grove, IL.
[3]Minerva Villacrusis, MOT, OTR/L, is Occupational Therapist, Special Education Department, Community Consolidated School District 59, Elk Grove, IL.

Full Text Word Count: 5531

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Title: Sidra Medicine establishes autism-friendly Hospital initiative

Source: Gulf Times (Doha, Qatar). April 1, 2025

Publisher Information: Knowledge Bylanes

Publication Year: 2025

Subject Terms: Drug therapy
Autism -- Drug therapy

Description: Sidra Medicine, a member of Qatar Foundation, has established an Autism-Friendly Hospital Initiative (AFHI) to create a more inclusive and supportive healthcare environment for children with Autism Spectrum Disorder (ASD). [...]

Language: English

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Title: Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme.

Authors: Pratt, K. (AUTHOR)
Baird, G. (AUTHOR)
Gringras, P. (AUTHOR)

Source: Child: Care, Health & Development. Nov2012, Vol. 38 Issue 6, p789-797. 9p.

Document Type: Article

Subjects: Child development deviations
Conceptual structures
Hospital admission & discharge
Learning disabilities
Medical personnel
Patients
Problem solving
Quality assurance
Patients' families
Family attitudes

Geographic Terms: United Kingdom

Abstract: Background Children and young people with autism spectrum conditions frequently have adverse experiences in accessing health care. Methods An audit of experiences of families known to our tertiary service and hospital staff was conducted. A checklist asking about particular aspects of behaviour and communication was developed and incorporated into pre-admission planning. Results Awareness of the child/young person's communication needs and behaviours, plus good preplanning by all staff involved and a team member allocated to ensure that the care plan is carried through, has resulted in a vastly improved 'patient experience' from the perspective of family and staff. Conclusion Children and young people with autism spectrum disorder, often with co-existing learning difficulties, vary greatly in their reactions to hospital admission. Preplanning that involves the family with a dedicated informed staff member can dramatically reduce distress and improve the patient and staff experience. [ABSTRACT FROM AUTHOR]

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Database: Psychology and Behavioral Sciences Collection

Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme.

Background Children and young people with autism spectrum conditions frequently have adverse experiences in accessing health care. Methods An audit of experiences of families known to our tertiary service and hospital staff was conducted. A checklist asking about particular aspects of behaviour and communication was developed and incorporated into pre-admission planning. Results Awareness of the child/young person's communication needs and behaviours, plus good preplanning by all staff involved and a team member allocated to ensure that the care plan is carried through, has resulted in a vastly improved 'patient experience' from the perspective of family and staff. Conclusion Children and young people with autism spectrum disorder, often with co-existing learning difficulties, vary greatly in their reactions to hospital admission. Preplanning that involves the family with a dedicated informed staff member can dramatically reduce distress and improve the patient and staff experience.

Keywords: challenging behaviour; hospital admission; pre-admission planning; autism

In a recent editorial in this journal, [7]) described the difficulties encountered by children and young people with learning disability and autism spectrum disorders (ASDs) when attending hospital and highlighted the lack of awareness among healthcare staff about how ASD can affect behaviour.

Although there is a helpful publication developed for families of children with ASD ([4]), there are few reports of modifications to service delivery made by service providers ([8]). We were aware that the experience of hospital admission of some of our young people with learning disability and co-existing conditions, particularly ASD, could be improved.

Our decision to embark on an audit pathway for this particular patient experience coincided with the publication of *Healthcare for All* in July 2008 ([6]), an independent enquiry into access to health care for people with learning disabilities which was in response to the MENCAP report *Death by Indifference* ([5]).

We describe the findings from our audit and change management process for this group of patients.

Audit cycle-continuous quality improvement

Identify

What are we trying to achieve?

We were aware that the experience of hospital admission of some of our patients with learning disability and co-existing conditions, particularly ASD, was less than comfortable for them and their families and resulted in challenging behaviour, distress for all, considerable additional perceived requirement for nursing staff and – frequently – medication. We considered that much of the distress was preventable with good co-ordinated planning.

Gather baseline information

Where are we now?

We carried out an initial audit of our children's inpatient service, which comprises both a secondary and a tertiary inpatient service with a large paediatric intensive care unit. We formally gathered demographic and numerical data from ward staff regarding any child admitted with a neurodevelopmental problem during one calendar month, and asked them to record any behavioural problems. We then conducted informal interviews with 20 staff and 4 families. Staff were asked about their concerns in relation to coping with challenging behaviour and about their knowledge of neurodevelopmental disorders. The results of this initial fact finding were discussed and combined with the experiences of an

expert panel, as well as a focus group of carers, to reach a guiding set of principles to try to modify the process of admission with a view to improving child, family and staff experience.

Initial results

Over a 1-month period, 52 children were admitted who had neurodevelopmental problems; of these, five children had severe challenging behaviour during admission.

Staff The experience of the nursing staff was that challenging behaviour caused them anxiety, that they felt de-skilled and that they considered it to pose a risk to other patients. Staff indicated a lack of knowledge about learning difficulties beyond that contained in basic training, and a particular uncertainty about ASD. The result was a perceived need and request for additional staff on the wards, often with mental health training.

Carers We talked to parents whose children had been admitted for both elective procedures (the majority) and as emergencies, and identified key times and experiences that had been problematic. Most of the children who had found the experience particularly challenging had an ASD. Many parents thought that the problems they had encountered could have been avoided with adequate modification of a planned admission and increased awareness of both process and the individual's needs.

Agreeing standards and principles

We used these initial audit findings to start to identify specific measures that could be addressed, and to improve the outcome of admission of these young people within a hospital setting. In addition to considering audit results, expert consensus, literature reviews and feedback from young people and families helped us to reach a set of core principles related to the ASD that itself often contributes to both distress and challenging behaviour in the hospital setting. Over many years, the National Autistic Society schools have developed a framework for understanding and responding to the needs of children and adults on the autism spectrum. The framework is also useful in identifying underlying issues, reducing the disabling effects of the condition and providing a cornerstone for communication. Their acronym for this framework is SPELL ([1]). SPELL stands for Structure, Positive (approaches and expectations), Empathy, Low arousal, Links. To these, we added functioning developmental age, communication difficulties (often with literal understanding) and sensory sensitivities.

Change

Do something to make things better.

We translated these basic principles into practical changes that we anticipated would improve the outcome of our admissions.

- a

- Development of a structured checklist was key (see Appendix I), and examples of its utility are presented below. The improved structure of pre-admission information gathering allowed better anticipation and planning for problems. The structured checklist was developed to be completed either by telephone or during face-to-face contact.

- b

- We agreed to always identify a key member of staff both prior to admission and on the ward during admission. In our case, the pre-admission key member of staff was a named outreach nurse with considerable experience of working with children who have autism and learning difficulties. This person's role was primarily:

- •

- to contact the parent/carer to collect the checklist information;

- •

- to develop in consultation with parents an admission plan;

- •

- to liaise with ward and other relevant staff;

- •

- to identify a named ward key worker who would oversee the implementation of the admission plan.

Reaudit/monitor changes

Have we made things better?

Following the introduction of these changes, we asked 20 staff and 8 parents who had undergone admission with a child with autism and challenging behaviour about their experiences. Two parents had experienced admissions both before and subsequent to the pre-admission planning.

The structured checklist

The checklist was well received by staff and parents. Our audit showed that parents/carers preferred it, and more information was gained, if it was completed in outpatients or during a home visit. We found that it can take up to 1 h to complete.

For this report, we felt it would be helpful to present specific examples where the checklist was helpful, by checklist item.

Functioning age The functioning age of a child/young person (YP) is important and often gets overlooked by ward and medical staff. Knowing and understanding the functioning age level can aid in understanding some of the challenging behaviours. For example, a 10-year-old boy may have the learning abilities of a 2-year-old. It is common developmentally for 2-year-olds to exhibit temper tantrums. The 10-year-old may have temper tantrums because functionally he reacts as a 2-year-old but he is a lot bigger, so

these would be harder to deal with, and people do not usually expect or tolerate this type of behaviour in a 10-year-old. Also, communicating and explaining procedures appropriately requires us to know the child/YP's level of understanding. Parents are reliable informants of developmental functioning age (correlation = 0.7, $P < 0.05$) (G. Baird, unpublished).

The child/YP's communication competence and method used by the child/YP Those who are non-verbal may use a communication device or pictures and/or symbols. Whatever method is used by the child/YP needs to be used throughout an admission to avoid or reduce the frustration of not being able to communicate needs or anxieties. This may sound obvious, but frequently the child/YP either has no communication passport or does not bring it, or staff are not aware of what it is for.

One child was aggressive to members of staff every time they approached and needed to do some care task. The staff asked for advice and explained that the child was non-verbal. When asked how the child would normally communicate their needs, staff were unsure and then found out that a communication device was normally used but had been left at the child's school. Once the device was obtained and the child was able to use it, the behaviour dramatically improved.

Motivating factors and interests Knowing about what motivates the YP to co-operate is also important. Inevitably during any hospital admission, procedures need to be carried out which can be unpleasant and anxiety-provoking. Good communication and use of rewards that are particularly motivating may make these challenges a little easier. Remembering to break down the tasks if at all possible, so rewards can be easily obtained, can also be useful.

Challenging behaviour

• 1

- Whether the child/YP exhibits challenging behaviour.

• 2

- Triggers for challenging behaviour.

• 3

- What defuses the situation.

We ask about antecedents to outbursts, for example, giving medicines, noise, etc. Some children had sensitivity to loud noises which could be easily solved by allocating a cubicle when possible. Other children have rigid likes or dislikes, sensitivities to a variety of stimuli or may adhere to fixed routines and rituals.

Knowing how to defuse any behaviour is also important, but the principle is to try to anticipate and pre-empt before an outburst, thus everyone can be adequately prepared to ensure that staff and the rest of the ward are safe.

Learning from previous experience We ask about previous admissions and type of procedures that the child/YP has had before. It was very useful to know what went wrong but also whether there were any strategies that were successful. These can then be used again.

Developing the admission plan This needs to be discussed and written down in detail from the time the child/YP enters the hospital and ward, through exactly what procedures are planned and what will happen (e.g. how to get a child/YP to the anaesthetic room with minimal distress), post procedure and discharge home.

The admission plan is then sent out to all relevant consultants and junior staff, anaesthetic staff, ward staff and play specialists and the person identified who will carry through the plan.

Practical issues outside the pre-admission checklist

Again here we have detailed some fairly obvious, but we would anticipate very common, problems across all hospitals, with the solutions we adopted.

a Car parking –'no spaces outside the hospital or cannot park for more than an hour. We need the car to bring the child/YP to hospital as behaviour is too difficult for public transport.'

Solution: Speak with security and give details of the car and date of procedure to get permission to park outside all day. Check into security at front desk on the day to record arrival.

b Our child is not able to wait around for long periods.

Solutions: Minimize length of stay in hospital. Request that they are admitted to the ward as late as possible, i.e. admit on day of procedure, sometimes an hour before, instead of coming in the night before. Discharge needs to be as quick as safely possible, i.e. having eaten and drunk without vomiting and if parents are happy YP is well enough to go home. Sometimes this may be in the early hours of the morning but if parents are still happy to go home then this needs to be respected. Again, if ward and medical staff are aware of this potentially happening this is not normally a problem.

Ensure YP is first on surgical list to minimize waiting time and also that their nil by mouth times are no longer than necessary. Many YPs with learning difficulties and challenging behaviour are motivated by food, so having to remain nil by mouth for long periods can provoke behaviour that becomes problematic.

Ensure staff are 100% ready in the anaesthetic room so YP does not have to wait outside for a period of time while they are getting medicines and equipment ready.

c We are anxious about the noise of the ward and how our child will react.

Many parents were also worried about how other parents will perceive the behaviour of their child and safety with regards to equipment and other children.

Solution: A cubicle is required with adequate things to do for YP to access – for example, if YP likes Thomas the Tank Engine DVDs, ensure a TV and DVDs are accessible. Sometimes during completion of proforma, parents tend to say what activities and distractions they will bring in.

d Our child does not like to be touched.

To do so increases anxiety and challenging behaviours, especially in environments and with people they are not familiar with.

Solution: Observations, i.e. pulse, blood pressure, temperature to be undertaken only while YP is under anaesthetic or if parents say it would be OK. This needs to be documented in YP's notes so everyone is aware of the reasons why observations were not taken.

e He has sensitivities to certain materials and does not like getting undressed.

Putting on a hospital gown may also make them aware that something different is to happen and provoke anxiety.

Solution: Bring own clothing which would be appropriate and is 100% cotton with no metal, for example, zips.

f My child cannot swallow tablets.

Solution: Check exactly what medications are likely to be needed and whether liquid preparations are available if necessary. As an example, one child assessed only took his medicines in lemonade; otherwise, he would refuse to take them. This was solved by checking with the anaesthetists what medicines he was likely to have, then confirming with the pharmacy that those medicines could be mixed with lemonade.

g How will we get my child to the anaesthetic room?

Solution: Careful discussions on whether YP would prefer to walk or travel on the bed. Could they watch a DVD to distract them while being wheeled down? Different strategies can be thought of to suit YP's needs.

h My child does not like needles.

Solution: If at all possible, and after discussion with anaesthetist, give YP gas and then all blood tests and procedures involving needles to be carried out while under anaesthetic.

If for some reason gas cannot be used or if even this process is too anxiety-provoking, i.m. ketamine may be suggested. Again, this needs to be in discussion with the anaesthetist; then while the child is on the bed being wheeled into the anaesthetic room the anaesthetist is ready to give the injection as quickly as possible without the child having time to worry about it. As this takes effect, the YP will relax enough for the procedure to be carried out. Parents also need to be aware that recovery times may be longer.

i I want to be there when he wakes up.

Solution: This is normal practice anyway but we have tried to encourage recovery staff to transfer the child/YP back to the cubicle on the ward when safe but earlier than normal so that they can wake up in the same room where they were admitted and which is now familiar to them. In those with autism sensitive to a very familiar environment, this has been very helpful.

Results of reaudit

The 'feedback' was overwhelmingly positive from both staff and parents.

The staff felt it was 'extremely' useful to know in advance how best to cater for these children's needs. They all felt it helped in 'making the hospital experience a more positive one for them on the ward and for the child and families', as the care plan with suggestions did relieve stress and anxiety. Giving staff strategies and warnings about possible challenging behaviour and how to prevent it reduced the likelihood of any serious incidents occurring. The only frustration ward staff felt was when they could not allocate a cubicle to a child with severe autism while knowing and understanding that a cubicle would be best suited to them. Unfortunately, infection control takes priority.

Some quotes from families who sent in letters of thanks demonstrate that preplanning for children with challenging behaviour is essential and worth doing.

Amazed how much help and support we had to make the whole day go without any problems at all!Was first on the theatre list, which was brilliant, if he had to wait longer he would have started wanting food and drink and his condition would never allow him to understand why he couldn't have anything.Without this careful planning and the team's understanding of my son's problems, this could have been a very stressful event for us but instead it was a faultless experience.Having our own room made all the difference.Discharged so quickly, as soon as we thought he was ready and he had eaten and drunk something.Could not have asked for any more, what normally would be an extremely stressful experience ended up being a very calm, positive day and felt like I was listened to for the first time!

Conclusion

The implementation of a process of continuous quality improvement using audit and change management principles for families with children or YPs with complex needs has hugely improved the 'patient' and staff experiences and led to more successful access to health care for this client group, echoing the experiences of [8]).

The *Healthcare for All* recommendations ratified in *Valuing People Now* ([2]) – a 3-year strategy for people with learning disabilities – are intended to provide people with learning disabilities with 'universal, fair, equally accessible and effective healthcare', pointing out that ' "equal" does not always mean "the same" '. Recommendation 10 of the *Healthcare for All* report was: 'All Trust Boards should demonstrate. . . that they have effective systems in place to deliver effective, "reasonably adjusted" health services. . . for all those who need it. . . including people with learning disabilities.' That includes suitability of information, appropriate surroundings, and timing of appointments and admissions, as well as suitably modified processes of care. Each child/YP with developmental problems and challenging behaviour needs a different strategy and person-centred planning. A specific pre-admission checklist completed with the parent/carer and a specialist member of staff who understands the difficulties and how the system works are essential. Changing this process of care saves time in the long run with huge improvement in the quality of experience of care for both the families and young people, and staff, as outlined in Domain 4 of the *NHS Outcomes Framework for 2011/12* ([3]).

Key messages

- •
- Hospital admissions are often suboptimal for young people with learning difficulties and/or autism.
- •
- A recognized audit framework is useful in identifying key areas for improvement.
- •
- A pre-admission key worker and person-centred questionnaires for key behavioural and communication needs are essential.

Appendix

Appendix I

Checklist for intended admission of a child or young person with a learning disability including an autism spectrum disorder and autism information sheet

The key to a successful admission is planning and involvement of the parent or caregiver and young person themselves in that planning. SIGNATURES DATE

When considering admission of a child or young person, please ask: Does the child have a learning disability? NMC NO

If the answer to the question is Yes please complete this checklist with the help of the child's carers and school, identify and contact the ward key co-ordinator, and file this in the notes.

Child's name:

Likes to be called:

Age Ht Wt

Parent contact tel. no:

School contact details:

Identify the key co-ordinator for the admission of a child with learning disability and co-occurring conditions – usually the play specialist for the relevant ward.

_____ contact details:

Others

_____

_____

_____

The key co-ordinator contacts the family to complete the checklist.

1. Information about the child

1a. Functioning age equivalent. At what age do you think _____ is functioning? – e.g. a parent might estimate their 10-year-old child to have learning abilities at a 4-year-old level.

_____

_____

_____

1b. Method of communication. How does _____ communicate?

If non-verbal, does _____ use signs/picture exchange system or an augmentative communication device? Does the child have a communication passport?

_____

_____

_____

1c. What makes _____comfortable/what do they need with them to be comfortable?

_____

_____

_____

1d. What rewards does _____ work for? How do you get co-operation? (motivators/reinforcers).

_____

_____

_____

2. Challenging behaviour

2a. Does _____ display challenging behaviours, e.g. running away, throwing things, verbally abusive, aggression towards others? To whom would that be – anyone in the vicinity or a targeted person?

_____

_____

_____

2b. If _____ has challenging behaviours, what are the likely trigger points? e.g. giving medicines, noise, etc.

_____

_____

_____

2c. What tactics can defuse challenging behaviours?

_____

_____

_____

2d. Does _____ display self-injurious behaviour?

_____

_____

_____

2e. Should you as parent/carer be with _____ all the time? Will a single room be needed?

2f. Has _____had an anaesthetic before? Were there particular problems or strategies that worked? _____

2g. Are there any other particular problems that are likely to arise during admission to hospital? e.g. needle phobia.

For the key co-ordinator

Aim: Admission and procedures to be personalized

3a. Make a list of what procedures need to be done and their timing.

3b. Is a cubicle needed?

3c. Decide in advance and discuss with anaesthetist in order to discuss with parents what sort of admission observations are necessary and whether they are likely to cause distress. Discuss what medications the child is on. What about pre-admission sedation?

3d. Is 1:1 nursing required?

3e. List the basic measurements (e.g. BP) and any tests that could be done while child or young person is anaesthetized.

3f. Plan the timing: minimize waiting by putting first on the list and minimize the length of admission by admitting on the morning of the procedure.

3g. Prepare appropriate communication strategies, e.g. visual (pictures/card/symbols) if these are needed.

3h. Suggest appropriate clothing, e.g. track suit/shorts to minimize undressing if this is a problem. Also bring own food/snacks if a particularly fussy eater.

4. Day of admission

4a. Key worker to ensure that the team and designated health team are fully briefed. Again discuss everything about process with parent or carer.

4b. Do not do observations, or even give premed if it is going to distress the child or young person. Take samples if possible under anaesthetic. Ensure there are no delays; be 100% ready. Minimize the personnel present (ketamine i.m. as anaesthetic has been very successful; it may lengthen recovery period). Ideally allow recovery to take place in the cubicle from which the child has come which will be left completely unchanged and therefore familiar.

4c. Discharge home as soon as practicable. Remember that on any subsequent visits some children with autism will expect the routine to be completely unchanged.

4d. Document what worked well on that particular child and what did not, so that it can be used/omitted on another occasion.

Who else is available to advise?

Paediatric Clinical Psychologist

Name:

Contact details:

Liaison Child & Adolescent Psychiatry if there are severe behaviour difficulties and mental health problems

Name:

Contact details:

The neurodisability team:

AUTHOR: Karen Pratt Clinical Nurse Specialist

Review date: 24 January 2011

For information

What is autism and an autism spectrum disorder (ASD)?

Autism is the description given to the following group of behaviours:

A qualitative impairment in:

- 1 sociability, empathy and the ability to infer what another person is experiencing or thinking;
- 2 the communicative use of language and creative imaginative play;
- 3 flexibility of cognition and behaviour and range of activities and interests;
- 4 other features such as altered response to the sensory environment and stereotyped movements.

About 1% of children and young people are now thought to have some form of autism – referred to as the ASDs.

Autism is the more severe expression of the above features. Approximately 75% with autism have additional learning problems including severe learning problems and some will be non-verbal (5% of all ASD). Many (>50%) will have additional emotional and behaviour problems.

Asperger syndrome describes the group of children and young people with ASD who have good language skills and usually average ability.

What effect might autism have on function and behaviour, remembering that not all children will show identical behaviours?

- 1 failure to understand the communication of others/ignoring or misreading social cues
- 2 communication that may be physical (to person, self or environment) rather than verbal/gestural, and which can be seen as challenging behaviour;
- 3 anxiety/challenge to change in environment/routine/expectation or disturbed completion of task including rituals;

- 4 motivation by own interests/overfocus of self-interests including stereotyped behaviours;
- 5 lack of empathy yet sensitivity to expressed emotion;
- 6 negative idiosyncratic response to sensory stimuli;
- 7 context-bound behaviour, rigidity of thought, perfectionism, 'just rightness', maintenance of sameness;
- 8 a tendency to take everything literally;
- 9 obsessional thinking/behaviour;
- 10 specific fears/phobias.

Most children and young people with autism like routines and predictability but not all children/young people have all the above features: each is an individual.

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By K. Pratt; G. Baird and P. Gringras

Reported by Author; Author; Author

Record: 15

Title: Development of a Novel Multi-Disciplinary Specialized Care Service for Children and Adolescents with Autism Spectrum Disorder and/or Intellectual/Developmental Disability in a Tertiary Children's Hospital Setting.

Authors: Huber, Joelene F.
Loh, Alvin
Monga, Suneeta
Esufali, Jessica
Shouldice, Michelle

Source: Children; Jan2023, Vol. 10 Issue 1, p57, 12p

Publication Year: 2023

Subject Terms: DIAGNOSIS of autism
EVALUATION of medical care
SOCIAL support
CHILDREN'S hospitals
CHILD development
STAKEHOLDER analysis
TERTIARY care
DEVELOPMENTAL disabilities
MENTAL health
BEHAVIOR therapy
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PATIENT-centered care
HUMAN services programs
MEDICAL protocols
HEALTH care teams
INTELLECTUAL disabilities

Author-Supplied Keywords: autism spectrum disorder
behavior-medicine
developmental pediatrics
Intellectual/Developmental Disability
mental health
tertiary care

NAICS/Industry Codes: NAICS/Industry Codes 622310 Specialty (except Psychiatric and Substance Abuse) Hospitals
622112 Paediatric hospitals
622110 General Medical and Surgical Hospitals
621330 Offices of Mental Health Practitioners (except Physicians)
624190 Other Individual and Family Services

Document Type: Article

Abstract: Children and adolescents with autism spectrum disorder (ASD) and/or Intellectual/Developmental Disability (IDD) are at greater risk of developing comorbid medical conditions, mental health diagnoses, behavioral challenges, and having overall poorer physical and mental health outcomes. Hospital environments present unique stressors and challenges for children and adolescents with ASD/IDD including a change in familiar environment, unpredictable routines, and exposure to sensory stimuli that may be overwhelming. While many school boards have specialized multi-disciplinary special needs support teams and services made up of professionals with expertise in supporting students with ASD/IDD, most hospitals do not have a formal multi-disciplinary ASD/IDD support team in place to support patients, families, and health care staff across the hospital. There is an emerging recognition of the need for specialized multi-disciplinary developmental-behavioral and mental health expertise in hospital inpatient settings. This paper describes the framework for the development of an innovative multi-disciplinary program to better support children and adolescents with ASD/IDD within a tertiary children's hospital setting. [ABSTRACT FROM AUTHOR]

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Database: Complementary Index

Record: 16

Title: Improving the management of children with learning disability and autism spectrum disorder when they attend hospital.

Authors: Vaz, I. (AUTHOR)

Source: Child: Care, Health & Development. Nov2010, Vol. 36 Issue 6, p753-755. 3p.

Document Type: Editorial

Subjects: Hospital care of children
Anxiety in children
Autistic children
Hospital emergency services
Children with developmental disabilities
Learning disabilities
Emergency medical diagnosis
Patient management
Medical care

Abstract: The author offers opinions on hospital care for children who have learning disability and autism spectrum disorder (ASD). It is noted that children with this disability often suffer severe anxiety when receiving medical care, particularly in a hospital emergency department, which in turn makes diagnosis extremely difficult. Means of alleviating the anxieties of autistic child patients are suggested including limiting waiting time, allowing parents to wait with their children and recognition that more time is likely to be needed in diagnosis.

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Database: Psychology and Behavioral Sciences Collection

Improving the management of children with learning disability and autism spectrum disorder when they attend hospital.

Health professionals are likely to encounter persons with learning disability and autism spectrum disorder (ASD) at sometime in their career. Approximately, 2% of patients on a general practitioner's register are expected to have learning disability ([18]). It is estimated that 26% of people with learning disability are admitted to hospital every year, compared with 14% of the general population ([13]). Specific data for children are not available. Children with learning disability have reduced ability to understand new and complex information ([7]). They may have limited language skills, may not be able to report their symptoms and concerns, and their distress may manifest as challenging behaviour. Health care services have a legal duty to provide appropriate level of support to patients who have learning disability ([14])

The prevalence of ASD is estimated to be approximately 1% in the child population ([2]). They have varying levels of verbal and intellectual abilities and may have special needs unique and very specific to the individual ([16]). They can find attending hospital particularly upsetting ([6]). There is some overlap in the difficulties children with learning disability and those with ASD experience. Medical and nursing staff have to adapt their approach to children with a learning disability and ASD to be able to assess and manage them appropriately.

Children with ASD often find the experience of going into a medical setting frightening because of their inability to cope with a change in their routine and problems in comprehending what is happening to them and around them. They find attending accident and emergency (A&E) departments particularly anxiety-provoking because of the sudden nature of the clinical event, the unpredictable waiting time on arrival, which is dependant on triage priority, and the sensory overload from noise, lights and crowded busy waiting rooms even in child centred areas within the A&E department. The need to undergo a number of urgent investigations and treatment can also exacerbate anxiety. They may get overwhelmed with anxiety and become withdrawn or have behavioural outbursts making clinical examination and investigation a challenge. Hand flapping, rocking or other repetitive body movements sometimes seen in children on the autism spectrum can be due to anxiety, and a coping mechanism in a stressful environment ([9]; [12]). Staff can help to reduce these children's anxiety by ignoring unwanted behaviour, complimenting cooperative behaviour and dealing with them in a calm and reassuring manner. A survey conducted among our A&E staff, which included doctors and nurses, indicated that the majority (83%) had a reasonable understanding of the general features of ASD. However, a significant proportion (50%) did not realize that sensory overload that often occurs in an A&E setting could exacerbate their behavioural problems ([20]). This could be because they do not encounter children with ASD frequently.

There are a number of measures that the health professionals can take to ensure a successful health encounter with these children. They need to be aware that many children with learning disability and ASD are able to understand visually presented information and modelling or imitation better than verbal explanation. Where possible, using objects and equipment to 'act out' the intervention on the carer or a model before carrying it out on the patient can increase the chances of gaining their cooperation. The use of pictures or photographs to show what will happen is also helpful. Children on the autism spectrum may have difficulties interpreting facial expressions and gestures. It is important to speak in simple language and break down the actions needed in short steps ([10]). Direct requests help to avoid misunderstanding from literal interpretation of speech often seen in persons on the autism spectrum. They may get upset if they are asked too many questions or their personal space is entered. Explanation and warning must be given before getting close or touching for physical examinations, investigations and treatment. Distraction with conversation on topics of their special interest, toys or objects they like, and singing or counting can be useful in reducing anxiety in a medical setting.

Parents and carers always have a key role in trying to get cooperation from children. This role is even more pivotal in children with learning disability and ASD ([4]; [1]) as they know best their child's specific sensitivities, their usual mode of communication and the sort of rewards that generally produce the desired behaviour. A brief conversation with the parent or carer prior to seeing the child could make the clinical encounter successful. Parents and carers often prepare their children for a planned medical encounter in different

ways ([11]) including using photographs, pictures, symbols and social stories ([8]). Social stories are a short description of a particular situation, event or activity that includes specific information about what to expect and why and the framework for appropriate behaviour ([17]). Even a seemingly trivial request made by a parent should not be ignored because it may make the difference between having a positive or negative encounter ([5]). Paediatric nurses may also be able to help in understanding and meeting the needs of these children in parts of the hospital not staffed by children's nurses.

Health-care staff in a hospital setting may lack training and skills in understanding the symptoms in people with learning disability, and the parents and carers have a key role in interpreting their behaviour ([15]). Parents or carers usually inform the staff that their child is on the autism spectrum or has a learning disability. From the outset the staff need to work with them on how best to deal with their child. It has also been suggested that a system is put in place for identifying on the medical records, those individuals, who have a learning disability ([14]). This would alert staff to modify their approach where necessary and deal with them appropriately.

Waiting is one of the most difficult tasks for children with ASD and learning disability. Some may prefer the choice of a first or last appointment of the day. However, the time for assessment is unpredictable in a busy A&E department and the anxiety caused by waiting and the break from usual routine can provoke a behavioural disturbance particularly in children on the autism spectrum. Consideration should be given to seeing them first irrespective of the clinical priority assigned at triage. If waiting is inevitable, the parent or carer should stay with the child in a quiet area, where there is minimal sensory stimulation, using strategies they usually deploy to occupy the person during waiting times. If clinically appropriate, there should be flexibility in allowing the child the option of waiting with the parent outside the medical environment until it is time for assessment ([1]). Limiting the number of staff involved in treating the child also helps them to understand what is happening to them and the role of the care provider ([6]). Staff also need to recognize that more time is generally required for assessing symptoms in people with learning disability ([14]; [3]).

There is often frequent turnover of staff, particularly trainee doctors in hospitals. They have many priorities for training and there are limitations by way of time and resources available. Nevertheless there should be opportunities during the doctors training and professional development to increase their awareness regarding the special needs of children with learning disability and ASD and how best to address them so that they can deliver optimum health care to them. Relevant information and educational material that is easily accessible should be available on the hospital intranet ([1]; [6]; [19]). The memory of a distressing experience in a medical setting can have a detrimental effect on subsequent attendances.

Many children are understandably apprehensive about attending hospital. Those with learning disability and ASD may find it particularly anxiety-provoking. Creating awareness of their special needs among health professionals can minimize the anxiety these children experience, resulting in a more positive encounter for everyone.

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By I. Vaz

Reported by Author
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Record: 17

Title: Autism Comes to the Pediatric Hospital: Perspectives of Child Life Specialists.

Authors: Burnham Riosa, Priscilla
Randhawa, Amanpreet
Muskat, Barbara

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Document Type: Article

Subjects: Treatment of autism
Social support
Children's hospitals
Families
Pediatrics
Comparative studies
Thematic analysis
Allied health personnel
Parents
Children

Abstract: The hospital setting may be especially difficult for pediatric patients on the autism spectrum and their families compared to those not on the spectrum. Child life specialists are healthcare professionals specifically trained to support parents and their children and help prepare them for hospital procedures. Because of this specialized skill set, these professionals likely have a wealth of expertise to share relevant to caring for autistic patients. This study aimed to understand 21 child life specialists' experiences working with patients on the spectrum. Our findings highlighted the following themes: Parents are the Experts, Proactive and Individualized Care, Disclosure, and Hospital-Wide Suggestions to Improve Patient Care. We discuss the practice implications of these findings on the healthcare experiences of pediatric patients on the spectrum. [ABSTRACT FROM AUTHOR]

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Autism Comes to the Pediatric Hospital: Perspectives of Child Life Specialists

The hospital setting may be especially difficult for pediatric patients on the autism spectrum and their families compared to those not on the spectrum. Child life specialists are healthcare professionals specifically trained to support parents and their children and help prepare them for hospital procedures. Because of this specialized skill set, these professionals likely have a wealth of expertise to share relevant to caring for autistic patients. This study aimed to understand 21 child life specialists' experiences working with patients on the spectrum. Our findings highlighted the following themes: Parents are the Experts, Proactive and Individualized Care, Disclosure, and Hospital-Wide Suggestions to Improve Patient Care. We discuss the practice implications of these findings on the healthcare experiences of pediatric patients on the spectrum.

Keywords: Autism spectrum disorder; Pediatric; Hospital; Child life specialists; Health care

Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by restrictive and repetitive movements and impairments in social communication and interaction (American Psychiatric Association, [1]). In addition, children on the autism spectrum[1] may have co-occurring medical (e.g., epilepsy, cerebral palsy, hearing and visual impairments; Kielinen et al., [24]) or psychological conditions (e.g., depression, anxiety, behavioural or conduct problems; Gurney et al., [17]) that would benefit from specialized health care services. As such, this population is likely to require a host of healthcare services (e.g., preventive care, hospital emergency visits, non-emergency visits) and interact with a variety of healthcare practitioners (HCPs; Gurney et al., [17]; Muskat et al., [32]; Scarpinato et al., [37]). In fact, previous research has indicated that autistic patients were more likely to visit healthcare settings than children without autism in the United States (Gurney et al., [17]). To date, a limited body of research focuses on the hospital experiences of families with a child on the autism spectrum (e.g., Gurney et al., [17]; Kouo et al., [26]; Muskat et al., [32]; Wilson & Peterson, [45]).

The hospital setting itself may be overwhelming for patients on the autism spectrum (Scarpinato et al., [37]; Wilson & Peterson, [45]; Zwaigenbaum et al., [47]). Autistic patients who have sensory sensitivities (e.g., issues with fluorescent lighting, wearing hospital gowns), difficulties waiting their turn (e.g., waiting to be triaged in the emergency department) or transitioning (e.g., moving across different waiting areas; moving to a different area of the hospital for X-rays), may experience challenges navigating the hospital environment (Muskat et al., [32]; Nicholas et al., [34]; Zwaigenbaum et al., [47]). These environmental barriers have been reported to heighten the healthcare needs of patients on the autism spectrum (Warfield et al., [44]). Physicians reported that expecting autistic patients to travel to and wait in different locations within a medical-care facility may not be feasible. The associated stressors may lead to patient reactions that negatively and directly affect other patients (e.g., a patient on the spectrum becomes anxious in the hospital environment and hits another patient; Warfield et al., [44]). These negative interpersonal experiences often exacerbate the already stressful experience of being in the hospital and feeling unwell.

Existing research also indicates that the healthcare needs of patients on the autism spectrum may not be well understood by the HCPs who support them (Heidgerken et al., [18]; Nicholas et al., [34]; Wilson & Peterson, [45]; Zerbo et al., [46]; Zwaigenbaum et al., [47]). For example, Nicholas et al., ([34]) used semi-structured interviews to explore the hospital experiences of autistic children and youth and their families. They found that children and youth on the autism spectrum faced several challenges, especially in the emergency department. These difficulties included communication issues with emergency department staff and a lack of knowledge of ASD (Nicholas et al., [34]). Further, Kouo et al. ([26]) examined the medical encounter experiences of 40 family members of a person on the autism spectrum. They found that approximately half of the participants reported dissatisfaction with HCPs with specific concerns when HCPs did not have ASD knowledge, or the hospital setting did not have resources to support the distinctive needs of patients with autism. Muskat et al., ([32]) and Zwaigenbaum et al., ([47]) reported additional challenges with HCPs, notably the inflexibility of some HCPs in caring for the idiosyncratic needs of pediatric patients on the spectrum. Parents and HCPs have expressed the need for specialized or continued education and training in caring for autistic patients (Muskat et al., [32]; Zerbo et al., [46]; Zwaigenbaum et al., [47]). More recently, Kouo and Kouo ([25]) highlighted studies in which HCP training approaches have been integrated into patient-centred practices and empirically examined (e.g., Johnson et al., [21]; Lucarelli et al., [28]) in their scoping review. Scarpinato et al. ([37]) and Vaz ([42]) provide recommendations and strategies that HCPs working in hospital settings may adapt for patients on the autism spectrum. When HCPs can accommodate the individualized needs of autistic pediatric patients, families have reported positive healthcare experiences (Muskat et al., [32]).

Child life specialists, who work primarily in hospital settings, may offer valuable insight into supporting the needs of pediatric hospital patients on the autism spectrum (Jensen et al., [20]). In Canada, child life specialists are healthcare professionals who hold a graduate degree in child life and complete a minimum of 600 h of clinical experience during their training. These professionals are responsible for supporting parents and children in understanding the hospital setting and preparing children for hospital procedures. Child life specialists are often called to help support children on the spectrum at the hospital because of their specialized experience and education in providing psychosocial care (Jensen et al., [20]). Parents of children on the spectrum and allied health professionals (e.g., social workers, speech-language pathologists) have described child life specialists as critical in caring for autistic pediatric patients and supporting their families at the hospital (Muskat et al., [32]). Child life specialists are likely to have a wealth of experience and knowledge to share with others who care for patients on the spectrum. Therefore, the purpose of this study was twofold: (1) to understand child life specialists' experiences supporting pediatric patients on the autism spectrum and their families and (2) to inform policy and best practice approaches in delivering hospital-based healthcare services to pediatric patients on the autism spectrum.

Method

Research Approach and Paradigm

A qualitative methodology was used to understand the experiences of child life specialists caring for pediatric patients on the spectrum at a Canadian pediatric hospital, with the goal of informing health care delivery. Interpretive description (Thorne et al., [41]), a qualitative methodological framework used to explore small-scale health research phenomena, guided the analysis. Thorne et al.'s ([41]) approach has been used to inform health care and clinical practice, which was central to the current study. We adhered to a constructivist paradigm (Guba & Lincoln, [15]) whereby the subjective experiences of child life specialists were understood through the meanings participants assigned to them (Deetz, [13]).

Researcher Characteristics and Reflexivity

The first author (PBR) worked in a research position at the hospital and had been involved in research and clinical practice working with children and young adults on the autism spectrum and their families for over 10 years at the time of data collection. The second author (AR) had no direct interactions with participants in the sample; she joined the research team as a master's level graduate student with training in applied behaviour analysis (ABA) and experience providing services to children on the autism spectrum for over 4 years. The third author (BM) had pre-existing clinical and professional relationships with participants through her director role in a department of the hospital that worked closely with child life specialists, in addition to over 20 years of clinical and research experience related to autistic people and their families at the time of recruitment.

Research Context and Sampling Strategy

The study was conducted at a large urban Canadian pediatric hospital in Ontario. Purposeful and snowball sampling approaches were used to recruit participants. The strategy was purposeful because we were looking for "information-rich cases for in-depth study" (p. 182) to learn about the issues of central importance to our study (Patton, [35]). We initially invited child life department management staff to participate. Using a subsequent snowball sampling strategy, we asked our key informants (i.e., management staff) to identify other information-rich informants, in other words, child life specialists who would be willing to share their experiences supporting children on the autism spectrum at the hospital. Interested participants contacted the researchers by phone or email.

Participants

Twenty-one child life specialists participated in the study across two focus groups (n = 11; n = 10), which took place in the child life department at the hospital. All participants were female. Child life specialists mainly worked in inpatient and selected ambulatory units. They had all worked at the hospital for at least 1 year and with at least some patients on the autism spectrum; however, we did not collect other demographic data (e.g., years of experience). The sample size was based on the most convenient time and availability of most child life specialists interested in participating in the study who could be covered by other child life specialists who were not identified through our sampling procedures as key informants to our research question (Patton, [35]).

Procedure

All research protocols were approved by the hospital's research ethics review board.

The first and third authors coordinated their availability and provided interested participants with the selected focus group dates and times as recommended by the management staff to capitalize on the availability of most child life specialists. Interested participants contacted the first author. The first author confirmed group allocation with interested participants in one of two groups arranged approximately equal in size. The third author was the primary moderator, and the first author was the secondary moderator responsible for audio recording the focus groups and taking notes. Both focus groups took place in the child life specialist department's lounge area, which was the most convenient location as recommended by the key informants (child life department managers). The researchers provided refreshments and food.

Each research session was scheduled as follows: (1) welcome and overview of the study, (2) consent and confidentiality, (3) focus group ground rules, (4) focus group questions, and (5) closing remarks and thank you. The interview guide consisted of open-ended questions grounded in the health care experiences of child life specialists working with patients on the spectrum at the hospital. Initial questions were broad (e.g., *What are your experiences with children with ASD in the hospital setting? Are there any issues or challenges?*). Other interview questions focused on the needs of pediatric patients on the autism spectrum (e.g., *What do patients with ASD need? What strategies have you found to be helpful? Unhelpful?*) and child life specialists' recommendations to best support and care for patients on the autism spectrum and their families while at the hospital (e.g., *Based on your professional experiences, what do pediatric patients with ASD need at the hospital?*). Probes and follow-up questions (e.g., *Could you tell me more? Do others have similar or different experiences?*) were included to elicit additional detail from participants. We invited all participants to share additional feedback with us after the focus group.

Each focus group was approximately 60 min in duration. Throughout the focus groups, moderators promoted discussion by developing rapport, using techniques such as paraphrasing and reflective statements, and asking probing and follow-up questions as appropriate. Focus groups were audio-recorded and transcribed verbatim by a hired transcriptionist. Square brackets were then added to either substitute any identifiable content or to improve the clarity of the narrative. The first author checked the transcripts against the audio recordings before conducting the analysis.

Data Analysis

Focus group data were entered into MAXQDA Analytics Pro 2020, a qualitative data management and analysis software program. Two research team members (AR and PBR) were the primary data analysts. The first step involved each of the two researchers independently reading the transcripts to become familiar with the data sets and took notes. After the transcripts were read in their entirety, the research team developed an initial codebook (MacQueen et al., [29]) with details on how the codes related to one another. Researchers proceeded with a combination of deductive and inductive thematic approaches (Creswell, [12]; Thomas, [40]) to analysis, starting with open coding and broad categorization based on the initial transcript reviews and discussions, followed by iterative codebook refinements. After multiple iterations of the codebook, details were finalized (i.e., code label, short and full definitions, examples of when and when not to use each code; Guest et al., [16]). The first (PBR) and second authors (AR) independently coded the first transcript and met to discuss the codes. Twelve coding disagreements were identified and resolved. The second author coded the second transcript, and the first author (PBR) independently reviewed AR's codes against the codebook. Three disagreements were identified and resolved.

Data Quality

We incorporated various strategies to establish the dependability (Lincoln & Guba [27]) and credibility (Lincoln & Guba, [27]) of our findings: establishing researcher credibility, codebook development, thick description, and investigator and analytic triangulation. First, the rigour and methodological soundness of the data were established through *researcher credibility* (Patton, [36]) or *prolonged engagement*. Research team members had considerable experience, training, and expertise working with families and children on the autism spectrum in the hospital setting and beyond. Training, perceptions, and experience impact the research process and how the findings may be received (Patton, [36]). Second, we developed a codebook to strengthen the rigour and methodological soundness of the data. Codebooks are used to support a systematic approach to data analysis (Guest et al., 2014). Third, we used several participant quotes for *thick description* (themes included rich descriptive participant experiences), as support for our data interpretations (Brantlinger et al., [7], p. 201). Chenail ([11]) stated that quotes are the "stars" of qualitative research and are the foundation of the analysis. Fourth, we implemented investigator triangulation (Brantlinger et al., [7]) or *triangulation through multiple analysts*, such that the first and third authors conducted the focus groups and the first and second authors conducted the analysis with input from the third author. Finally, we incorporated *analytic triangulation* (Patton, [36]) or *member checking*, where preliminary study findings were shared with the child life specialists at the hospital for their review and feedback.

Results

Overarching Themes

Child life specialists described a variety of insights and recommendations into caring for pediatric patients on the spectrum in the hospital setting. Findings from our analysis resulted in the following four themes: (1) *Parents are the Experts*, (2) *Proactive and Individualized Care*, (3) *Disclosure*, and (4) *Hospital-Wide Suggestions to Improve Patient Care*. Each theme is described and substantiated with supporting quotes.

Parents are the Experts

Participants underscored the importance of prioritizing the expertise of parents when making care decisions at the hospital. Child life specialists emphasized listening to parents and asking them questions to understand what could be done to improve their child's hospital experience. One participant said, "I find asking the parents really helps...'cause they're obviously the best expert of their child." (Focus Group 1). Child life specialists in this sample considered parents as integral to the care team. One child life specialist explained this as follows, "...We're saying [to the parent], hey, you're part of the team and you're the expert on your child, I think it's also not just a win for us but a win for families too." (Focus Group 1).

Another participant described the importance of listening to parents:...a lot of what we do is listen to the parents. So other staff members think we've come up with brilliant strategies but all we've done is asked mom and dad what works for them, because no matter how many courses any of us take on autism, no matter how many things we know,

we may know a lot about kids on the spectrum, but it doesn't tell us a single thing about this kid on the spectrum, so we ask the parents. So, when we come across as experts it's because we asked. (Focus Group 2)

Proactive and Individualized Care

Participants described a variety of proactive and individualizedstrategies to care for pediatric patients on the spectrum. These approaches were carried out to make the child's visit to the hospital as comfortable as possible. One participant advocated for a child who was having sensory difficulties with the hospital call bell:I had a patient, on my busier unit, where the call bell's going all the time and it's really hectic and people are waiting around, and this patient was having a lot of difficulty coping, and I figured out after talking to them that it was the noise...and the nurse was just so frustrated...so I went back and said, 'the call bell's like really bothering her.' So we took blue pads and taped them up and covered and muffled the intercom system; you could still hear it but it was so much better and all of a sudden the patient was more compliant and she went to sleep and she wasn't agitated and dad was so thankful, and the nurse was like, 'I guess that wasn't really that hard.' And, then everything's so much better, and it didn't really solve it but it helped, and I think even just knowing that we were trying different things...[the parent] could see that we were doing something to help [their child], and it worked really well... (Focus Group 1)

This relatively simple solution made a meaningful difference to a patient and their family.

Child life specialists referred to the value of implementing strategies proactively to support patients on the spectrum at the hospital. One participant emphasized,We're so effective proactively, in all areas you know, but again especially with children with autism, to be able to get to them so that you don't get to the screaming hysterical fits, because once they're already escalated, it's a different ballgame. (Focus Group 1)

Other instances of when proactive strategies were most helpful was making use of 'pre-op' phone calls, which were completed by child life specialists as requested by staff across departments for pre-planned hospital visits. For example, one participant described these phone appointments with parents:...we do pre-op phone calls to help parents in the beginning...the parent calls the pre-anaesthesia clinic, identifies that their child has either a developmental delay, has autism, or whatever, and then [the pre-anaesthesia clinic says], call Child Life, do a pre-op tour, do all that. And then we're sort of the first go-to to set that plan in place because we do the tour and then we see them on the day of. (Focus Group 2)

One of the child life specialists created a sheet to communicate to staff their patients' needs:I've actually created...a sheet that goes on the outside of the door, 'this is what works for me'...not that everybody reads it but I'm hoping that somebody will read it...I tried it with the last patient I had, and it did help somewhat, if people took a moment...put...10 things...the more important things up at the top...that seemed to help." (Focus Group 1)

Child life specialists described helpful visuals, sensory items, and communication tools that they have tried with patients. One participant referred to the available materials to child life specialists, including technology with communication programs, a Snoezelen room, bubbles, squeeze balls, "...and everything at our disposal within our department..." (Focus Group 1). Participants referred to visual boards and stories as ways to communicate to their patients, different hospital procedures. One child life specialist described how creating a visual board helped with a child with various sensory sensitivities:[One of my patients] was really super-sensitive to even blood pressure, noise, sounds; mum was an amazing advocate, said right away, we need to get something in place so we started a 'first and then' board for vitals, and then we worked from vitals up to every single test and procedure he had through his entire stay. And they got into a routine where they just brought it with them, we put it up and we used the same things that they used at home to just sorta, work our way through. (Focus Group 2)

One of the child life specialists described how in-the-moment visual supports could be created, "like a minute before we even meet [the patient], we can just take pictures of the journey that they take down the hall, and then show them the pictures and then walk them into the space" (Focus Group 2). Another participant described customizing a simplified

version of a complicated picture board that worked better for a particular family. They said:I have something like [a picture board] on my unit, it's huge, and overwhelming, so I found that it was easier to find out from the family, which ones of those that they would want to have on a board, and make something really simple, but it's having the time to make something. It depends on, our area, and how many patients. (Focus Group 1)

Disclosure

Disclosing an ASD diagnosis is a family's decision of what to tell, who to tell, and when to tell. As one participant stated, "...it's up to a parent to disclose." (Focus Group 1). Participants referred to instances when families did and did not disclose their child's ASD diagnosis to the hospital health care team. In one example a child life specialist said, "I have met patients, who the parents haven't admitted to anyone, that they have the diagnosis..." (Focus Group 1). Alternatively, participants also described parents who were forthcoming with their child's needs ahead of non-emergency, pre-planned hospital visits. One participant referred to situations where families shared an ASD diagnosis with the health care team and it was included on the child's electronic hospital chart: "There has [sic.] been situations where in [the electronic charting system], I will see that it is written, that someone has taken the time to put it in. My feeling from that and having worked with the families where that is written, is the family is very forthcoming, and they want the medical team to know right away, and then it gets taken care of." (Focus Group 1). Advance notice of a patient with special needs may give the health care team time to prepare for the visit:...if parents are proactive and they call and say, I'm coming to the hospital and I'm needing to do this, this is my child, what can you do for me? It goes so much smoother. Unfortunately, because when they show up, staff try, and if there aren't the key people potentially involved in order to create a better experience for that particular child, they try, they feel bad, they call, we can't do anything in that moment, most of the time, sometimes it's amazing and it works. But then it's backtracking and starting from, well okay let's try this again at another time and let's work on putting all those key things in place. But if the parent does it right away and they know before that child has that bad experience, and this goes for everything here in the hospital but, specifically, obviously a little bit more heightened with this population – that's when I find it's obviously more effective. (Focus Group 2)

Even when families disclose, participants described instances when the diagnostic information ends up "lost in translation". One participant referred to the difficulties that might occur when a child visits different hospital units:Because kids travel through different parts of the hospital...the information isn't always shared. We've all had kids who come through our door in clinic who were in [another area of the hospital] yesterday and it's nowhere in their chart and then, I'll chat with one of our colleagues and they don't know the kid has autism. (Focus Group 2)

Participants also described the benefits of knowing about an ASD diagnosis up front and how it can positively influence the health care experience for the child and their family. One child life specialist described a situation where staff members were informed about an ASD diagnosis after the visit had gone awry. Staff commented that if they had known about the ASD diagnosis beforehand, the situation would have been handled differently:And along the same lines, I think a lot of it, staff is willing to be flexible if they know. And, you know, most recently we had a little one that came from out-patient to in-patient, no one let out-patient know, the child was being diagnosed on the spectrum, and so when we communicated, and I was able to go back and tell the staff, everyone was like, oh, if I had only known, because it's hard to tell with a brand new 3 year old, if they're being non-compliant or if they have other issues. (Focus Group 1)

One participant described how their department adjusted the intake process for pediatric patients with identified special needs based on a previous encounter that escalated and resulted in aggression toward another patient:...if we knew a kid was coming in who was on the spectrum, there were certain, the clinic would immediately page me, we'd put them in a separate room. They didn't necessarily fast-track the line, but they were, didn't need to go into the playroom or, and if the kid came in, the parent identified, if they said, you know what, that wait seems like a lot, my son or daughter is on the spectrum, we'd do the same protocol, but it all stemmed from a kid who we did not know was on the spectrum, was in the playroom for 3 hours...and he actually escalated and ended up running down the hallway of the [clinic]... (Focus Group 2)

Hospital-Wide Suggestions to Improve Patient Care

Through their experiences, child life specialists provided several hospital-level suggestions to positively impact the care experiences of patients on the spectrum and their families. These recommendations included standardizing the intake and triage process, expediting procedures where possible (i.e., minimizing waiting), providing suggestions on how to signal to HCPs and staff that a patient has special needs and to share that knowledge consistently across the team, and suggesting strategies that the specific health care teams could implement to make visits as positive as possible.

Standardized intake. Participants described the value of standardizing the intake process at the hospital for all children. They discussed the benefits of a formal script with intake questions to understand a child's unique needs if any. Child life specialists suggested that the script include tips and prompts so that the person asking the questions could understand the purpose and feel comfortable asking them. One participant added that the prompts and standardization would help in that, "You feel safe asking the question..." (Focus Group 1). Other participants agreed that providing parents with a rationale for why potentially sensitive questions (i.e., asking about an ASD diagnosis) are being asked, is essential. Child life specialists acknowledged the possible hesitation by parents to disclose that their child may have unique care needs. One child life specialist said, "I think if they knew why they were answering it, that it could help their whole hospital experience; make it better, easier, maybe they would be more forthcoming with the information." (Focus Group 1). Another participant added, "Say, something like, you know, we can accommodate our services to better meet the needs of your child, you know, that kind of very concrete..." (Focus Group 1). One participant described politely asking the question and contextualizing it for the parents:And I think there's no harm in posing that question cause at the end of the day, it's up to the parents, whether they want to answer it or not, you know what I mean, like they, if they feel like they don't want to admit, or whatever, that their child has autism, then they don't have to disclose that information, right? (Focus Group 1)

Factor autism into triage and planning processes to decrease waiting time. For unplanned emergency visits, participants recommended that the initial questions about special needs and autism should be asked at the first point of contact - triage:P:...should be in Triage.P: Yep. It should be, first point of contact, a few little checks, like does your child have any sensory issues; is your child on the autism spectrum; what is your child's cognitive age? Some of it may be beyond parents' comprehension but, it's helpful for everyone to know that yes, this child is 8, but when you go into talk to them, developmentally they're 5.P: Or yes, when you go into talk to them, you need to use literal sentences because they're on the spectrum. Those would be helpful things to know.P: That way Emerg staff will know sooner, too. It's just like a red flag. (Focus Group 2)

Other participants agreed with a standardized triaging process:Yeah, if that's the protocol of the hospital, right? That's what you're doing. It's not, this child with autism gets to have a half an hour wait and this child gets to have a 6-hour wait. If it's standardized, the way we triage everything else, if it's factored in, in whatever algorithm they use, you know, I think that, I think there's excellent argument to be made for that, especially if you could've gotten a procedure accomplished within the first 30 minutes of them getting there, but because they've been there for X number of hours, they're no longer able to cope and you can't treat them for what it was they came in for – how is that providing care... (Focus Group 1)

Participants discussed the process of triaging or prioritizing patients on the spectrum who have different needs. One participant referred to triaging according to age, a non-medical acuity comparison:When we see patients in the [operating room], we put the youngest kids in first, that's not medical. We do it because, to ask a 2-year-old to be NPO [*nothing by mouth*] for 24 hours is too much, right, so we see the infants first. And we try to see kids with autism first – it doesn't always happen that way but, if they can make that rule then, why not? That's not medical acuity. (Focus Group 1)

One participant provided a rationale for prioritizing patients on the spectrum, discussing that even though it might not immediately present as a medical acuity issue, they stated, "But it could become a medical acuity if they wait too long." (Focus Group 1).

Participants described waiting as a challenge for many families with a child on the autism spectrum in emergency circumstances and planned visits. Participants agreed that a standardized booking process to reduce waiting for scheduled visits would be helpful. One participant commented on the benefits of reducing the wait times for patients on the

autism spectrum, saying, "It would be nice if it could be standardized and parents could rely on us to make those simple changes, to make it easier for their kids." (Focus Group 1). The rationale for decreasing waiting times for patients on the autism spectrum was also crucial for other HCPs, as stated by one participant, "...and maybe help [staff] understand why waiting is much harder for children with special needs" (Focus Group 1).

Signaling an ASD diagnosis. Participants described relatively simple procedures to communicate to hospital staff that a child has an ASD diagnosis. One child life specialist described a simple door magnet to signal that the child in the room has autism:I went to a session on autism and Emerg...at another children's hospital...they have magnets that go on the door frame to indicate...I can't remember if it's like a star or if it's like a rainbow or what it is, but it's a magnet that just goes above the door and you look, and if you see that, you know that kid has autism, I need to stop, I need to figure out what, how many people can go in the room, so on rounds, they have only minimal doctors...And it's just a little magnet...And they use it in Emerg in this specific spot so at Triage, once you got put into Emerg, they put it up there so you would know...I thought it was pretty brilliant that they did that. (Focus Group 2)

One participant thought it might be helpful to generalize this idea to other situations to quickly signal the health care team something important that the family wants to be communicated to the team. The child life specialist provided an example of a family who did not speak English:A stash of like, signs, or something, where you pick like the most appropriate ones to put up so that the doctors know. So [at a previous hospital], when I worked there, every time the family had, like first language was not English, it said, my family prefers to speak, and there was a line, and you wrote in the language, and it was so simple. [Compared to where I work now] I go in, and I talk for 5 minutes, like do my spiel, and they look at me and they're like, we don't understand anything you just said to me. And then I'm like, oh I need to get an interpreter. That would have been so much easier if I knew that your first language wasn't English. And then we could have been prepared and I wouldn't have stressed you out with another whole spiel. So, my whole thought is, the same thing as, 'my child has autism', or 'my child is highly anxious', or I don't know, I just feel like there could be a way that you just like, put it there and it's like, this is what we feel is the most important information to know about us. (Focus Group 2)

Participants discussed where it would be ideal to flag an ASD diagnosis so that staff could easily see it rather than having to search for it. Some participants suggested posting it on the door as a magnet or sticker. One child life specialist said, "Wherever the allergy alert is. That's what people want to know about, right? Put it front and centre, you know. [General chuckling] Alert!" (Focus Group 1). Other participants recommended placing information on the patient's electronic chart as an alert that would be visible each time the chart was opened. Another child life specialist suggested that it could be documented on the brief patient communication form, which is a hardcopy sheet that includes important patient information such as, "reason for admission, medical history, status of their vitals" (Focus Group 1) because "[p]eople will often check the brief summary in the patient communication and it's short. And you're not having to go through everything to find it." (Focus Group 1). One participant recommended a sticker on the paper chart and a second sticker that could be given to the family:So, [at a different pediatric hospital]...each kid that comes in through, I guess Emerg, anywhere in the hospital, we have a risk, a fall risk assessment that we put, so if they are at high risk of a fall, we put a sticker on their chart, so that this way we know like, to be alert, all the staff, volunteers, that's how we know. So maybe we can even come up with a way where, in combination with [other strategies], to put it in their chart, and as well, have the family carry it with them so that they can be proactive, but at the same time, if us, as staff, we see that there's a sticker on their chart, we'll know to look at the plan and follow through with it and have that communication piece going. (Focus Group 2 Participant)

While participants shared many ideas about streamlining concise communications to the health care team about an ASD diagnosis, one child life specialist highlighted that the label alone does not provide enough information in and of itself, stating:And in the [operating room], it's always listed, on my patient list for the day, there's a space where they would write in, autism or developmental delay. My, my issue with that is that autism, the spectrum is so broad that it doesn't tell me enough; it tells me OK, you should go see this patient, but I don't know if they're non-verbal or if they have Asperger's, you know, or anything in between. And I know that some of that is around the, the labeling, right, and we can't necessarily do a lot about that but, something, 4 more words, in addition to autism, would make a big difference, for me to know, when I'm looking on paper, who I need to,

who I need to see. Because in the [operating room], there could be, out of 50 kids a day, 10 or 12 of them could have autism, so it's, you know, I need more than autism; I need to narrow it down even further from that. (Focus Group 1)

Participants agreed that some form of brief documentation that followed the patient in the hospital to communicate to staff what does or does not help the patient can be a powerful yet simple tool.

Unified care approach and response strategies. Another set of important recommendations from child life specialists focused on consistently implementing the patient support plan across the healthcare team. Participants discussed this as follows:P: I think getting the whole team, like whether or not it's like, like schedules in place or things like that, getting the whole team to understand, to be compliant with that. So, you want to keep things as consistent and as routine as possible but with so many people involved, it's really hard for everybody to take the time, to do, you know, like a before and after, and take the time to explain things or give them, you know, a 5- or 10-minute warning, things that take time – I think it's harder for some team members to be compliant with that.P: Especially the ones who maybe share the opinion that you had talked about, that this isn't a place where we can be flexible.P: Yeah.P: We have things that we need to get done, and so those few people who think, well if I'm the only person who doesn't adhere to what this request is, I'm just the only one, so it won't make a big difference and then all those people during the day who feel the same way. (Focus Group 1)

For scheduled visits, child life specialists discussed proactive planning. Plans for patients coming to the hospital with autism, "needs to be addressed long before they walk in the door, communication between staff, whether that's us, and the family, to develop the coping plan, to help the child practice it at home, so that once they get there, the whole team is aware of what the plan is..." (Focus Group 1). Participants went on to state that "if, one team member might put a plan in place that might get to the next 1 or 2 team members but it doesn't get to everybody..." (Focus Group 1), it could be problematic.

Minimize the number of healthcare providers where possible. Concerning the healthcare team, participants also recommended that patients on the spectrum have a core healthcare team to avoid having "a lot of extra people" (Focus Group 1). While child life specialists acknowledged that this could be challenging to implement, they stated, "but those kind of things are usually pretty important." (Focus Group 1). Participants underscored "the value of less people in the room" (Focus Group 2). One child life specialist spent time explaining to other health care providers why minimizing the number of people in the patient's room was in the best interest of the patient and their family. The participant described a situation as follows:I had to get everybody out of the room after lots of education, sometimes it would work if it was me and the nurse and mom, or whoever was their comfort person, and it took 3 to 4 good successes, before we didn't have nurse, doctor, 14 other people waiting in the hallway just in case. Because the kid's, you know someone's out there in the hallway, let's be honest. (Focus Group 2)

This child life specialist acknowledged that at least some of the emphasis on having more people in the room and involved is because "the culture is so ingrained with the belief that autism is scary" (Focus Group 2).

Autism training. A final hospital-wide suggestion was to expand training opportunities to health care providers about ASD. One participant stated:...I find a lot of people I work with want more training, I want more training on how to work with kids on the spectrum and help cope with their experience here; we all just want to do what's best for them. And we don't often know, know, where to go next. Often, it'll come to us and then, it'll maybe go to Psych and then you know but, sort of, there are a lot of things that doctors and nurses could know how to do and they want to know how to do those things so they don't have to page us, you know, so they can handle it themselves. (Focus Group 1)Another participant emphasized the necessity of training staff across many areas of the hospital to learn how to support this population:I feel like we have the whole cultural competence education and training for all staff, but this is very similar, right? Like all staff, PSAs, you know, techs, everybody engages and works with these kids that, it needs to be hospital wide. It can't just be frontline staff, it's gotta be everybody. (Focus Group 2)

Discussion

Overall Findings

The purpose of the present study was to (1) understand the experiences of child life specialists providing care to pediatric patients on the autism spectrum and their families and (2) inform hospital-based healthcare policies on providing care for this population. Participants described parents' expertise and willingness to disclose an ASD diagnosis and how that influenced their child's care. They described implementing proactive and individualized approaches to supporting autistic patients. Finally, child life specialists provided recommendations to improve the hospital experiences of pediatric patients on the autism spectrum and their families who visit the hospital. Not only are these findings consistent with previous research (e.g., Muskat et al., [32]; Zwaigenbaum et al., [47]), but they contribute uniquely to the scholarship in understanding the hospital experiences of patients on the spectrum from the perspective of HCPs who have specialized training in the "developmental impact of illness and injury" with the role of improving "patient and family care, satisfaction, and overall experience" (Association of Child Life Professionals, 2022).

Parents are the Experts

Participants in our sample underscored parent expertise as critical to caring for autistic patients. Previous research has highlighted the importance of collaborating and consulting with parents about their children in providing hospital care (e.g., Jensen et al., [20]; Muskat et al., [32]; Zwaigenbaum et al., [47]). Carter et al. ([10]) developed a team comprised of hospital staff and caregivers of adults on the spectrum to meet the inpatient hospital needs of adults on the spectrum. The goal of this collaborative team was to develop education and resource materials to inform care pathways at a local hospital. While Carter et al.'s ([10]) focus was on adult hospital patients, parental input on developing best practices materials was essential.

In an invited commentary for a special issue on early intervention models for children on the autism spectrum, Dunlap (1999) emphasized how essential parent involvement was in intervention efforts. While Dunlap (1999) wrote this in the context of early intervention (e.g., applied behaviour analysis-based interventions for children), the summary applies to parental involvement in the hospital care context. Dunlap (1999) stated, "...families are usually the most influential, durable, and valuable contexts that children will ever experience. It is likely that a child's well-being is closely connected to the well-being of the family system." (p. 224). Our participants emphasized that pediatric health care teams who prioritize parental collaboration and expertise are better equipped at supporting patients on the autism spectrum.

Proactive and Individualized Care

Child life specialists described various ways in which they used their training to attend to the individualized needs of patients on the autism spectrum, including proactive (e.g., communication boards, visual supports, pre-op tours) and responsive (e.g., sensory toys) strategies. For example, findings across several studies support the utility of visual supports to address the sensory needs and the benefits of often minor environmental modifications to help with sensory sensitivities (Kouo et al., [26]; Muskat et al., [32]; Walsh et al., [43]; Zwaigenbaum et al., [47]). In their systematic review, Walsh et al. ([43]) indicated a common barrier for families reported across studies centred around HCPs' inflexibility in accommodating the needs of patients on the autism spectrum. Participants in the present study implemented their expertise to best support their patients as informed by their training in child development.

Disclosure

Disclosure of a diagnosis may impact the care a person on the spectrum receives within the hospital setting. Not only might disclosure be important for the physical visit to a hospital, but it may also be important for HCPs to provide appropriate recommendations and suggestions to families following the patient's discharge, thus influencing the patient's overall care. Child life specialists in our sample described instances where disclosure of an ASD diagnosis from the parent is either forthcoming or not and how it may influence health care experiences. Previous research has shown that informing HCPs about an ASD diagnosis before a hospital visit may help to ensure that appropriate supports are available (Jensen et al., [20]). Parents reluctant to share diagnostic information with HCPs may be impacted by social stigma that continues to influence parents of children on the

spectrum. For example, Desai et al. ([14]) interviewed parents of children on the spectrum living in India. Their findings indicated how others' assessments of their children influenced parents' own perceptions of their children and their own parenting. One parent described the experience of being blamed by an HCP of "poor parenting" (p. 621). In an earlier study, Hutton and Caron ([19]) interviewed 21 New England parents of children on the autism spectrum about their experiences with professionals and found that while approximately half of their sample reported positive and respectful experiences with professionals, the remaining participants had negative experiences with professionals where they felt blamed for their child's disability. Two participants reported feelings of self-blame as it related to their child's ASD diagnosis (Hutton & Caron, [19]; Mak & Kwok, [30]) described the relations between self-blame and stigma associated with their child's ASD diagnosis in a sample of families in Hong Kong. The authors suggest that societal education on ASD is a necessary step to reducing the stigma experienced by children with ASD and their families. Muskat et al. ([33]) identified benefits and risks associated with disclosure within a pediatric emergency setting. Benefits included encouraging positive perceptions of autism, fast-tracking care, and providing HCPs appropriate time to prepare for the patient's care. Risks included potential negative assumptions about the child and the parent's discomfort. In the present study, participants identified similar benefits to disclosure, providing examples of their ability to provide accommodations. Future research should continue examining ways to create safe spaces, so parents are more likely to disclose their child's diagnosis. Given our current understanding of the blame experiences of parents of autistic children and reluctance to disclose diagnostic information, what can HCPs do to offer families a 'safe space' to advocate for their child's needs? Parents have recommended creating an 'alert system' to identify a diagnosis and that this be kept in the child's file or having HCPs ask questions related to the care needs of each child during the intake process (Muskat et al., [33]). These recommendations were similar to those suggested by the participants in this study.

Hospital-Wide Suggestions to Improve Patient Care

Participants had several mainly proactive recommendations for hospital-level changes to best care for pediatric patients on the autism spectrum. They suggested a standardized intake process, which could positively impact patients with and without autism. Standardization included at the first point of hospital contact (i.e., asking about any unique care needs while contextualizing the question) and as part of a planned triage process for autistic patients to decrease their waiting time. Research has shown that waiting for health care procedures can be challenging for people on the spectrum (e.g., Barry et al., [4]; Stein Duker et al., [38]; Taghizadeh et al., [39]; Walsh et al., [43]). Participants described some strategies to signal a patient has an ASD diagnosis, which was a practice identified at other pediatric hospitals that supported patient care. Overall, participants advocated for a unified approach to care and response strategies, which includes minimizing the number of healthcare providers wherever possible.

Child life specialists also recommended autism-specific training for HCPs. Limited knowledge about ASD could lead to incorrect assumptions about the patient, which may inevitably impact their care. On the contrary, a clear understanding of an ASD diagnosis may be associated with higher self-efficacy ratings in caring for individuals on the autism spectrum (Atun-Einy & Ben-Sasson, [3]). Although experienced clinicians express confidence in caring for people on the spectrum and less need for training, this may not always translate into the best care. Future researchers should explore potential incorrect beliefs about the healthcare needs of autistic patients and how best to protect future patients from erroneous assumptions. Specialized training to care for autistic patients has been identified across other pediatric- (e.g., Burnham Riosa et al., [8]; Muskat et al., [32]) and adult-focused studies (e.g., McGonigle et al., [31]). Autism-specific HCP training benefits patient care and family well-being. Training equips HCPs with the knowledge and skills needed to flexibly respond competently and compassionately to autistic patients and their families. Kouo et al. ([26]) highlighted the importance of HCPs' approach to interacting with families with a family member on the autism spectrum. They included a participant quote about HCP training, "Compassion and empathy go a lot further than judgment and being harsh on a child you don't know and don't know what triggers they have." (p. 7).

Study Limitations

This study was not without its limitations. Participants in our sample represented a group of child life specialists working in an urban city teaching hospital specializing in pediatric health care. Although participants were from a single pediatric hospital, the transferability (i.e., the utility of the findings to practitioners in other related care settings) may be high. The focus of our study was on the experiences of child life specialists with results that were consistent with findings from other studies that included health care and allied health

care professionals across different settings. Limitations to the direct transferability of our findings, for example, implementing participants' recommendations, may depend on the size and capacity of the health care setting. We did not collect information about the patients supported by our participants (e.g., child age and language level). This information may have been helpful to contextualize the perspectives of child life specialists in our study. Relatedly, we did not collect demographic data on the direct practice experiences of our participants (e.g., how many autistic patients were cared for). Future researchers who pursue similar research might consider collecting additional descriptive data to supplement the qualitative data, further enhancing the transferability of the findings. Another limitation of the current study was the length of the focus group. While child life specialists provided much insight on their care experiences of patients on the autism spectrum, the focus groups were approximately an hour long. Additional time to discuss the topics would have allowed participants to explore the topic in more depth; however, we were capitalizing on the availability of child life specialists working at a busy pediatric hospital. We also note a general limitation associated with focus group methodology: some participants may have been hesitant to share their perspectives in a group setting with colleagues (e.g., differences in job positions, qualifications, introversion). We attempted to address this limitation by having skilled and experienced moderators facilitate the focus group and inviting all participants to share any additional feedback after their group session. It is also possible that the third author's prior clinical and professional relationships with participants may have influenced participants' engagement in the focus group. Finally, because we held a lunch hour focus group, we may have missed diverse perspectives among those interested but were not available at this time. One possibility may have been to identify child life specialists interested in the study but unable to participate in the focus group and invite them to participate in an individual interview.

Practical Implications

Our preliminary findings have several practical implications, including informing policy, improving training opportunities, and fostering collaboration amongst HCPs. First, results may inform policies on both an individual and broader level, thus improving care for autistic pediatric patients. Further, child life specialists provided simple solutions (e.g., pre-operative phone calls) that HCPs could incorporate in hospital and other medical settings (e.g., dentist appointments, occupational therapy). Second, our results are consistent with previous literature emphasizing the need to train HCPs to care for patients on the spectrum (e.g., Kouo & Kouo [25]). These results may help hospital staff (e.g., managers and providers) identify areas that require additional resources or attention. Finally, these results underscore the role of child life specialists in caring for pediatric autistic patients within a hospital setting. Our findings may encourage future collaborations between child life specialists and other HCPs at the hospital.

Future Research

An important future step of this research is to examine the feasibility and effectiveness of implementing participants' hospital-wide suggestions on the experiences of families of children on the spectrum who visit the hospital. Child life specialists in our sample recommended practices, including relatively simple ones (e.g., asking about special needs at the first point of contact) that could have collateral positive effects on the hospital experiences of patients on the spectrum and their families. The findings of this study provide preliminary and encouraging support for the need to continue exploring the perspectives of child life specialists working with pediatric patients on the spectrum in a hospital setting. Future research using various research designs with larger participant groups and across different healthcare settings is critical.

While participants described their perspectives about caring for patients on the spectrum at the hospital, future research might consider investigating hospital experiences directly from pediatric patients. For example, Muskat et al.'s ([32]) study included the voices of six autistic youth, and their narratives were analyzed alongside parent and practitioner interview data. Beyond our recommendation for future researchers to use traditional interview methods with youth, other creative options are available to access a variety of youth perspectives, including creative and arts-based research approaches to data collection (e.g., photographs, drawings).

Conclusion

The focus of this investigation was to understand the experiences of child life specialists caring for autistic pediatric patients at the hospital. Participants described a variety of ways in which they support patients on the autism spectrum throughout their hospital experiences, including recognizing the expertise of parents, disclosure, and the provision of

dynamic and individualized care. Child life specialists provided suggestions on how to improve the hospital experiences of families with a child on the spectrum. These suggestions included standardizing the intake process and using a triaging strategy to reduce waiting times. These findings may be used to guide hospital-level changes to improve the hospital experiences of patients on the spectrum and others with related healthcare needs. Future research surrounding the implementation of practices that support the unique healthcare needs of this vulnerable population are highly warranted.

Author Note

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Publisher's Note

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Footnotes

Throughout the manuscript, we interchange the terminology "autistic patients" and "patient on the autism spectrum" (except in participant narratives) to acknowledge and respect the diversity of terminology perspectives (i.e., person-first vs. identity-first language) of this debate. For further reading on the critical discussion of language use, see Bottema-Beutel et al., ([6]), Botha et al. ([5]), Bury et al., ([9]), Kapp et al., ([22]), and Kenny et al., ([23]), among others.

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By Priscilla Burnham Riosa; Amanpreet Randhawa and Barbara Muskat

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Tremoulet, Patrice D.

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Thematic analysis

Abstract: Hospitals, with many features that can evoke severe behavior in patients with autism spectrum disorder (ASD), often use restraint as a behavior management strategy. Prior research on restraint in patients with ASD has primarily focused on children or specific departments. Twenty-five physicians and medical trainees from an urban teaching hospital participated in discussions about experiences managing severe behavior in patients with ASD across the lifespan. Twenty themes emerged from thematic analysis of participant transcripts. The five most salient themes included: lack of procedural knowledge with restraint implemented by other hospital professionals; alternative strategies to manage severe behavior; negative perceptions of restraint; helpful role of caregivers; and limited experience treating patients with ASD, and critical need for training in function-based management. [ABSTRACT FROM AUTHOR]

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Physician Perspectives on Severe Behavior and Restraint Use in a Hospital Setting for Patients with Autism Spectrum Disorder

Hospitals, with many features that can evoke severe behavior in patients with autism spectrum disorder (ASD), often use restraint as a behavior management strategy. Prior research on restraint in patients with ASD has primarily focused on children or specific departments. Twenty-five physicians and medical trainees from an urban teaching hospital participated in discussions about experiences managing severe behavior in patients with ASD across the lifespan. Twenty themes emerged from thematic analysis of participant transcripts. The five most salient themes included: lack of procedural knowledge with restraint implemented by other hospital professionals; alternative strategies to manage severe behavior; negative perceptions of restraint; helpful role of caregivers; and limited experience treating patients with ASD, and critical need for training in function-based management.

Keywords: Restraint; Autism spectrum disorder; Severe behavior; Hospital

Severe behavior, such as aggression, self-injury, and property destruction, is more common in individuals with ASD than their neurotypical peers (Newcomb & Hagopian, [50]). The majority of research on severe behavior in individuals with ASD is limited to children, and prevalence estimates vary widely. Hill et al. ([30]) estimate that between 8 and 68% of children with ASD engage in aggressive and destructive behavior, while others estimate that as many as 82% (Murphy et al., [48]) to 93.7% (McTiernan et al., [46]) exhibit challenging behavior. This discrepancy in estimates has been attributed to differing operational definitions of severe behavior, assessments used, and study participants (Hill et al., [30]).

Severe behavior may cause property damage or lead to injury of self or others (Kanne & Mazurek, [33]; Newcomb & Hogopian, [50]); it can impair social relationships with peers, family and community members; and it may also lead to social stigmatization (Werner & Shulman, [61]). Individuals with ASD who engage in severe behavior likely require more costly healthcare, education, residential, habilitative, and vocational services than individuals with ASD without severe behavior (Buescher et al., [9]; Hill et al., [30]). In addition, severe behavior may interfere with skill acquisition and on-task behavior, which may ultimately affect educational and vocational status and attainment (Deavenport-Saman et al., [15]; Emerson et al., [17]).

Applying restraint is a common strategy for managing severe behavior, despite associated increases in an individual's risk of depression, anxiety, and post-traumatic stress disorder following restraint implementation (Evans & Cotter, [18]; Friedman & Crabb, [19]). Mechanical restraint, which entails using equipment such as arm splints or waist straps to restrict movement, may result in skin breakdown and difficulties with balance, strength, and gait, loss of muscle mass, and infection (Evans & Cotter, [18]). Use of physical restraint, in which at least one person uses their body to restrict an individual's ability to move their torso, arms, legs or head, is associated with distrust of medical professionals (Wong et al., [64]). Both physical restraint and chemical restraint, which entails using medication (e.g., Benzodiazepines) to inhibit patient movement and manage emergent

behaviors, can cause serious injury, functional decline, and even death (Friedman & Crabb, [19]). Restraint can be implemented both reactively to manage emergent behaviors and proactively to facilitate medical compliance and access to medical care (Allen et al., [1]; Kupzyk & Allen, [36]).

Initiatives to reduce restrictive behavior management for individuals with ASD, such as staff training, reformed organizational policies, and mindfulness-based interventions, are associated with positive outcomes, including improved safety and decreased long-term costs (Sturmey, [59]). Nonetheless, restraint is still used in institutional, residential, day habilitation, vocational, and school settings. Similarly, although healthcare professionals have identified alternative approaches to restraint (e.g., clear communication, visual cues; Johnson & Rodriquez, [32]), and researchers have suggested that physicians should only use restraint after all safer alternatives have been exhausted (Blumberg & Roppolo, [6]), many hospitals currently use restraint to manage behaviors in patients with a variety of diagnoses (Schnitzer et al., [55]).

The decision to implement restraint in healthcare settings is multifactorial in that patient characteristics, including diagnoses; care team's knowledge, experience and attitudes; organizational policies and culture; and physical environment all interact during split-second decisions about whether or not to restrain a patient (Roy et al, [54]). One hospital system witnessed a drastic culture shift in how its medical providers viewed and used restraint after instituting a program that included more expansive training and education, goal-setting across departments, multidisciplinary rounds, and alternative equipment (e.g., soft belts, arm sleeves; Cosper et al., [13]). Although many healthcare providers recognize that restraint should be a last resort, researchers have reported an increased risk of inappropriate restraint use in children with ASD and intellectual disability due to limited staff training and knowledge of ASD (Gabriels et al., [20]). More recent research indicates that children with a diagnosis of ASD and intellectual disability continue to experience higher rates of restraint compared to those without those diagnoses (O'Donoghue et al., [51]).

For adult patients, alcohol or drug use and psychiatric conditions increase the likelihood of restraint. Age, ethnicity, and gender also influence healthcare providers' decisions about using restraint (Grimes, [24]; Mann-Poll et al., [43]). One study reported that a majority of restrained patients were perceived as a danger to self or others (60.6%) or non-compliant or unwilling to follow directions (28.1%; Wong et al., [65]). Although these studies present valuable information on predictors of restraint, little research specifically focuses on use of restraint for adult patients with ASD, whose acute medical care needs might differ from those of other adult patients.

Moreover, many healthcare providers have characterized their knowledge and practical skills in treating patients with ASD as poor or fair, though mental health providers tend to have more knowledge and skills than providers of adult medicine and obstetric/gynecological services (Zerbo et al., [66]). Even neurologists have reported less comfort treating adult patients with ASD than adults with other neurological disorders (Oskoui & Wolfson, [52]). Similarly, pediatric and family physicians have rated their competency treating children with ASD as lower than their competency treating children with other neurodevelopmental disorders (Golnik et al., [22]).

Deficits in knowledge and lower confidence about treating patients with ASD is concerning as it may affect physicians' ability to deliver safe and effective treatment to patients with ASD. In particular, physicians may over-rely upon restraint, when function-based treatments are known to be more effective (Campbell, [10]; Heyvaert et al., [29]). These treatments are developed by identifying the maintaining consequence (i.e., function) of the patient's behavior, such as access to attention, escape from aversive tasks or stimuli, and sensory stimulation (Iwata et al., [31]/1994), access to a tangible item (Day et al., [14]), and routine restoration (Hagopian et al., [25]). For example, a patient with ASD may engage in severe behavior to escape the distress caused by bright lights in an exam room. For this patient, dimming the lights could be a simpler, safer, more effective strategy than restraint. Kupzyk and Allen ([36]) reviewed behavioral interventions to increase medical compliance, finding that graduated exposure and contingent reinforcement are most commonly used followed by modeling and prompting, distraction or relaxation, and behavioral momentum. However, numerous barriers to implementing function-based treatment may exist, including a lack of resources, time, provider knowledge, and interdisciplinary collaboration, and concern with insurance reimbursement (Mazurek et al., [45]).

As the prevalence of ASD increases (Christensen et al., [12]), healthcare providers are likely to treat more patients with ASD. Moreover, individuals with ASD use hospital services more frequently than others. Adolescents with ASD alone are four times more likely to visit emergency rooms annually than their neurotypical peers (Liu et al., [38]), and

individuals with ASD frequently have comorbid medical and psychiatric concerns (e.g., anxiety, depression, and gastrointestinal symptoms) which may necessitate emergency medical services (Lunsky et al., [41]; van Steensel et al., [60]). Further, Lunsky et al. ([41]) reported that children with ASD commonly engage in severe behavior in hospitals, even if their presenting concern at the time of hospitalization was medical. For instance, one patient engaged in severe head banging due to frustration and another engaged in aggression due to an undetected urinary tract infection causing pain at the time of the medical evaluation (Lunsky et al., [41]).

Meanwhile, hospital settings can be particularly challenging for individuals with ASD who experience social communication challenges, sensory sensitivity, and routine rigidity (American Psychiatric Association, [2]). A patient in a hospital setting may encounter unfamiliar physicians, bright lights, loud noises, crowded spaces, and unpredictable routines, any of which could evoke severe behavior (Hazen et al., [28]; Muskat et al., [49]). In addition, frustration surrounding communication with healthcare providers may contribute to the occurrence of severe behavior. Communication challenges experienced by patients with ASD may also contribute to physician difficulty understanding and interpreting pain, physical discomfort, or signs and symptoms of medical conditions in patients with ASD (Broder-Fingert et al., [8]). Thus, presenting medical concerns alone may not predict the level of care an individual with ASD and comorbid severe behavior requires during their hospital stay.

As a result, some families have developed autism-specific care plans (ACPs) to improve experiences of healthcare for patients with ASD and their families. These ACPs may include communication preferences and strategies, environmental modifications, and safety concerns. Initial research indicates that ACPs could help to improve the experience of pediatric patients with ASD and their families; however, use of ACPs for treating patients with ASD across the lifespan and their efficacy across various hospital departments and diverse gender and racial groups has not been established (Broder-Fingert et al., [8]).

In general, little is known about physician experiences managing severe behavior in patients with ASD. Similarly, most of the established literature on restraint occurrence and predictive variables is focused on those without ASD or pediatric patients with ASD. Taken together, the increasing incidence of ASD in the United States, higher rate of hospitalization experienced by individuals with ASD, features of hospitals that could trigger severe behavior in individuals with ASD, and serious implications of restraint compared to alternative behavior management strategies indicate a critical need for healthcare workers to be prepared to use methods other than restraint to manage severe behavior in patients with ASD. An initial step toward meeting this need is exploring physicians' experiences in managing severe behavior in hospital patients with ASD.

Method

Multidisciplinary focus groups and interviews were conducted with medical trainees and early-career physicians, respectively, who work in a large urban teaching hospital in the Northeastern United States; such hospitals tend to experience the highest rates of patients with ASD (Lokhandwala et al., [39]). Discussions focused upon the following topics: (a) experiences with severe behavior management in patients with ASD, including restraint implementation; (b) treatment differences across patients and departments; (c) relevant training received; (d) relevant knowledge of ASD and behavioral function; and (e) perceived needs. This research complied with the American Psychological Association Code of Ethics and was approved by Rowan University's Institutional Review Board. Informed consent was obtained from each participant.

Recruitment

A total of 22 medical trainees (students, *n* = 17; residents, *n* = 4) and three early-career physicians were recruited from an urban hospital and affiliated medical school via direct emails from the research team, emails from hospital leadership and hospital administrators (e.g., Dean, Student Affairs Officer, program director, department chairs or heads), and posted recruitment flyers. Medical trainees included students, residents, and fellows who were currently in or had recently completed a rotation in the target departments of Emergency Medicine, Psychiatry, Pediatrics, and Neurology. Early career physicians (herein referred to as "physicians") were serving in their first 1-to-5 years of post-supervised practice in one of the target departments. Departments most likely to treat patients with ASD were selected for inclusion.

Participants

A majority of participants were female (68%) and medical students (72%). Races included White (52%), Asian (20%), Hispanic (16%), and African American (12%). All target departments were represented, with many medical trainees selecting multiple departments to reflect their rotations across disciplines. Primary departments included: Pediatrics (80%), Neurology (76%), Psychiatry (76%), Emergency Medicine (72%), Surgery (76%), Internal Medicine (76%), Family Medicine (72%), and Obstetrics/Gynecology (64%). Table 1 presents participant demographics.

Table 1 Demographics

Variable	**N**	**%**
Gender		
Female	1768	
Male	8	32
Race		
White	1352	
Asian	5	20
Hispanic	4	16
African American	3	12
Status		
Student	1872	
Resident	4	16
Physician	3	12
Department		
Pediatrics*	2080	
Neurology*	1976	
Psychiatry*	1976	
Emergency medicine*	1872	
Surgery	1976	
Internal medicine	1976	
Family medicine	1872	
OB/GYN	1664	
Pediatric emergency	4	16
Anesthesia	2	8
Student clinic	2	8
NICU	2	8

Variable	N	%
Integrative medicine	1	4
PICU	1	4
Radiology	1	4
Ultrasound	1	4
Urology	1	4

Department = all current departments/rotations completed. Asterisk indicates departments targeted during recruitment. Participants could endorse multiple departments to represent current placement or rotations completed *OB/GYN* Obstetrics/Gynecology, *NICU* neonatal intensive care unit, *PICU* pediatric intensive care unit

Focus Groups with Medical Trainees

Each focus group included six to eight participants, as guided by previous health research (Bender & Ewbank, [5]). Focus group participants were assigned to their respective group based on overlapping availability. Two trained facilitators co-conducted three virtual focus groups using Cisco WebEx® v.40.11.4.15, a HIPAA-compliant video conferencing platform. The facilitators were located in separate private areas where discussions could not be overheard. Facilitators requested that participants join from a private and confidential area and that they remain unmuted with video cameras on during the entire session. The chat feature was disabled to more closely resemble an in-person interaction and to promote active participation. Each focus group was audio and video recorded.

At the start of each session, facilitators requested that participants only discuss experiences treating patients at the hospital from which they were recruited. Any examples from other institutions were redirected and were omitted from data analysis. The facilitators used a semi-structured interview guide with open-ended questions about participants' perceived needs with regard to treating patients with ASD, their training, and their experiences managing and documenting severe behavior and restraint. See Appendix 1 for the question guide. When the lead facilitator judged that the session had reached a point of saturation, and no new information or themes were being discussed, she ended the session.

One medical trainee had to leave the first focus group early due to an unexpected emergency. All other focus group members actively participated for the entire duration of their sessions, which may be attributed to the online format and enhanced perception of anonymity (Stewart & Shamdasani, [57]) or the relevance of topics to all participants (Malterud et al., [42]). Comments from the trainee who left early were included in the qualitative data analysis.

Interviews with Physicians

Due to significant challenges scheduling physicians for a focus group session, three physicians were interviewed instead, using the same structured interview guide.

Autism Stigma and Knowledge Questionnaire

After focus groups and interviews were ended, participants (except the trainee who had to leave her focus group early) were directed to complete an online version of the Autism Stigma and Knowledge Questionnaire (ASK-Q; Harrison et al., [26]). The ASK-Q measures participants' perceived knowledge of the core features of ASD, and yields a total knowledge score and the following subscale scores: (a) diagnosis, (b) etiology, (c) treatment, and (d) stigma. The ASK-Q was selected due to its strong psychometric properties, including high internal consistency (Cronbach's Alpha = 0.88) and test–retest reliability across subscales (range 0.93 to 0.98; Harrison et al., [26]). Cross-cultural utility of the ASK-Q was indicated by adequate internal consistency (Cronbach's Alpha = 0.72) and high test–retest reliability (ICC = 0.86; Harrison et al, [27]). This questionnaire took a median of 3.5 min to complete (range 2.4 to 18.1 min).

Data Preparation

Recordings of the focus groups and interviews were transcribed for analysis. Participants were described by participant number with no identifiable information. Transcripts were thematically analyzed using the constant comparative method of qualitative data analysis (CCM; Glaser & Strauss, [21]; Strauss, [58]), as the study's goal included identifying physician experiences and perceived needs, rather than provisional hypothesis testing.

Researchers coded transcript data into explicit categories to establish theory and highlight salient themes. They followed the six phases of thematic analysis in psychology as described by Braun and Clarke ([7]): (1) becoming familiar with the data, (2) identifying initial codes of interesting ideas, (3) searching for themes, (4) reviewing themes, (5) defining themes, and (6) generating a scholarly report. Data were sorted into themes by comparing text to previous entries or introducing new themes. As themes emerged, operational definitions were created and revised. Subthemes were used to accurately reflect theme content and facilitate consistent coding across the two coders. Data that could have been coded in multiple themes were standardized by establishing specific rules and exclusionary criteria to promote interobserver agreement by independent data analysts. Interobserver agreement, based upon randomly selecting and double coding 33% of each focus group and interview transcript was 91.7%. The majority of disagreements were omission (77.5%), where one coder missed a theme, and the rest were commission, where coders disagreed in theme assignment.

To quantify salience within and across participants, the total occurrences of each theme was summed for each participant and summed across participants (Morgan, [47]). Each example or rationale provided by participants was counted as one occurrence. A separate occurrence was documented once the participant provided a different rationale or another participant responded. Revisiting a previous example or rationale was counted as a separate occurrence. Participant salience for each theme was determined by dividing the frequency of occurrences in one theme by the total occurrences in all themes.

Results

Mean duration of focus groups was 115.7 min (range 109 to 119 min), and mean duration of interviews was 39 min (range 36 to 41 min). A total of 20 themes were identified across all discussions. Table 2 shows frequency and percentage of themes by participant status. The mean rank order correlation between rankings for each focus group and the overall focus group rankings was 0.69 (range 0.46 to 0.86), representing a strong positive correlation. In the first focus group, all 20 themes emerged. During remaining focus groups, 19 of the 20 themes were represented. The five most salient themes, in order of salience at the focus group level included:

- Trainees are not responsible for managing severe behavior and implementing restraint, and were thus unfamiliar with comprehensive restraint protocols.
- Trainees described or suggested alternative strategies used by themselves or others for treating patients with ASD and severe behavior.
- Trainees discussed negative reactions or perceptions of restraint by themselves, physicians, caregivers, and patients.
- Trainees reported the helpful role of accompanying caregivers during patient appointments in the treatment of patients with ASD and severe behavior.
- Trainees indicated limited practical experience treating patients with ASD and that experiences may vary by hospital department.

Table 2 Frequency and percentage of themes by participant status

Theme	Description	Medical trainees		Physicians	
		#	%	#	%
1	Deferred responsibility/limited restraint protocol	60	12.40	19	10.22
2	Alternative strategies severe behavior	48	9.92	17	9.14
3	Negative perception restraint	40	8.26	22	11.83
4	Caregivers helpful	36	7.44	16	8.60
5	Limited ASD experience	29	5.99	4	2.15
6	Internal causes severe behavior	28	5.79	6	3.23
7	Lack of ASD training	28	5.79	9	4.84
8	Observable predictors restraint	27	5.58	23	12.37
9	External predictors restraint	25	5.17	6	3.23
10	Limitations/improvements service delivery	23	4.75	10	5.38
11	Negative description severe behavior	19	3.93	5	2.69
12	Lack crisis training/knowledge	17	3.51	8	4.30
13	Higher tolerance ASD	14	2.89	4	2.15
14	Restraint algorithms	14	2.89	7	3.76
15	Documentation limitations	13	2.69	13	6.99
16	External causes severe behavior	13	2.69	4	2.15
17	Different severe behavior types	13	2.69	2	1.08
18	Proactive medication use	13	2.69	2	1.08
19	Negative perception ASD	12	2.48	3	1.61
20	ASD knowledge	12	2.48	6	3.23

Themes with equal frequency were ranked in order of highest percentages of each focus group # number of occurrences; % percent of total occurrences

Theme 1: Restraint Implementation and Protocols

Medical trainees reported that other hospital professionals were responsible for implementing restraint, so they were not consistently able to report restraint protocols. Sub-themes included: (a) consulting others (i.e., nurses, rapid response teams, security, psychiatry, child life specialists, behavioral medicine) to help manage severe behavior; (b) removing themselves from the situation, (c) observing protocols implemented by others (e.g., physicians ordering restraint); and (d) noting that protocol knowledge and responsibility may vary by status (e.g., resident vs. medical student) and department (e.g., increased responsibility of psychiatry in restraint protocols). For example, one participant noted, "... we have a procedure called ... behavior rapid response team ... for when a patient's behavior is escalated ... and I'm not sure how often it's used with patients with autism." Another described management of severe behavior as, "having the security staff nearby and nurses nearby and technicians who are very brave people and can be there ready to assist" and a third indicated, "the nurses ... are usually the ones to suggest [restraint] and then I believe that the physicians have to put in the order for it."

Theme 2: Alternative Strategies to Treat Patients with ASD and Severe Behavior

When asked to describe their response to patients with ASD engaging in severe behavior, medical trainees reported alternative strategies to restraint that they have used personally or have observed used by others, and also proposed strategies they would use. Subthemes included: (a) adapting the physical environment (e.g., moving patient to a different physical location, reducing noise and distraction, reducing number of professionals present during appointment); (b) changing their medical approach (e.g., calmer/quieter tone, altering or forgoing medical assessments, conducting a more comprehensive physical examination to avoid undetected medical issues, attempting to involve the patient, providing simple explanations and repetition); (c) using alternative equipment, if available (e.g., helmet, pillow); (d) providing access to attention or tangible items (e.g., active play, access to stethoscope) and reduced demands (e.g., allowing the patient to engage in special interests and/or repetitive behaviors that may otherwise interfere with medical examinations, breaks); and (e) encouraging appropriate behavior and discussing reinforcers with the patient. One participant commented, "I also try to be really careful to keep things like as low stimulation as possible, so bringing my voice down, not being any louder than necessary." Others stated, "I think [it] was handled very well by the resident, because they did all the things that [the parent] said, made sure that the patient got a room away from a lot of the noise", and "... when the physician would talk to the patient, they'd kind of talk about what are things that the child with autism would want to do after the appointment." Another shared, "I had a little girl and she was on the autism spectrum and she was really fixated on my stethoscope, so while I was examining her, I just let her just play with my stethoscope and it just made things a lot more [*sic*] easier."

Theme 3: Negative Reactions and Perceptions of Restraint Implementation

Medical trainees shared negative reactions/assessments of their own and of physicians, caregivers, and patients. Sub-themes included: (a) observing patient expressions of pain or resistance to restraint, (b) observing patient disinterest in further medical care post-restraint, (c) observing caregivers having sad or ambivalent reactions to restraint, (d) avoiding reporting restraint use to caregivers, (e) having the desire to remove restraint, (f) perceiving restraint as restricting patient's rights or treating a patient as nonhuman, (g) perceiving the use of restraint as a last resort, and (h) reporting observations of restraint implementation as uncomfortable. One trainee reported, "I think her grandmother was with us and her reaction was both like she was very sad, but at the same time she knew it was the right thing." Others stated, "So now we had to move him and treat him like an animal"; "I just remember, like the scared intern watching patients get put down and it was like, horrifying"; and "the last thing we want to do is put someone down into four-point restraint against their will."

Theme 4: Helpful Role of Caregivers During Appointments for Patients with ASD

Focus group participants indicated that accompanying caregivers were often helpful in managing severe behavior. Sub-themes included caregivers: (a) providing a model of how to best interact with the patient for the medical trainee to follow, (b) assisting with communication and triggers to severe behavior, (c) implementing restraint rather than other hospital professionals, (d) distracting patients, and (e) providing a sense of comfort. One participant stated, "... when I'm dealing with pediatric patients in particular, I tend to follow suit with the parent or the caregiver, because they know more about that child than I do ... they understand their communication a little bit better, and so I try to mimic or shadow what mom is doing, or dad is doing to kind of leverage the child to participate in the exam or interview." Another shared, "Instead of using the papoose, we let the mom hold, which we kind of typically don't do, just because it's like a lot easier to just papoose them, you can place the sutures or remove them. But instead, you know, having the mom kind of be the restraint there so that we could remove the staples."

Theme 5: Limited Practical ASD Experience and Experience Varying by Department

Medical trainees indicated that experience may vary by hospital department, and thus, departments that serve more individuals with ASD (e.g., neurology and pediatrics) are perceived to have more successful patient interactions and treatment of patients with ASD. They also noted that treatment of unrelated concerns in patients with ASD does not build self-perceived competency specific to treating patients with ASD. Participant comments included, "I've probably only taken care of a handful of patients in ED with autism" and "[In] other departments ... neurology, or wherever there may be other comorbidities where you see autism ... interactions were handled better."

The remaining 15 themes are grouped by categories for ease of discussion.

Category A: Training, Knowledge, and Treatment Specific to ASD (Themes 7, 19, 20)

Focus group participants indicated that medical school training included only a few lectures and/or didactics about the core features of ASD; they identified formal training in ASD as a gap in their curriculum. They reported that most of their knowledge about ASD was gained through direct patient experiences, from their mentors, or pursuing knowledge themselves, such as from the American Psychological Association (Theme 7). One participant noted, "I wish that there was more formal training, but there's not, at least not, there wasn't for me," while another explained "[treating patients with ASD is] something I've been taught to do by my faculty, but again nothing formal." A third commented, "I've really never received any training or formal education on the treatment of autism in terms of like the disease progression. And I think that that's like a huge miss now that we're talking about it, and honestly, I hadn't reflected about it."

Although participants had limited experience with patients with ASD and severe behavior, they exhibited knowledge of the core features of ASD (Theme 20). Their comments indicated an awareness of: (a) sensory sensitivities, (b) communication differences, (c) fixations/restricted interests, and (d) differences in severity of ASD. Responses also revealed negative perceptions about treating patients with ASD among some medical professionals, such as viewing patients with ASD as more challenging or difficult to treat (Theme 19). For example, "I don't know if it's my own bias that I'm like, 'Oh, this person or child has autism, I must treat them differently.' And so I feel like that unconscious or subconscious bias comes in a little bit."

Category B: Severe Behavior in Patients with ASD (Themes 6, 11, 13, 16, 17)

Participants reported higher tolerance for severe behavior in patients with ASD, noting that their response for patients with an ASD diagnosis who are engaging in severe behavior may be different compared to their response to others without an ASD diagnosis (Theme 13). They suggested that patients with ASD may exhibit severe behavior due to internal causes (Theme 6) such as: an inability to communicate, loss of control, pain, a coping mechanism and/or self-regulation, anger or feeling misunderstood, sensory stimulation/overload, and a low frustration tolerance, but also commented that severe behavior might be caused by external factors (Theme 16) such as the hospital environment being loud, scary, and/or intimidating; severe behavior having been reinforced previously; and an inappropriate or failed intervention.

Participants shared negative perceptions and/or evaluations of severe behavior in medical settings (Theme 11), and their comments indicated that they differentiate between different types of severe behavior (Theme 17). Behaviors likely to be considered severe are those perceived as violent, aggressive, threatening, harmful to oneself or others. For example, "Anytime I think of severe behavior, I would say it's anything that poses an immediate threat to the individual themselves or to anybody around them." Meanwhile repetitive behaviors, especially some self-injurious behaviors where a single instance is unlikely to cause immediate harm (e.g., skin picking) and disproportionate reactions were considered "challenging" rather than severe. One participant distinguished crisis behavior from severe behavior as follows, "I think the word crisis has a time element to it versus severe behavior could just be sort of like a descriptive term, or like a noun with an adjective sort of added to it, that doesn't have to be as time sensitive."

Category C: Restraint of Hospital Patients (Themes 8, 9, 14, 18)

Participants described specific strategies for deciding whether restraint was warranted (Theme 14). They also described different responses to severe behavior, depending on its type. In particular, reported restraint was implemented faster for self-injurious behavior than for aggression, and faster for physical aggression than for verbal aggression. Another factor influencing decision-making included whether hospital staff safety or patient safety was at risk. Participants reported using a step-wise progression, such as first verbal de-escalation, then chemical restraint, followed by physical restraint. A participant explained, "But if it was just like aggressive, like verbal behavior ... then I would certainly like not necessarily jump to physical or chemical restraint if I could try to deescalate the situation in other ways. But if I were in, you know, harm's way, then I would move towards more physical restraint or ... chemical restraint."

Medical trainees also noted that, in their experience, observable patient characteristics (Theme 8) such as age, race, gender and size, behavioral factors such as suicidality, homicidality or non-compliance or threatening behavior, and non-observable factors (Theme 9) such as criminal status, diagnosis, communication ability/language barrier, cognitive ability may all influence decision-making about restraint implementation. They also indicated that geographic location, time of day, and accessibility of alternatives in a given department can influence restraint decisions. One trainee noted, "... if it was a patient coming off the street and especially like being in [city], there are so many different stereotypes about like drug seeking behaviors and things like that, that kind of jump to other conclusions." Related to age, another participant stated, "But certainly, I'd be more inclined to restrain someone older because I would think that they're—it could escalate to a point that's more dangerous than a—like child." Focus group participants indicated that age is associated with perceived threat such that older participants who engage in severe behavior may be perceived as more threatening than their younger counterparts. Participants reported that age is often compounded by additional factors (e.g., size, height, weight) which may increase the physician's perception of threat, and thus, lead to a higher incidence of restraint for older patients with ASD. They also noted differences in available resources for managing severe behavior across the lifespan. For example, a child may be accompanied by a caregiver who may offer additional sources of assistance such as managing severe behavior themselves or providing a high-preferred tangible item (e.g., iPad, toy) to compete with a potentially aversive situation. Medical trainees also reported specialized teams that are available for enhanced care of younger patients (e.g., Child Life Specialists), whereas those resources or additional sources of support may not exist for adult patients with ASD.

Finally, participants reported medication was sometimes used as a proactive strategy for treating patients with ASD (Theme 18), including prescribing medication for medical procedures, and administering medication during the appointment to limit behaviors perceived to interfere with the medical care. For example, "I think because of his known behavior, and, you know, not wanting to risk, you know, him biting or getting worked up, and for his comfort, we opted to do like a full sedation for the procedure."

Category D: Limitations to Treatment of Patients with ASD and Severe Behavior (Themes 10, 12,...

Noting that institutional policies impact the treatment of patients with ASD who engage in severe behavior, participants identified a need for unified protocols to manage severe behavior in hospitals. They also indicated that lack of training in working with patients with ASD who may exhibit severe behavior and limitations in existing documentation systems negatively impact treatment of these patients (Theme 10). Medical trainees shared ideas for training, such as, "...a formal training on what even is severe behavior, how is that defined?"; "a simulated patient situation with patients with autism"; "having like a protocol ... whether it's something that can be included within [electronic medical record system], or if it's posted up, just because I think we like algorithms to follow"; and "training ... [to be] able to communicate effectively, both with patients and families when trying to provide medical care."

Participants also reported that inconsistent documentation of severe behavior and current diagnoses in the electronic health record system inhibit physicians' ability to effectively treat individuals with ASD (Theme 15). In particular, they cited inconsistent use of pop-ups and/or flags to alert them that the patient may exhibit severe behavior, electronic records lacking comprehensive patient information, limited documentation accessibility across external healthcare systems, and current diagnoses not accurately reflected in the presenting concerns section of the patient electronic health record. For example, one participant stated, "It's not like a specific red flag that says like the patient has been agitated before, it's more of just like something that you might figure out through digging, at least in my experience," and another explained, "Even for like a restraint note itself, you would have to pretty much just kind of flip through all the different notes to see if there happens to be one for a behavioral rapid response or something like that."

Finally, participants expressed a lack of foundational knowledge, training, and experience regarding crisis (Theme 12). They added that crisis knowledge and training vary by department and/or specialty. Comments included, "I got absolutely [no crisis training] in medical school, even though I think that really would have been important. And then even in residency training, I feel like it's limited."

Interviews with Physicians

During each of the three physician interviews, all 20 themes identified during medical trainee focus groups were discussed. Four of the five most salient themes from the medical trainee participants (i.e., restraint implementation and protocols, alternative strategies, negative perceptions of restraint, role of caregivers) were also in the five most salient themes for the physician participants. The eighth most salient theme for medical trainees "observable patient characteristics are predictor of restraint" was the most salient theme in the physician interviews. The fifth most salient theme for medical trainees "limited ASD experience" moved down to sixth in salience in the physician interviews. The mean rank order correlation between each interview and the overall interview ranking was 0.69 (range 0.55 to 0.85) and the mean rank order correlation between focus groups and interviews was 0.66. See Table 2 for frequency and percentage of themes by participant status.

Autism Stigma and Knowledge Questionnaire

Medical trainees demonstrated a mean score of 15.2 out of 18 (*SD* = 1.4) in the diagnosis/symptoms subscale, 12.4 out of 16 (*SD* = 2.2; range 12 to 18) in the etiology subscale, 12.3 out of 14 (*SD* = 1.4; range 7 to 15) in the treatment subscale, 0.9 out of 7 (*SD* = 1.0; range 0 to 3) in the stigma subscale, and 39.9 out of 48 (*SD* = 3.8; range 30 to 45) in the total score. All trainees demonstrated adequate scores in the diagnosis/symptoms subscale, 80.9% in the etiology subscale, 90.4% in the treatment subscale, 90.4% in the stigma subscale, and 95.5% in the total score.

Physicians obtained a mean score of 15 out of 18 (*SD* = 2; range 13 to 17) in the diagnosis/symptoms subscale, 14.7 out of 16 (*SD* = 0.6; range 14 to 15) in the etiology subscale, 13.3 out of 14 (*SD* = 1.2; range 12 to 14) in the treatment subscale, 0.3 out of 7 (*SD* = 0.6; range 0 to 1) in the stigma subscale, and 43 out of 48 (*SD* = 1; range 42 to 44) in the total score. Physicians demonstrated 100% adequate total and subscale scores. See Fig. 1 for individual scores and means across the medical trainee focus groups and physician interviews.

Graph: Fig. 1 ASK-Q results. FG focus group, Solid line: maximum score, Dashed line: adequate score

Discussion

Aims of this exploratory research were to (a) gather qualitative information about how physicians manage severe behavior in patients with ASD and (b) identify variables that may affect physician decision-making in restraint implementation. Existing restraint research has largely focused on general patient populations (e.g., Grimes, [24]; Larue et al., [37]) or examined restraint use within a single department (e.g., psychiatry or emergency; Delaney & Fogg, [16]; Wong et al., [65], [64]). A few studies have considered neurodiverse populations or specifically individuals with ASD, but those investigations were limited to pediatric populations (Friedman & Crabb, [19]; Johnson & Rodriquez, [32]; O'Donoghue et al., [51]). The current study focused on hospital treatment of patients with ASD and severe behavior across the lifespan, including input from medical trainees and physicians in multiple hospital departments. Although all study participants were affiliated with the same facility, the wide array of patients served in the targeted departments of this urban level 1 trauma teaching hospital resemble patients seen in other hospital systems across the nation. The majority of participants identified as White, which is similar to national physician demographics; however, there was a higher representation of women and racial/ethnic minorities in our sample compared to national estimates provided by the Association of American Medical Colleges ([3]).

This study did not find differences between medical trainees' and physicians' experiences with and perspectives about severe behavior in patients with ASD. Both groups articulated strong need for enhanced education about treating patients with ASD and more training in severe behavior management, both during medical school and early career practice. Both groups also identified a need for institutional policies that can help improve service delivery for patients with ASD. Importantly, even though the behavioral literature has widely examined behavioral interventions for increasing compliance with medical procedures (e.g., Kupzyk & Allen, [36]; Riley & Freeman, [53]), neither the medical trainees nor the physicians in this study demonstrated a strong understanding of behavioral function, as evidenced by attributing severe behavior to internal factors such as "maintaining inner peace."

Interestingly, participants reported that they generally consulted other hospital professionals to manage severe behavior, assist in a crisis situation, and/or implement restraint. As a result, they were unfamiliar with comprehensive restraint protocols. This finding is consistent with a recent literature review indicating that the rapid response teams commonly used to assist with acute medical crises have more recently been adapted to help manage psychiatric crises (Choi et al., [11]). Behavioral rapid response teams (BRRTs) are led by a nurse and security guard at minimum, and often do not include physicians. Once a response team is alerted, medical trainees and physicians are expected to attend to other patients; one medical trainee participant reported receiving guidance from an attending physician to continue treating other patients while the severe behavior was managed by the BRRT.

Although studies demonstrate that BRRTs help improve medical outcomes for the general patient population (e.g., cardiac arrest; Bellomo et al., [4]) and behavioral outcomes for patients with psychiatric crisis (e.g., reduced restraint use; Choi et al., [11]), there is little research about the use of BRRTs to manage patients with ASD and severe behavior. Given the demands placed on physicians and the wide range of clients they treat, relying on BRRTs may be an effective means to assist with managing severe behavior in patients with ASD. However, this does not alleviate the need for hospitals and/or medical schools to provide better training on managing severe behavior in patients with ASD. Teams called in to manage these patients' severe behavior must possess practical skills for assessing behavioral function and safely treating neurodiverse patients. Future research should investigate the competencies and ASD-specific training provided to BRRT members.

Meanwhile, study participants uniformly indicated that they wished they had more formal medical training specific to *treating* patients with ASD. The results of the ASK-Q indicated appropriate overall knowledge of ASD among the participants; however, being able to identify or describe ASD's core features does not translate into practical knowledge about addressing these features in a hospital setting. Moreover, several medical trainees' ASK-Q sub-scale scores indicated stigma associated with ASD, suggesting a need for specialized training that can not only help to improve the standard of hospital care for patients with ASD across the lifespan but also decrease potential stigma associated with treating this population. A recent study found that patients and caregivers are likely to report a positive medical experience when physicians have ASD-specific knowledge, provide detailed explanations of the exam or procedure, and use positive reinforcement (Wilson & Peterson, [63]). Given the increasing prevalence of ASD nationwide (Christensen et al., [12]) and the many challenging features of hospital environments for patients with ASD, training specific to treating patients with ASD and severe behavior is likely to become even more important in future years.

One participant suggested including simulated patients with ASD in medical school training. Simulated patients, trained actors who portray a predetermined set of symptoms or a specific diagnosis (Kaplonyi et al., [34]; Williams & Song, [62]), are effective in allowing medical trainees to practice and refine technical, non-technical clinical (e.g., communication), and cognitive skills (Kaplonyi et al., [34]; Williams & Song, [62]). A standardized simulated patient that accurately portrays the core features of ASD may increase both physician competency and comfort in treating this unique patient population. Strategic exposure to different features of ASD that may manifest during hospital visits has the potential to prepare physicians to quickly adapt their approach to support patients exhibiting severe behavior.

Interestingly, although restraint is typically implemented by teams that do not include physicians, participants reported that the attending physician is responsible for documenting the justification for restraint, restraint type, and follow-up assessment. They also noted that nurses often need to remind physicians to complete assessment procedures and subsequent documentation. Moreover, participants explained that restraint documentation may not include data that would be helpful to others who treat the patient later such as restraint duration; patient's, caregivers', and surrounding patients' responses to restraint; and if/when/how a post-restraint explanation was provided. In fact, participants identified some limitations to their hospital's electronic health records system which make it difficult for physicians to find relevant information about patients with ASD who have a history of severe behavior. They reported that the flagging system designed to alert the physician to a particular presenting concern or diagnosis and the 'problem list' section are not used consistently. Participants noted that flagging a patient's record currently requires special paperwork and processing through institutional departments, which seems unnecessarily time consuming, and they pointed out that unified smartphrases (i.e., note templates) could facilitate efficient, consistent documentation of behavioral information in problem lists.

They further noted that if the documentation process were standardized, physicians could more easily focus on relevant pieces of documentation within a patient's electronic file. In addition to the potential of ACPs to improve the quality of healthcare services for patients with ASD and their families (Broder-Fingert et al., [8]), these plans could facilitate streamlined electronic health record documentation systems. For example, ACPs could be expanded to include detailed behavioral information about a patient and integrated with alerts to physicians to review the plan prior to treating a patient.

Whereas others have reported using chemical restraint to reactively manage severe behavior in adults (Friedman & Crabb, [19]), participants in this study indicated that chemical restraint was most often applied to proactively manage characteristics of ASD or to facilitate completion of medical procedures. This finding is consistent with proactive use of chemical restraint to facilitate safe medical procedures in pediatric patients (Kirwan & Coyne, [35]). Differences in the literature could be due to differing interpretations of the term "chemical restraint"; study participants may characterize reactive medication administration as "medicating emergent behaviors."

Although this study produced several important findings, there are several limitations to note. Given that the primary aim of this research was to gather physician experiences treating patients with ASD and severe behavior, obtaining knowledge of ASD was a secondary goal and we did not want to cause physicians to question their expertise prior to participating. However, completion of the ASK-Q questionnaire immediately following focus group participation may have resulted in an increase in knowledge of ASD and decreased stigma from discussing these topics with their colleagues. Further, given participant-reported concerns with documentation of diagnosis and accessing of information in electronic health records, it is possible that physicians may be unaware of an ASD diagnosis in some patients treated for unrelated medical needs, thus influencing their comprehensive reporting of all patients treated with ASD. In addition, restraint can be a controversial, uncomfortable topic for physicians, which may have impacted focus group and/or interview responses. Participants may have hesitated to elaborate on open-ended questions due to a desire to present as competent and using evidence-based clinical practice (e.g., not endorsing overuse of restraint). To reduce potential discomfort, participants were encouraged to report not only their experiences but also observed experiences of others, so they did not need to take ownership of treatment decisions that might be negatively perceived. To facilitate open discussion among medical trainees including identifying potential improvements in their work environments, focus groups were limited to trainees. With all qualitative research, there is the potential that facilitators misjudged session saturation which may have led to premature conclusion of data collection and, thus, inadequate sample sizes (Braun & Clarke, [7]). Instead, researchers have moved past theoretical saturation to consider pragmatic saturation (rather than being an absolute end point; Low, [40]) and emphasized the concept of information power (i.e., the greater the relevant information in the sample, the fewer participants needed; Malterud et al., [42]), which both suggest that qualitative researchers use interpretative judgement related to the study aims to determine when the number of participants is sufficient. The total sample size in the current study is adequate relative to the purposes of this study, as supported by the literature (Malterud et al., [42]; Marshall et al., [44]; Sim et al., [56]). However, subgroup composition may be a limitation of this study given that a majority of participants were medical trainees, specifically medical students. Recruiting early-career physicians proved to be difficult, possibly due to additional stressors placed on them during the COVID-19 pandemic, which may have decreased their availability and/or willingness to participate in research outside of scheduled patient hours.

However, the three early-career physicians who did participate in this study echoed the same themes as medical trainees. Moreover, medical trainees are known to be a valuable population to target when aiming to improve quality of medical research and practice (Gould et al., [23]) and they are generally considered to be representative of the larger medical population. Future investigations should also include physicians with more experience as more clinical exposure might increase practical knowledge and skills related to the treatment of severe behavior in patients with ASD.

This exploratory study represents a valuable first step towards improving healthcare for patients with ASD. Results from focus groups and interviews discussing physicians' experiences treating patients with ASD and severe behavior at an urban teaching hospital in the northeastern United States indicate a need for more hospital staff training in how to manage severe behavior in patients with ASD. Future research should explore how to most efficiently and effectively train hospital staff in managing severe behavior in patients with ASD. This work also highlights the need for research focused on establishing consistent hospital protocols for supporting patients with ASD and severe behavior, which should

include developing best practices for documentation such as consistent use of flags and a specific vocabulary to be used in problem lists and progress notes. Finally, future research in this area should drive adaptations to electronic health records which facilitate consistent use of flags and standardized language to describe behaviors and behavior management for hospital patients with ASD.

Author contributions

All authors contributed to the study conceptualization and design. Material preparation, data collection and analysis were performed by Giovanna Salvatore. Funding acquisition was completed by Giovanna Salvatore and Christina Simmons. The first draft of the manuscript was written by Giovanna Salvatore and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Appendix 1

Focus group question guide.

Topic 1: Autism

1. Describe your experience treating individuals with autism

i. Prompt: Across the lifespan

2. What training or education have you received specific to autism?

3. How would you approach treating a patient with autism vs. a patient without autism?

Topic 2: Severe Behavior

4. What do you consider to be severe behavior?

5. Describe your experience(s) with patients with autism who engage in severe behavior in a hospital setting

i. Prompt: Across the lifespan

6. Describe how you would manage severe behavior in patients with autism vs. those without autism

7. Why do you think that patients with autism engage in severe behavior?

8. What do you consider a crisis situation?

9. If you had a patient in your department with autism who aggressed toward you, what would you do?

10. If you had a patient in your department with autism who was engaging in severe head banging against a hard surface, what would you do?

Topic 3: Restraint Implementation

11. Describe specific instances in which restraint was used in your department

i. Prompt: Behavior description, restraint implementer, restraint type

12. Describe crisis and restraint training you have received throughout the course of your professional career

13. Describe any variables that impact restraint use

Topic 4: Post-restraint

14. Describe how your patients and/or families have reacted to restraint use
15. Describe the protocols you have to follow after restraint use
16. Do you know ahead of time if your patient has a history of severe behavior?
17. What do you think would help you to better treat patients with autism who engage in severe behavior?

Closing

18. Is there anything else you would like to share about restraint or severe behavior in patients with autism?

Publisher's Note

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By Giovanna L. Salvatore; Christina A. Simmons and Patrice D. Tremoulet

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Record: 19

Title: PCR155 Circumstances of Hospital Care of Autistic Children in Hungary from Parental Perspectives

Authors: Peter, M
Szunomár, S
Turcsán, J
Wirthné-Gyergyák, K
Far, G
Kovács, A
Stromájer-Rácz, T
Pakai, A
Boncz, I
Takács, K

Affiliation: 1 University of Pécs, Budapest, PE, Hungary
2 University of Pécs, Pécs, Hungary
3 University of Pécs, Kaposvár, Hungary
4 University of Pécs, Pécs, ZA, Hungary

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Title: Parental Stress among Family Caregivers of Children with Autism in a Teaching Hospital.

Authors: Hamidon, Nur Ashida
Mohd Anuar, Nur Ily Shazwany
Ahmad Sharoni, Siti Khuzaimah
Mohd Isa, Nur Azah

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Title: Simulation-Based Education for Staff Managing Aggression and Externalizing Behaviors in Children With Autism Spectrum Disorder in the Hospital Setting: Pilot and Feasibility Study Protocol for a Cluster Randomized Controlled Trial

Authors: Mitchell, Marijke Jane
Newall, Fiona Helen

Sokol, Jennifer
Williams, Katrina Jane

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Description: BackgroundChildren with autism spectrum disorder (ASD) frequently demonstrate aggression and externalizing behaviors in the acute care hospital environment. Pediatric acute care nursing staff are often not trained in managing aggression and, in particular, lack confidence in preventing and managing externalizing behaviors in children with ASD. High-fidelity simulation exercises will be used in this study to provide deliberate practice for acute care pediatric nursing staff in the management of aggressive and externalizing behaviors. ObjectiveThe purpose of this study is to conduct a pilot and feasibility cluster randomized controlled trial (RCT) to evaluate the effectiveness of simulation-based education for staff in managing aggression and externalizing behaviors of children with ASD in the hospital setting. MethodsThis study has a mixed design, with between-group and within-participant comparisons to explore the acceptability and feasibility of delivering a large-scale cluster RCT. The trial process, including recruitment, completion rates, contamination, and completion of outcome measures, will be assessed and reported as percentages. This study will assess the acceptability of the simulation-based training format for two scenarios involving an adolescent with autism, with or without intellectual disability, who displays aggressive and externalizing behaviors and the resulting change in confidence in managing clinical aggression. Two pediatric wards of similar size and patient complexity will be selected to participate in the study; they will be randomized to receive either simulation-based education plus web-based educational materials or the web-based educational materials only. Change in confidence will be assessed using pre- and posttraining surveys for bedside nursing staff exposed to the training and the control group who will receive the web-based training materials. Knowledge retention 3 months posttraining, as well as continued confidence and exposure to clinical aggression, will be assessed via surveys. Changes in confidence and competence will be compared statistically with the chi-square test using before-and-after data to compare the proportion of those who have high confidence between the two arms at baseline and at follow-up. The simulation-based education will be recorded with trained assessors reviewing participants' abilities to de-escalate aggressive behaviors using a validated tool. This data will be analyzed using mean values and SDs to understand the variation in performance of individuals who undertake the training. Data from each participating ward will be collected during each shift for the duration of the study to assess the number of aggressive incidents and successful de-escalation for patients with

ASD. Total change in Code Grey activations will also be assessed, with both datasets analyzed using descriptive statistics. ResultsThis study gained ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC) on November 1, 2019 (HREC reference number: 56684). Data collection was completed in February 2020. Data analysis is due to commence with results anticipated by August 2020. ConclusionsWe hypothesize that this study is feasible to be conducted as a cluster RCT and that simulation-based training will be acceptable for acute care pediatric nurses. We anticipate that the intervention ward will have increased confidence in managing clinical aggression in children with ASD immediately and up to 3 months posttraining. Trial RegistrationAustralian New Zealand Clinical Trials Registry (ANZCTR) ACTRN12620000139976; http://www.ANZCTR.org.au/ACTRN12620000139976.aspx International Registered Report Identifier (IRRID)DERR1-10.2196/18105

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Title: To flag or not to flag: Identification of children and young people with learning disabilities in English hospitals.

Authors: Kenten, Charlotte (AUTHOR)
Wray, Jo (AUTHOR)
Gibson, Faith (AUTHOR)
Russell, Jessica (AUTHOR)
Tuffrey-Wijne, Irene (AUTHOR)
Oulton, Kate (AUTHOR)

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Geographic Terms: England

Abstract: Background: Children and young people with learning disabilities experience poor health outcomes and lengthier hospital admissions than those without learning disabilities. No consistently applied, systematic approach exists across the NHS to identify and record this population. This paper describes practices in English hospitals to identify children and young people with learning disabilities. Method: Interviews: 65 NHS staff. Questionnaire: 2,261 NHS staff. Conducted across 24 NHS hospitals in England. Results: No standardized approach exists to identify children or young people with a learning disability or for this information to be consistently recorded, communicated to relevant parties within a hospital, Trust or across NHS services. Staff reported a reliance on parents to inform them about their child's needs but concerns about "flagging" patients might be a significant barrier. Discussion: Without an integrated systematic way across the NHS to identify children with learning disabilities, their individual needs will not be identified. [ABSTRACT FROM AUTHOR]

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To flag or not to flag: Identification of children and young people with learning disabilities in English hospitals

Background: Children and young people with learning disabilities experience poor health outcomes and lengthier hospital admissions than those without learning disabilities. No consistently applied, systematic approach exists across the NHS to identify and record this population. This paper describes practices in English hospitals to identify children and young people with learning disabilities. Method: Interviews: 65 NHS staff. Questionnaire: 2,261 NHS staff. Conducted across 24 NHS hospitals in England. Results: No standardized approach exists to identify children or young people with a learning disability or for this information to be consistently recorded, communicated to relevant parties within a hospital, Trust or across NHS services. Staff reported a reliance on parents to inform them about their child's needs but concerns about "flagging" patients might be a significant barrier. Discussion: Without an integrated systematic way across the NHS to identify children with learning disabilities, their individual needs will not be identified.

Keywords: children; hospitals; identification; learning disabilities; UK

INTRODUCTION

Following on from the "Six Lives" report (Parliamentary & Health Service Ombudsman & Local Government Ombudsman, [8]), the current policy drive around the care of patients with learning disabilities (LD) (known internationally as intellectual disabilities) reinforces the view that to be in a position to meet needs and to prevent premature death, needs must first be identified. The UK's Confidential Inquiry into Premature Death of People with Learning Disabilities (CIPOLD), for example, recommends the "clear identification of people with LD on the National Health Service central registration system and in all health-care record systems" (Heslop et al., [2]: 894). Identification, the process of "flagging," to mark for attention or treatment in a specified way, has since been incorporated into the Care Quality Commission (CQC) best practice guidelines for children and young people with LD in hospital and in the recent LD improvement standards for NHS Trusts. Here, it states that "Trusts must have mechanisms to identify and flag patients with learning disabilities, autism or both from the point of admission through to discharge; and where appropriate, share this information as people move through departments and between services" (NHS Improvement, [5]: 6). There is limited guidance or evidence available as to what mechanisms of identification might be most effective or how they should be used in practice, but suggestions have included using "electronic flags in patient administration systems" (NHS mprovement, [5]: 6) and ensuring that flags are "clearly visible on the patient's records" (Glasper, [1]: 65). Fundamental to the process is that the flag is accompanied by "a statement of the reasonable adjustments required" (CIPOLD) such that care can be adapted (Sheehan et al., [11]) and monitored for adherence with equality legislation (Tuffrey-Wijne et al., [12]).

There is little evidence to support what actually happens in practice. The identification of LD may not rest solely on a diagnosis as this does not necessarily indicate a need and the diagnostic category is not homogeneous. For some children and young people, a formal diagnosis of LD may never be made despite a continuing acknowledgement of their global development delay as they progress towards adulthood. Furthermore, where LD are known to exist, a better healthcare offer may arise, but there is limited evidence of that automatically leading to care that responds to or takes into account individuals' needs. Evidence suggests that staff rely on parents to supervise, protect, advocate and look after their child's medical needs and behaviours whilst in hospital (Mimmo, Harrison, & Hinchcliff, [4]).

There is clearly an important difference between identifying that a child or young person has LD and recording what reasonable adjustments are required, and ensuring those reasonable adjustments are consistently delivered during their hospital admission in a timely way (Turner & Robinson, [14]). One study of adults with LD has found a lack of staff knowledge, expertise, willingness to identify and flag LD, and a reluctance to routinely record and "label" people exists across junior and senior staff (Tuffrey-Wijne et al., [12]; Tuffrey-Wijne & Hollins, [13]), and this reluctance can also be seen in other sectors such as education (Ho, [3]). Evidence is also lacking around staff education or training needs and their confidence and capability to meet the needs of this particular population.

"Pay More Attention" is a NIHR funded mixed methods study aiming to identify the factors that facilitate and prevent children and young people with long-term conditions with and without LD from receiving equal access to high-quality hospital care and services. This paper reports on the practices of a sample of English hospitals who employ (or not) a

process to identify this population with LD. The wider context and overall findings are reported in Oulton et al. ([6]).

METHOD

Health Research Authority approval was given for Phase 1 of the study (IRAS: 193932), the results of which are reported in this paper. Full ethical approval for this study was obtained from London-Stanmore Research Ethics Committee (16/LO/0645). Staff who took part in interviews were provided with a participant information sheet and consent form and provided verbal consent prior to taking part in the interview. Survey participants were informed that their completion and return of the anonymized survey would be taken as their consent to participate.

Semi-structured interviews were conducted with at least two senior managers per hospital with responsibility for the organization or management of care for patients with learning disability. These were conducted by CK or JR. Questions addressed the identification of children with LD and for all children: (a) equality of access to appointments, investigations and treatments; (b) the involvement of families as active partners; (c) satisfaction with care; and (d) safety concerns. Specifically, the interview explored what policies, procedures and systems were in place for identifying and/or flagging children within their Trust. The interview was piloted with two senior NHS managers.

An online questionnaire (with paper copies available) was developed for all clinical and non-clinical staff with contact with this patient group to elicit perceptions of their ability to identify the needs of those with and without LD and their families and provide high-quality care to effectively meet these needs. This was piloted with seven NHS staff at non-participating sites with revisions made to improve clarity. Five questions related to the identification of children and young people with LD.

Setting

Twenty-four NHS hospitals in England including specialist children's hospitals (n = 15) participated. The nine non-specialist hospitals all had at least one paediatric inpatient ward as well as paediatric outpatient clinics and services. A local collaborator managed the study at each site.

Data management and analysis

Qualitative

Audio-recorded interviews were transcribed verbatim, anonymized and uploaded to NVivo 11 to utilize the framework option. Framework analysis, developed by Ritchie and Spencer ([10]), was used to analyse the data. It is well recognized as an appropriate approach for applied research and focuses on describing and interpreting experiences in specific settings. It offers a systematic approach, which fitted the research and data collected (Ritchie & Spencer, [10]). The five stages of framework analysis were followed: familiarization with the data; identifying a thematic framework; indexing; charting and mapping; and interpretation (Ritchie & Lewis, [9]; Ritchie & Spencer, [10]). CK and JR charted, mapped and interpreted the data individually using Parkinson, Eatough, Holmes, Stapley, and Midgley ([7]) as an example. The final review was undertaken by KO, JW and FG.

Quantitative

Descriptive statistics were used to characterize the sample. Responses from participants at specialist children's hospitals were compared with those at non-children's hospitals using Mann–Whitney tests in terms of (a) the perceived usefulness of identifying this population at an organizational level; (b) the usefulness of visibly flagging; (c) whether or not their organization provided information to identify these young people; and (d) their own confidence in identifying whether or not a patient in their care had LD.

RESULTS

Participants

The interview participants covered a range of senior staff within the participating hospitals with responsibility for people with learning disabilities. The present authors set out to conduct two interviews per site giving a minimum sample size of 48. This was to ensure all the interview questions were answered. The present authors continued interviewing staff until questions were answered with local collaborators asked to identify and invite additional participants. The final sample size was 65. Interviews lasted 30–45 min (Table).

Participants in Phase 1 staff interviews and survey

Method	Number of hospital sites	Number of participants	Staff groups		
			Dr	N	AHP
Interviews	22	65	10	26	2

LDN	SM	Other
10	1	44

Participants in Phase 1 staff interviews and survey

Method	Number of hospital sites	Number of participants	Staff groups		
			Dr	N	AHP
Survey	24	2,261	377	984	375

HCA	Non-clinical/other
129	396

1 Abbreviations: AHP, allied health professional; Dr, doctor, HCA, healthcare assistant; LDN, learning disability nurse; N, nurse; SM, senior manager.

The quantitative and qualitative findings are presented using headings that provide a very broad linear narrative from identifying children with LD, what is done with that information, staff communicating with CYP with LD through to their own capacities and capabilities. This structure comes from the mapping and interpretation stage of framework analysis where patterns in the data were identified and offer a way to understand the current situation across the participating hospitals.

Identifying children with learning disabilities

Interview data revealed that 10 of the 24 hospitals in our sample had a process in place for identifying children and young people with LD and this was more prevalent in specialist children's hospitals (*n* = 8, 53%) than non-specialist hospitals (*n* = 2, 22%). Staff referred to the use of "flagging" and "alerts," although there appeared to be no clear distinction in the data between these two terms. Furthermore, no common or consistent formal or informal approach appeared to exist to identify this population with various practices being described including via a general practitioner (GP) referral letter or from a school, the use of hospital records; via pre-assessment clinics, another hospital service or department; or via parents during the nursing assessment upon admission or in outpatients. It was evident that if a diagnosis of LD was made in a community setting, this information may or may not be transferred to the hospital. In four sites, staff felt that parents may not support the identification and subsequent labelling of children with LD because it felt simply wrong to "label" or there was a fear of getting it wrong even in Trusts where adults with LD are flagged. Interviewees tended to emphasize children as "individuals" and that all children should be treated "the same." The implication was that if those with LD were flagged, it would mean these children were not being treated the same and this explained the hesitance or resistance to flag:[W]e're a Trust with a specific Children's Hospital we'd like to say, 'Well actually, all children matter and are individuals based on their presentation and it's not this blanket approach, if you like,' it's that you, you know, dare I say it, sometimes get in a DGH [District General Hospital] or a lesser experienced work force who look after children, but we're all children's nurses in the Children's Hospital and Paediatricians so, absolutely the distinct needs are assessed and catered for. I guess regardless of whether they've got learning disabilities or not, you know, you could say a child who has, I don't know, chronic orthopaedic issues around brittle bones is catered for differently than a child who attends regularly with their diabetes, do you know what I mean? It's a very personalised approach we have here, I like to think as well. (Specialist Children's, Consultant)

In some hospitals, parental agreement was sought for their child with LD to be flagged with the benefits of flagging outlined to them.Every family will be asked, 'Do you consider your child or young person to have a learning disability?' If they say 'yes', we'll talk them through what the flag does and the benefits of it and put the flag on. If they say 'no', we'll tell them what the benefits are and see if they want to change their mind [Where it is thought by clinical staff that a child does have a learning disability]. If they still say 'no', we won't force them to have that, but that does mean huge numbers of children who use our service are not flagged at the moment. So there is a flag, but it's not comprehensive in any way. (Specialist Children's, Deputy Chief Nurse)

This example highlights particularly well the challenges associated with identifying and flagging children and young people with LD in hospitals when no guidelines exist on how this should be done, by whom and on what basis.

Survey responses indicated that most staff saw the benefit of having a process in place, with 81% recognizing the *usefulness* of identifying children with LD at an organizational level and 72% recognizing the *usefulness* for such patients to be visibly "flagged" (72%) (Table). There were no differences between the specialist and non-specialist hospitals in relation to such views. Only half of all survey respondents reported being given information about how to define LD, with an additional 14% not knowing whether they had information or not. The distribution of responses from specialist and non-specialist hospitals was similar.

Staff survey questions relating to flagging

Question	**1**	**2**	**3**	**4**	**5**
A. How useful do you think it is that children and young people with learning disabilities are identified at an organizational level (e.g., central database, electronic patient record)? 1,014 (50%)	Extremely useful 617 (31%)	269 (13%)	71 (4%)	39 (2%)	Not at all useful
B. How useful do you think it is that children and young people with learning disabilities are visibly flagged at an organizational level (e.g., sticker on patient notes)? 851 (43%)	Extremely useful 572 (29%)	343 (17%)	130 (7%)	78 (4%)	Not at all useful
C. In my role, I am routinely informed that a child or young person has a learning disability 396 (19%)	Strongly agree 604 (29%)	560 (27%)	313 (15%)	190 (9%)	Strongly disagree
D. In your role, how easy is it for you to use these systems to identify that a child or young person has a learning disability? 291 (18%)	Extremely easy 472 (29%)	482 (29%)	213 (13%)	200 (12%)	Not at all easy

Question	1	2	3	4	5
E. How confident are you about identifying that a child or young person in your care/who you meet has a learning disability? 562 (27%)	Extremely confident 980 (47%)	379 (18%)	107 (5%)	47 (2%)	Not at all confident

The present authors asked survey respondents about the systems in place at their Trust to identify and record that a CYP has a LD. Most frequently reported were medical notes (56%) or nursing notes (42%), followed by electronic documentation (27%). Seven per cent reported that no system was in place and 25% did not know what systems were in place at their Trust. Very few respondents referred to the use of databases (8%) or a sticker on the patient's notes (5%).

What happens when children with LD are identified?

When a child is known to have LD, the admission type, planned or unplanned, may affect what has been or can be put in place. Several sites reported in the interviews that where a child or young person was known to have LD or additional needs prior to admission, then a senior member of ward staff, for example, a ward manager would contact the child's parents and aim to identify and make reasonable adjustments for their admission. In contrast, unplanned admissions were regarded as more challenging for staff as reasonable adjustments could take time to organize despite the best efforts of the staff to accommodate a child's individual needs:So when it's a planned elective case, we can, kind of, do a bit more planning. The difficulties, I think are it's harder when a child comes in acutely. Yes, they get the flag, but sometimes we aren't able to put everything in place that we can to try and support them in the best way. (Specialist Children's, Matron)

Once a young person with LD is identified, what happens with this information at each hospital varied considerably, from it simply being recorded in the child's hospital notes through to wider dissemination and engagement. Some hospitals had very clear formal pathways for sharing this information, for example, at one site, once a LD flag was added to a child's records, an automated email was sent to the LD nurse; at another site, an email alert was sent to the LD team for them to contact staff to review and consider reasonable adjustments or alternatively when a child was admitted with a LD flag already on their hospital notes an alert was sent to the LD team who then contacted relevant ward staff.It's a mandatory field now, when you access somebody which has not been completed before, you have to say yes or no to whether or not they have a learning disability. If you click 'Yes' that then automatically emails our learning disability lead nurse who then puts a flag on the system, so anytime anybody accesses that patient on the system, it will come up with a flag, they can go in and see what their learning disability is. (Specialist Children's, Matron)What we do with our alerts, is we've got something called [name of specific system] and our alert is linked to our email addresses and we all have an iPhone, so whenever that patient comes in, it's a live system, after two minutes of being clerked into the hospital, we'll get an alert on our phone to say the patient's name and where they are. (Non-Specialist, LD nurse for Adults)

These pathways may be triggered through a flag or an alert already on the patient's records, identified during a pre-admission appointment or recorded on their admission paperwork. Accessing specific information about a patient could be difficult; for example, staff may be able to see a child has LD but not all staff can access a child's record to ascertain more detail:If people have got a learning disability and it's identified, they can have a flag put on, similar to those used in child protection flags or infection control flags. Then when you login to the system, you can see the patient's got a learning disability of some description, and then if you've got the right access level [permission level] and you go into that tab, you can see what their learning disability is. (Specialist Children's, Matron)

In contrast to formal routes, informal routes existed alongside or as standalone practices. Transfer of information between staff about children varied from a member of staff "knowing" the patient from a previous admission, verbal handover "huddles" during or when shifts changed, through to recording LD information in nursing and/or medical records.

Nearly half (48%) of all staff strongly agreed or agreed to being routinely informed that a child or young person in their care has LD (Table), with nearly a quarter (24%) of staff disagreeing or strongly disagreeing with that statement. With reference to particular staff groups, ancillary staff reported being routinely informed of patients with LD less than clinical staff (X^2 = 61.77; p < 0.001). Amongst clinical staff, nurses and healthcare assistants, but not doctors, were significantly more likely to report being routinely informed of a child/young person's LD than allied health professionals (Z = 2.74; p < 0.006).

Communicating about children with learning disabilities

It was acknowledged in the interviews that good communication between all parties was facilitative in identifying, understanding and meeting a young person's needs from pre-admission to discharge. Staff felt that parents played a critical role in informing staff and a degree of responsibility lay with parents as repositories of information about their child, to share this information to "guide" healthcare professionals. However, this was not always reported as a seamless transition of information. Staff reported the presence of parental barriers, including linguistic barriers where English may not be a parent's first language; timely access to interpreters; where parents themselves may have LD; and practical barriers whereby parents do not bring the correct information about their child to the hospital or inhibit healthcare professionals from eliciting information directly from their child:Barriers, in specific, if the parents are not willing to give that information or if they themselves have got some problems like, you know, safeguarding children; they might not have identified that their child has got learning difficulties. (Non-specialist, Consultant)[I]f I compare it with families where we know there's going to a barrier because of language, English isn't their first language, then it can be a real challenge to fit them into a ward round because you know you're going to have to use Language Line to communicate. So, I think it might put up artificial barriers. (Specialist Children's, Consultant)

Additionally, based on the assumption that a child had received a LD diagnosis, it was felt that some parents might be in denial about their child's LD, which could limit discussion about their needs and impact on implementing any reasonable adjustments:So while staff may think this child has definitely got a learning disability, the family may not have quite got there yet, so may not want to say, 'Yes, my child has got a learning disability.' Flagging them is a bit of a label, isn't it? So there is a whole range of things which I think is why some staff are anxious about asking the question. (Specialist Children's, Deputy Chief Nurse)

They may fear their child will be stigmatized or that the presence of LD may lead to inequalities in their treatment, together resulting in parental reluctance to share information:I think if their child's got very difficult behaviour or very, very hyperactive or things like that, I think they're a little bit worried about how their child is presenting and whether that will prevent things happening. I'm not necessarily saying it's real, but I think that sometimes it's a fear of the parents. (Specialist Children's, Learning Disability Nurse)

Additionally, issues associated with the degree of severity of a child's LD, with those at the milder end of the spectrum being potentially harder for staff to identify.Unless it's overt or the parents actually formally identify, there may be milder learning difficulties that get missed because they're not specifically stated to the staff during the admission process, or pre-admission. (Specialist Children's, Senior Nurse Manager)

It was noted that parents often had to repeat the same information to staff, and at times they may become frustrated with having to repeat information readily available in their child's hospital notes or hospital passport.So, obviously, it's a real irritation for parents to have to go through the same information all the time, you know, at every contact. So we do have a system whereby, for those with particular issues, and they tend to be more medical issues, they can have an alert put on the system. (Specialist Children's, Consultant)

Staff capacities and capabilities

Overall 74% of respondents felt extremely confident or confident to identify a child or young person in their care or who they met has LD (Table Q. E). Respondents from specialist children's hospitals reported feeling more confident to identify that a patient in their care had LD compared with respondents from non-specialist hospitals (Z = 3.03; p = 0.002). However, in both specialist and non-specialist hospitals, staff were more confident when their Trust gave them information about how to define LD (specialist hospital: Z = 7.40; p < 0.001; non-specialist hospital: Z = 4.36; p < 0.001).

The data appear to show a correlation between Trusts that flag LD and staff views related to reasonable adjustments and safety. For example, staff from hospitals who flagged felt more able to identify what reasonable adjustments are needed for CYP with a long-term condition and learning disabilities than those from hospitals who did not flag ($Z = 4.37$; $p < 0.001$), as well as feeling more confident that any reasonable adjustments would be accommodated in a timely way ($Z = 2.62$; $p = 0.009$).

Furthermore, staff from hospitals who flagged were more likely to report working in an environment that was deemed safe for meeting the needs of children and young people with a long-term condition and learning disabilities than those from hospitals who did not flag ($Z = 2.30$; $p = 0.021$). The former were also more likely to report that they were always able to deliver safe care than those from hospitals who did not flag ($Z = 2.68$; $p = 0.007$) and felt more confident to safely manage challenging behaviour ($Z = 3.07$; $p = 0.002$).

The NHS groups staff into Pay Bands for non-medical staff. Examples of different roles by Bands include Band 5 for a Staff Nurse and Band 6 for a Nurse Specialist through to Band 8 for a Modern matron. Survey data revealed that senior nursing and allied health staff (Bands 7 and 8) felt more able to identify children with LD ($Z = -3.193$; $p = 0.001$) but were not more likely to implement reasonable adjustments than their junior colleagues (Bands 1–4, 5 and 6) ($Z = -1.707$; $p = 0.088$). This finding was supported only in part by interview data, with interviewees suggesting that senior *and* more experienced ward staff were more likely to identify children with LD *and* to implement reasonable adjustments to meet their needs. Interviewees went on to describe a number of factors thought to impact whether CYP with LD are identified by staff and have their needs meet, from their initial and ongoing training, experience gained over time, having sufficient time with the patient and their family and access to appropriate resources. There was a general expectation by the interviewees that staff involved in a child's care would ask about any LD and/or would have read a patient's notes. However, it was recognized that staff may not have a sufficient level of knowledge about LD, which could mean this was omitted during admission; this was despite interviewees recognizing the value of specific training around caring for young people with LD to raise and maintain awareness and for training to be put into practice.

DISCUSSION

Reported here are a sample of strategies NHS English hospitals employ (or not) to identify children and young people with LD accessing their services, as well as staff views regarding the process. Prior to the introduction of the LD improvement standards for NHS Trusts (NHS Improvement, [5]), the present authors found that less than half of hospitals in our study had any process in place for flagging these patients and for those who did, there was no standardized way for this to happen or for this information to always be recorded, or for what is recorded to be confirmed as accurate, communicated to relevant parties within a hospital/Trust and acted upon.

A range of practices existed from a passive approach of simply noting a diagnosis of LD in a child's hospital records, asking parents' permission for a flag to be applied through to active engagement with this information, including a formalized chain of events leading, ideally, to the implementation of reasonable adjustments to meet a child's needs. As a result, the patient experience between hospitals is likely to be very different.

During interviews, an emphasis was placed by staff on caring for children as individuals and as found in relation to the care of adults with LD (Tuffrey-Wijne et al., [12]; Tuffrey-Wijne & Hollins, [13]), there was a reluctance to label "difference" at an organizational or individual level that could be perceived to lead to discrimination. However, comparing the survey responses of staff working in hospitals that flag LD with those working hospitals that do not revealed that the opposite occurs in practice, strengthening the argument for those with LD to be identified on the grounds of increased safety and to achieve equity of treatment and individualized care (Oulton et al., [6]) through identifying the need associated with that LD (Tuffrey-Wijne & Hollins, [13]) and accommodating those needs through the provision of reasonable adjustments.

Interviewees raised a number of issues about the complexities of identifying children and young people with LD, in relation to their parents. They felt that parents may not support a process of "labelling" their child, they may not agree with the diagnosis or they may need support themselves to articulate their views due to their own LD or language barrier. Such findings highlight the need for clear guidelines about how parents should be involved in the process of flagging children and young people with LD in hospital, particularly as some of the staff interviewed felt that children with "mild LD" can go unrecognized. In adult services it has been reported that "those without a formal diagnosis may remain

invisible" (Sheehan et al., [11]: 6). Included in these guidelines must be information about the use of definitions around LD, as well as how to ask parents the relevant questions in a sensitive manner.

Less than half of staff who the present authors surveyed reported being routinely informed that a child in their care has LD, but at least three quarters of them reported seeing the benefit of formally identifying this population and feeling confident to do this. Such findings suggest that the primary issue is the communication of information between staff rather than a lack of staff knowledge or willingness to identify the population, as found in adult services (Tuffrey-Wijne et al., [12]). The present authors cannot know how well feelings of confidence correlate to the ability to correctly identify children and young people with LD, but the present authors do know that staff who have been given information about how to define LD report feel more confident to do so in practice and that perceived confidence is greater for senior staff and for staff working in specialist children's hospital. Despite such confidence, there was a perception from interviewees that a degree of responsibility fell to parents to inform staff about their child's needs, supporting the argument that a flag alone is not sufficient, but must be accompanied by "a statement of the reasonable adjustments required" for each child. Whilst parents are an expected source of information about their child, a reliance on them may mask a need for staff to be better educated about LD. Certainly, published evidence from this study states that staff do feel less capable to meet the needs of children and young people with LD compared to those without LD and the former are perceived by staff to be less safe than those without LD (Oulton et al., [6]). Further research needs to identify the underlying causes, including whether there is a case for increasing the quantity and quality of undergraduate training around LD. This would mean that individuals' knowledge is not dependent upon their seniority or length of experience, their place of work or the parent's willingness or ability to proactively engage with them about their child's needs. However, as recognized by the LD improvement standards for NHS Trusts, Standard 3 requires training *within* hospitals must be responsive to patterns of local need (NHS Improvement, [5]). Being better informed and trained should lead to increased confidence and a more equitable partnership between parents and staff when discussing and providing care for children with LD.

Limitations

The data presented here provide the perspective of NHS hospital staff. It is important to gain the views of children, young people and their parents to understand how LD is correctly identified (or where identification is missed or an incorrect "label" applied) and the value of having LD identified and the perceived implications that this information will have on practice.

This wider study from which this data comes sought to map the provision of care for children with long-term conditions, particularly those with LD through a mixed methods approach. The NHS staff who participated in interviews were identified locally and comprised a wide variety of roles (e.g., medical consultants, matrons, clinical nurse specialist and managers) which may have produced a lack of consistency in the data. At two sites (non-specialist hospitals), no staff agreed to be interviewed. The 30-min interview was designed to encourage participation but limited in-depth discussion around site practices. Additionally, where a difference by "pay band" has been identified, the present authors cannot be certain that a lower band indicates a lack of experience in working with children and young people with LD.

Although the study did not aim to be proportionally representative of specialist children's hospitals and non-specialist hospitals, children are more likely to receive treatment in their local hospital, which for many, is unlikely to be a specialist hospital for children. If this study was repeated, a sample that better reflects this form of access might be incorporated.

CONCLUSION

There is no standardized way of identifying children and young people with LD and their individual needs across hospitals in the NHS in England. The identification of these children needs to be consistent within and across the NHS and for this identification to be the beginning of a standardized process whether through flagging or another form of alert. This is essential to not only inform health and social care professionals that a child has a LD but what reasonable adjustments they require as individuals and to ensure that these are put in place to provide them with the best possible care. This is dependent on healthcare professionals having a level of training, confidence, skills and knowledge to actively and positively respond to initially identifying LD and being able to put into place the adjustment required, drawing on the available resources from the individual to the

institutional. A robust and comprehensive system that works across the whole NHS is required to identify this population and their needs and provide equity of access to resources to meet these needs.

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CONFLICT OF INTEREST

No conflict of interest has been declared.

GRAPH

Footnotes

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By Charlotte Kenten; Jo Wray; Faith Gibson; Jessica Russell; Irene Tuffrey-Wijne and Kate Oulton

Reported by Author; Author; Author; Author; Author; Author

Record: 23

Title: Working with Children with Autism Undergoing Health-Care Assessments in a Day Hospital Setting: A Perspective from the Health-Care Professionals

Authors: Chiara Davico
Daniele Marcotulli
Elisa Succi
Carlotta Canavese
Ancuta F. Bodea
Mariacristina Pellegrino
~~~~~~~~

Enrica Cuffari
Valentina F. Cudia
Barbara Svevi
Federico Amianto
Federica Ricci
Benedetto Vitiello

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Subject Terms: autism
health-care professionals
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hospital
Pediatrics
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Description: Background: Hospitals can be especially stressful for children with autism spectrum disorder (ASD) due to the communication and social skills deficits, lower capacity to adapt to disruption, and sensory hypersensitivity that are typical of these patients. Purpose: This study investigated how health-care professionals (HPs) experienced the clinical care and management of children with ASD undergoing medical testing in a day hospital setting, and assessed the rate of successful completion of laboratory tests and instrumental examinations. Methods: A cross-sectional questionnaire was administered to 45 HPs, inquiring about their experience in obtaining blood and urine tests, ECG, audiometry, and EEG from children with ASD. The clinical sample included 153 consecutively referred children with ASD (74.5% males, mean age 5.6 years) undergoing a medical diagnostic work-up as part of their diagnostic evaluation. The success rate of completing the various assessments was examined. Results: HPs identified aggressive behavior and communication deficits as the major challenges when providing care to children with ASD. The parents were seen as an important resource for managing the children. The completion rate of the laboratory tests and instrumental examinations was high (between 88.5% and 98.4% according to the specific type of examination). The lowest non-completion rate was found for the EEG (12.5%). Conclusions: Despite considerable challenges being reported by HPs in managing children with ASD, the scheduled assessments could be completed in the large majority of cases. Targeted approaches to preventing aggressive behaviors and obviating the communication barriers in children with ASD undergoing hospital exams are warranted.

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Title: Dental procedures in children with or without intellectual disability and autism spectrum disorder in a hospital setting.

Authors: Azimi, S
Wong, K
Lai, YYL
Bourke, J
Junaid, M
Jones, J
Pritchard, D
Calache, H
Winters, J
Slack-Smith, L
Leonard, H

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POOR children
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Author-Supplied Keywords: Autism spectrum disorder
child health
data linkage
dental disease
intellectual disability

Document Type: Article

Abstract: Background: This population-based cohort study investigated dental procedures in the hospital setting in Western Australian children with or without intellectual disability (ID) and/or autism spectrum disorder (ASD) aged up to 18 years. Considering previously reported disparities in dental disease between Indigenous and non-Indigenous Australian children, this study also investigated the effect of Indigenous status on dental procedures. Methods: Data on Western Australian live births from 1983 to 2010 from the Midwives Notification System were linked to the Intellectual Disability Exploring Answers database and the Hospital Morbidity Data collection. Primary admissions for relevant dental diagnoses were identified, and treatment procedures for dental hospitalization were investigated. Descriptive statistics and Pearson's chi-squared test of independence were used for analysis. Results: Overall, 76 065 episodes of dental hospitalization were recorded. Amongst children with ID and/or ASD, Indigenous children experienced more extractions and fewer restorations (68.7% and 16.2%) compared to non-Indigenous children (51.5% and 25.9%). After 6 years, extraction occurred less often in children with ID and/or ASD than in those without, where most surgical dental extractions were in the age group of 13–18 years. Conclusions: This study indicates a need for further improvements in access to dental services and the quality of care provided in hospitals for children with ID/ASD. There is also concern that more vulnerable Indigenous and all disadvantaged children are receiving an inadequate level of dental services resulting in more emergency dental hospitalization and invasive treatment. [ABSTRACT FROM AUTHOR]

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Authors: Rizvi, Abid
Husain, Karrar
Ashraf, Sahar
Trivedi, Chintan
Jain, Shailesh (Bobby)
Safwi, Sadia R.

Source: Primary Care Companion for CNS Disorders (2155-7772); 2024, Vol. 26 Issue 5, p1-3, 3p

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Accession Number: 181078736

Database: Complementary Index

Record: 26

Title: Children with Autism Spectrum Disorder At a Pediatric Hospital: A Systematic Review of the Literature.

Authors: Johnson, Norah L.; [1]Rodriguez, Dana[2]

Affiliation: [1]Clinical Nurse Specialist-Education Services, Children's Hospital of Wisconsin, Milwaukee, WI, and an Assistant Professor, Marquette University, Milwaukee, WI
[2]Doctoral Student, Marquette University, Milwaukee, WI

Source: Pediatric Nursing (PEDIATR NURS), May/Jun2013; 39(3): 131-141. (11p)

Publication Type: Journal Article - research, systematic review, tables/charts

Language: English

Major Subjects:

Child, Hospitalized
Autism Spectrum Disorder -- In Infancy and Childhood

Minor Subjects: Human; Systematic Review; Patient Compliance; Hyperkinesis; Sensory Defensiveness; Family Centered Care; CINAHL Database; Psycinfo; Medline; Aggression; Self-Injurious Behavior; Communication; Professional-Patient Relations; Length of Stay; Child; Child, Preschool; Adolescence; Hospitals, Pediatric

Abstract: This review of literature describes the behaviors of hospitalized children with autism spectrum disorder (ASD) that health care providers find challenging. It also identifies strategies used to address these challenging behaviors. The systematic review of literature identified 34 articles from databases on health care of challenging behaviors of children with ASD. The review identified four categories of challenging behaviors (non-compliance, hyperactivity, sensory defensiveness, self-injury) and several strategies for reducing these behaviors. Partnering with parents to develop strategies is important for children with ASD to deliver timely and safe care.

Journal Subset: Core Nursing; Nursing; Peer Reviewed; USA

ISSN: 0097-9805

MEDLINE Info: *NLM UID:* 7505804

Entry Date: 20130624

Revision Date: 20191101

Accession Number: 88322765

Database: CINAHL Plus with Full Text

Record: 27

Title: Developing an e-learning curriculum to educate healthcare staff in the acute hospital setting about autism.

Authors: Kyle, Geraldine
Connolly, Aine

Source: British Journal of Nursing; 9/22/2022, Vol. 31 Issue 17, p894-900, 7p

Publication Year: 2022

Subject Terms: ONLINE education
HEALTH services accessibility
LABOR productivity
SOCIAL support
STRATEGIC planning

MOTIVATION (Psychology)
ATTITUDES of medical personnel
CURRICULUM
PATIENT-centered care
HUMAN services programs
LEARNING strategies
AUTISM
CRITICAL care medicine
MEDICAL referrals
PEOPLE with disabilities
NEEDS assessment
GOAL (Psychology)

Author-Supplied Keywords: Autism spectrum disorder
Communication
Curriculum development
Education
Health services accessibility
Online learning

NAICS/Industry Codes: NAICS/Industry Codes 624190 Other Individual and Family Services

Document Type: Article

Abstract: When attending acute hospital settings, autistic children and adults rely on health professionals and ancillary staff to interact with them appropriately to facilitate accurate diagnoses and management of health concerns. Health outcomes for autistic people are adversely affected by comorbidities as well as difficulties in accessing and navigating acute healthcare environments. These factors demonstrate a need to develop targeted education for healthcare staff working in the acute hospital setting. This article discusses the background to the project, including the results of a literature review that highlighted some of the difficulties this patient group experiences in accessing health care. It discusses the development and evaluation of an e-learning education programme for healthcare staff working in an acute hospital setting using Kern et al's (1998) six-step approach to curriculum development. Staff reported a desire to learn more about autism and how to make patient consultations and experiences more accessible and productive. It was acknowledged that there are many undiagnosed autistic adults navigating the acute health system and it is anticipated that the e-learning programme will assist staff in identifying and meeting their needs. During research with an autism advocacy group, there was a clear recommendation for the use of the term 'autistic person' rather than 'person with autism', which is reflected in the resulting education programme and this article. [ABSTRACT FROM AUTHOR]

ISSN: 09660461

DOI: 10.12968/bjon.2022.31.17.894

Accession Number: 159296679

Database: Complementary Index

Record: 28

Title: Working with Children with Autism Undergoing Health-Care Assessments in a Day Hospital Setting: A Perspective from the Health-Care Professionals.

Authors: Davico, Chiara
Marcotulli, Daniele
Succi, Elisa
Canavese, Carlotta
Bodea, Ancuta F.
Pellegrino, Mariacristina
Cuffari, Enrica
Cudia, Valentina F.
Svevi, Barbara
Amianto, Federico
Ricci, Federica
Vitiello, Benedetto

Source: Children; Mar2023, Vol. 10 Issue 3, p476, 10p

Publication Year: 2023

Subject Terms: HOSPITALS
ELECTROENCEPHALOGRAPHY
ATTITUDES of medical personnel
CROSS-sectional method

MEDICAL screening
REGRESSION analysis
AUTISM in children
QUESTIONNAIRES
ELECTROCARDIOGRAPHY
AUDIOMETRY
COMMUNICATION
SCALE analysis (Psychology)
DESCRIPTIVE statistics
ROUTINE diagnostic tests
AGGRESSION (Psychology)
DATA analysis software
CHILDREN

Author-Supplied Keywords: autism
EEG
health-care professionals
hospital
medical testing

NAICS/Industry Codes: NAICS/Industry Codes 622111 General (except paediatric) hospitals
622110 General Medical and Surgical Hospitals
621999 All Other Miscellaneous Ambulatory Health Care Services

Document Type: Article

Abstract: Background: Hospitals can be especially stressful for children with autism spectrum disorder (ASD) due to the communication and social skills deficits, lower capacity to adapt to disruption, and sensory hypersensitivity that are typical of these patients. Purpose: This study investigated how health-care professionals (HPs) experienced the clinical care and management of children with ASD undergoing medical testing in a day hospital setting, and assessed the rate of successful completion of laboratory tests and instrumental examinations. Methods: A cross-sectional questionnaire was administered to 45 HPs, inquiring about their experience in obtaining blood and urine tests, ECG, audiometry, and EEG from children with ASD. The clinical sample included 153 consecutively referred children with ASD (74.5% males, mean age 5.6 years) undergoing a medical diagnostic work-up as part of their diagnostic evaluation. The success rate of completing the various assessments was examined. Results: HPs identified aggressive behavior and communication deficits as the major challenges when providing care to children with ASD. The parents were seen as an important resource for managing the children. The completion rate of the

laboratory tests and instrumental examinations was high (between 88.5% and 98.4% according to the specific type of examination). The lowest non-completion rate was found for the EEG (12.5%). Conclusions: Despite considerable challenges being reported by HPs in managing children with ASD, the scheduled assessments could be completed in the large majority of cases. Targeted approaches to preventing aggressive behaviors and obviating the communication barriers in children with ASD undergoing hospital exams are warranted. [ABSTRACT FROM AUTHOR]

ISSN: 22279067

DOI: 10.3390/children10030476

Accession Number: 162747340

Database: Complementary Index

Record: 29

Title: Working with children with autism and their families: pediatric hospital social worker perceptions of family needs and the role of social work.

Authors: Morris, Rae[1,2] *rae.morris@redpathcentre.ca*
Muskat, Barbara[3]
Greenblatt, Andrea[3,4]

Source: Social Work in Health Care. Aug2018, Vol. 57 Issue 7, p483-501. 19p.

Document Type: Article

Subject Terms: *AUTISM
*INTERVIEWING
*RESEARCH methodology
*MEDICAL personnel
*NEEDS assessment
*RESEARCH funding
*SOCIAL stigma
*JUDGMENT sampling
*THEMATIC analysis

*BURDEN of care
*PATIENTS' families
*DATA analysis software
*SOCIAL worker attitudes

Author-Supplied Keywords: Autism
hospital social work
interpretive description
pediatric
qualitative research
social work

Abstract: Social workers with knowledge of autism can be valuable contributors to client- and family-centered healthcare services. This study utilized a qualitative design to explore pediatric hospital social workers' experiences and perceptions when working with children and youth with autism and their families. Interviews with 14 social workers in a Canadian urban pediatric hospital highlighted perceptions of the needs of families of children with autism in the hospital and challenges and benefits related to the role of social work with these families. Results suggest that pediatric social workers may benefit from opportunities to develop autism-relevant knowledge and skills. [ABSTRACT FROM AUTHOR]

Author Affiliations: [1]The Redpath Centre, Toronto, Canada
[2]School of Social Work, University of British Columbia, Vancouver, Canada
[3]Department of Social Work, The Hospital for Sick Children, Toronto, Canada
[4]Factor-Inwentash Faculty of Social Work, University of Toronto, Toronto, Canada

ISSN: 0098-1389

DOI: 10.1080/00981389.2018.1461730

Accession Number: 130147487

Database: Academic Search Index

Record: 30

Title: Mapping staff perspectives towards the delivery of hospital care for children and young people with and without learning disabilities in England: a mixed methods national study

Authors: Kate Oulton
Faith Gibson
Lucinda Carr
Angela Hassiotis
Carey Jewitt
Charlotte Kenten
Jessica Russell
Mark Whiting
Irene Tuffrey-Wijne
Jo Wray

Source: BMC Health Services Research, Vol 18, Iss 1, Pp 1-12 (2018)

Publisher Information: BMC, 2018.

Publication Year: 2018

Collection: LCC:Public aspects of medicine

Subject Terms: Learning disability
Intellectual disability
Long-term conditions
Mixed methods
Health services research
Public aspects of medicine
RA1-1270

Description: Abstract Background Children and young people (CYP) with learning disabilities (LD) are a vulnerable population with increased risk of abuse and accidental injury and whose parents have reported concerns about the quality, safety and accessibility of their hospital care. The Care Quality Commission’s (CQC) view of best practice for this group of patients includes: access to senior LD nurse provision; a clearly visible flagging system for identifying them; the use of hospital passports; and defined communication strategies (Glasper, Comp Child Adolesc Nurs 40:63-67, 2017). What remains unclear is whether these recommendations are being applied and if so, what difference they are making. Furthermore, what we do not know is whether parental concerns of CYP with LD differ from parents of other children with long-term conditions. The aims of this study were to 1) describe the organisational context for healthcare delivery to CYP with LD and their

families and 2) compare staff perceptions of their ability to identify the needs of CYP with and without LD and their families and provide high quality care to effectively meet these needs. Methods Individual interviews (n = 65) and anonymised online survey (n = 2261) were conducted with hospital staff working with CYP in 15 children's and 9 non-children's hospitals in England. The majority of interviews were conducted over the telephone and recorded and transcribed verbatim. Health Research Authority was obtained and verbal or written consent for data collection was obtained from all interview participants. Results The nature and extent of organisational policies, systems and practices in place within hospitals to support the care of CYP with LD differs across England and some uncertainty exists within and across hospitals as to what is currently available and accessed. Staff perceived that those with LD were included less, valued less, and less safe than CYP without LD. They also reported having less confidence, capability and capacity to meet the needs of this population compared to those without LD. Conclusion Findings indicate inequality with regards the provision of high quality hospital care to children and young people with LD that meets their needs. There is a pressing need to understand the impact this has on them and their families. Trial registration The study has been registered on the NIHR CRN portfolio 20461 (Phase 1), 31336 (Phases 2-4).

Document Type: article

File Description: electronic resource

Language: English

ISSN: 1472-6963

Relation: http://link.springer.com/article/10.1186/s12913-018-2970-8; https://doaj.org/toc/1472-6963

DOI: 10.1186/s12913-018-2970-8

Access URL: https://doaj.org/article/c9709e81bd334675bd91d69d5c9fb0c2

Accession Number: edsdoj.9709e81bd334675bd91d69d5c9fb0c2

Database: Directory of Open Access Journals

Record: 31

Title: Equal access to hospital care for children with learning disabilities and their families: a mixed-methods study

Authors: Kate Oulton
Jo Wray
Charlotte Kenten
Jessica Russell
Lucinda Carr
Angela Hassiotis
Carey Jewitt

Paula Kelly
Sam Kerry
Irene Tuffrey-Wijne
Mark Whiting
Faith Gibson

Source: Health and Social Care Delivery Research, Vol 10, Iss 13 (2022)

Publisher Information: NIHR Journals Library, 2022.

Publication Year: 2022

Collection: LCC:Medicine (General)
LCC:Public aspects of medicine

Subject Terms: learning disability
intellectual disability
health-care delivery
patient experience
family-centred care
mixed methods
inclusive research
Medicine (General)
R5-920
Public aspects of medicine
RA1-1270

Description: Background: To our knowledge, there has yet to be a comprehensive review of how well hospital services are meeting the needs of children and young people (hereafter referred to as children) with learning disability and their families. The extent to which their experiences differ from those of parents of children without learning disability is not known. The views and experiences of children with learning disability are almost non-existent in the literature. Aims: To identify the cross-organisational, organisational and individual factors in NHS hospitals that facilitate and prevent children with learning disability and their families receiving equal access to high-quality care and services, and to develop guidance for NHS trusts. Design: A four-phase transformative, mixed-methods case study design comparing the experiences of children with and children without learning disability, their parents and health-care staff. Methods: Phase 1 comprised interviews with senior managers (n = 65), content analysis of hospital documents and a staff survey (n = 2261) across 24 hospitals in England, including all specialist children’s hospitals. Phases 2–4 involved seven of these hospitals. Phase 2 involved (a) interviews and photography with children

and their parents (n = 63), alongside a parent hospital diary and record of safety concerns; (c) hospital staff interviews (n = 98) and community staff survey (n = 429); and (d) retrospective mapping of hospital activity. During phase 3, children (n = 803) and parents (n = 812) completed satisfaction surveys. Phase 4 involved seeking consultation on the findings. Data analysis: A model for mixed-methods data analysis and synthesis was used. Qualitative data were managed and analysed thematically, supported with NVivo (QSR International, Warrington, UK). Quantitative data were analysed using parametric and non-parametric descriptive statistics. Results: Nationally, there is considerable uncertainty within hospitals and variation between hospitals in terms of the policies, systems and practices in place specifically for children with learning disability. Staff are struggling to individualise care and are being let down by an inadequate system. Attitudes and assumptions can have a lasting impact on parents and children. The findings serve as a useful guide to trusts about how best to meet the Learning Disability Improvement standards that have been set. Conclusions: Safety issues and quality of care affect all children in acute hospitals and their parents, but the impact on children with learning disability and their parents is much greater. Individualising care is key. Our findings suggest that staff may need to undertake training and gain experience to build their skills and knowledge about children with learning disability generally, as well as generate knowledge about the individual child through proactively working in partnership with parents before their child's admission. The findings also suggest that we may need to address the impact of children's hospitalisation on parents' health and well-being. Future work: The greatest need is for the development and validation of an instrument for the assessment and management of risk in children with learning disability in hospital. Limitations: We cannot say with certainty that the sites selected are representative of all services caring for children with learning disability. Study registration: The study has been registered on the National Institute for Health and Care Research (NIHR) Clinical Research Network portfolio as 20461 (phase 1) and 31336 (phases 2–4). Funding: This project was funded by the NIHR Health and Social Care Delivery Research programme and will be published in full in Health and Social Care Delivery Research; Vol. 10, No. 13. See the NIHR Journals Library website for further project information.

Document Type: article

File Description: electronic resource

Language: English

ISSN: 2755-0060
2755-0079

Relation: https://doaj.org/toc/2755-0060; https://doaj.org/toc/2755-0079

DOI: 10.3310/NWKT5206

Access URL: https://doaj.org/article/824bbd3bf25448b39cfe8137cbc47da2

Accession Number: edsdoj.824bbd3bf25448b39cfe8137cbc47da2

Database: Directory of Open Access Journals

Record: 32

Title: Age Differences in Emergency Department Visits and Inpatient Hospitalizations in Preadolescent and Adolescent Youth with Autism Spectrum Disorders.

Authors: Schlenz, Alyssa
Carpenter, Laura
Bradley, Catherine
Charles, Jane
Boan, Andrea

Source: Journal of Autism & Developmental Disorders. Aug2015, Vol. 45 Issue 8, p2382-2391. 10p. 4 Charts.

Document Type: Article

Subjects: Accidents
Age distribution
Autism in children
Black people
Comparative studies
Confidence intervals
Hospital care
Hospital emergency services
Longitudinal method
Medical care
Nosology
Research funding
White people
Wounds & injuries
Logistic regression analysis
Statistical significance
Psychiatric treatment
Autism in adolescence
Cross-sectional method
Data analysis software

Adolescence
Children

Geographic Terms: South Carolina

Abstract: This paper evaluated age differences in emergency department care and inpatient hospitalizations in 252 preadolescent and adolescent youth with autism spectrum disorders (ASDs; ages 9-18). Records from youth with ASDs were linked to acute care utilization records and were compared to a demographically similar comparison group of youth without ASDs (N = 1260). A particular focus was placed on utilization for psychiatric concerns and injuries or accidents. Results suggested that psychiatric care was more likely for youth with ASDs in both the preadolescent and adolescent cohorts versus comparison youth, with no significant differences between age cohorts. In contrast, results for the accident and injury categories suggested age-specific findings. Results suggest opportunities for prevention efforts for youth with ASDs. [ABSTRACT FROM AUTHOR]

ISSN: 0162-3257

DOI: 10.1007/s10803-015-2405-x

Accession Number: 108509235

Database: Psychology and Behavioral Sciences Collection

Record: 33

Title: How to create an autism friendly hospital environment

Authors: F. Latif
S. King
A. Friedman
E. Valentine
K. Burley

Source: European Psychiatry, Vol 64, Pp S230-S230 (2021)

Publisher Information: Cambridge University Press, 2021.

Publication Year: 2021

Collection: LCC:Psychiatry

Subject Terms: autism
Child Psychiatry
Pediatric Hospital
Psychiatry
RC435-571

Description: Introduction Children with Autism Spectrum Disorder (ASD) struggle with communication, sensory sensitivities and social interaction. These difficulties can make hospital visits challenging. Every child with ASD is unique, and as such, some children can do well in clinical settings with minimal supports while others may require environmental modifications to achieve optimal care. ASD is prevalent worldwide and cultural differences can lead to varied care. Several hospitals, including Boston Medical Center in USA and Sidra Medicine and Research Center in Qatar, have attempted to address these challenges by developing strategies to create an ‘Autism Friendly’ environment. Objectives This workshop will 1. Describe the 4 domains of an “Autism Friendly” environment 2. Describe practical steps for successful implementation of interventions and modifications to consider based on setting and culture. Methods Didactic section 1 will describe the 4 domains for greating an ‘Autism Friendly environment’. Didactic section 2 will describe implementation in an inpatient and outpatient setting focusing on modifications based on environmental differences. These didactic presentations will be followed by a hands on, interactive section where participants will break out in small groups to learn specific implementation skills. Results Participants will learn how to improve care offered to children with ASD during hospital visits. Participants will develop the skills to implement similar interventions in their home institutions. Conclusions Hospitals can create an Autism Friendly environment by using 4 domains of intervention which could help improve provider skills and patient and family experience.

Document Type: article

File Description: electronic resource

Language: English

ISSN: 0924-9338
1778-3585

Relation: https://www.cambridge.org/core/product/identifier/S0924933821006155/type/journal_article; https://doaj.org/toc/0924-9338; https://doaj.org/toc/1778-3585

DOI: 10.1192/j.eurpsy.2021.615

Access URL: https://doaj.org/article/bc1dd055fa0147bc81d9907e0fb4df1f

Accession Number: edsdoj.bc1dd055fa0147bc81d9907e0fb4df1f

Database: Directory of Open Access Journals

Record: 34

Title: Development of a Training Curriculum for Hospital Security About Autism Spectrum Disorder

Authors: Christiansen, Audrey
Harstad, Elizabeth
Sideridis, Georgios
Weissman, Laura

Source: *Journal of Developmental & Behavioral Pediatrics*. Dec 01, 2020

Publication Year: 2020

Description: OBJECTIVE:: To evaluate whether a newly developed autism spectrum disorder (ASD)-training curriculum for hospital security officers improves comfort, knowledge, and practice. METHODS:: Participants were security officers. The ASD-training curriculum was a 45-minute interactive session, adapted from trainings developed for other types of hospital providers. The curriculum included information regarding the presentation of, and challenges faced by, children with ASD in the hospital setting. Officers completed surveys before (T1), immediately after (T2), and 3 months after (T3) the training to assess comfort, knowledge, and practice. Comfort (Likert scale 1–5; 5 = highest) and knowledge (11 yes/no questions) questions were adapted from previous measures. Application of skills was assessed using case scenarios (at T1, T2, and T3) and with officers' report of using various strategies (at T1 and T3; Likert scale 1–5; 5 = always). Data were analyzed using repeated-measures analysis of variance and a series of paired contrast. RESULTS:: For the 114 officers who completed surveys, mean comfort scores significantly increased from T1 to T2 (3.48 vs 3.9; $p < 0.05$), and these gains were maintained at T3 (4.1). Mean percent correct on knowledge questions significantly increased from T1 to T2 (74.6% vs 84.0%; $p < 0.05$) and was maintained at T3 (82.9%). Officers reported using 2 ASD-supportive strategies significantly more between T1 and T3: using pictures and written communication and asking the caregivers for advice. CONCLUSION:: This newly developed ASD-training curriculum for hospital security officers resulted in an immediate increase of self-reported comfort and demonstrated knowledge with continued gains 3 months after training.

Language: English

Author Affiliations: Department of Pediatrics, Boston Medical Center, Boston University School of Medicine, Boston, MA / Division of Developmental Medicine, Boston Children's Hospital and Harvard Medical School, Harvard University, Boston, MA. / Division of Developmental Medicine, Boston Children's Hospital and Harvard Medical School, Harvard University, Boston, MA. / Division of Developmental Medicine, Boston Children's Hospital and Harvard Medical School, Harvard University, Boston, MA.

ISSN: 0196-206X

DOI: 10.1097/DBP.0000000000000888

Availability: http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=fulltext&D=ovft&CSC=Y&NEWS=N&SEARCH=%2210.1097/DBP.0000000000000888%22.di

Accession Number: edsovi.10.1097.DBP.0000000000000888

Database: Journals@OVID

Record: 35

Title: Autistic children's parents and hospital dentistry

Authors: Dana Tahririan
Saharosadat Shariati
Firoozeh Nilchian

Source: Dental Research Journal, Vol 18, Iss 1, Pp 105-105 (2021)

Publisher Information: Wolters Kluwer Medknow Publications, 2021.

Publication Year: 2021

Collection: LCC:Dentistry

Subject Terms: autistic disorder
behavior control
child
dentistry
general anesthesia
Dentistry
RK1-715

Description: Background: It is difficult to perform dental procedures in autistic children, and parental involvement is necessary for successful hospital dental services. Therefore, in order to promote oral health in autistic children, this study was aimed to explore the knowledge, attitude, and performance of autistic children's parents with respect to hospital dentistry. Materials and Methods: This cross-sectional study was conducted with the parents of 100 autistic children aged 2–6 years selected from among the children of Isfahan autism treatment centers. A self-administered questionnaire, including parental demographic information and 22 items on the assessment of knowledge, attitude, and performance of autistic children's parents regarding hospital dental procedures under general anesthesia, was completed by 100 parents. P

Document Type: article

File Description: electronic resource

Language: English

ISSN: 1735-3327
2008-0255

Relation: http://www.drjjournal.net/article.asp?issn=1735-3327;year=2021;volume=18;issue=1;spage=105;epage=105;aulast=Tahririan; https://doaj.org/toc/1735-3327; https://doaj.org/toc/2008-0255

DOI: 10.4103/1735-3327.332099

Access URL: https://doaj.org/article/b7742ce213f04d0090ef916ce6e59f2b

Accession Number: edsdoj.b7742ce213f04d0090ef916ce6e59f2b

Database: Directory of Open Access Journals

Record: 36

Title: Do Children with Autism Overutilize the Emergency Department? Examining Visit Urgency and Subsequent Hospital Admissions.

Authors: Deavenport-Saman, Alexis; Lu, Yang; [1]Smith, Kathryn; Yin, Larry

Affiliation: [1]Department of Pediatrics, Harbor-UCLA Medical Center & Los Angeles Biomedical Research Institute, Torrance USA

Source: Maternal & Child Health Journal (MATERN CHILD HEALTH J), Feb2016; 20(2): 306-314. (9p)

Publication Type: Journal Article - research, tables/charts

Language: English

Major Subjects: Autism Spectrum Disorder
Emergency Service -- Utilization
Patient Admission
Health Services Accessibility

Minor Subjects: Human; Hospitals, Pediatric; California; Retrospective Design; Multivariate Analysis; Linear Regression; Logistic Regression; Odds Ratio; Confidence Intervals; Conceptual Framework; Child, Preschool; Child; Adolescence; Young Adult; Male; Female; Bivariate Statistics; Data Analysis Software; T-Tests; Health Care Costs

Abstract: Background Children with autism spectrum disorders (ASD) are more likely to have difficulties accessing health care compared to other children with special health care needs. National data based on parent report indicate that children with ASD are overutilizing emergency

department (ED) services, but data on actual ED use has been limited to children with psychiatric diagnoses. This study examined factors associated with ED utilization (rate, urgency, and hospital admissions) among children with ASD compared to those without ASD. Methods Data from an urban, tertiary children's hospital level 1 trauma center were examined retrospectively 2006-2009. Anderson's model of health services utilization served as the study framework. The NYU ED algorithm was used to predict nonurgent visits. Multivariate linear and logistic regression analyses were performed on the rate, urgency, and subsequent hospital admissions of these ED visits. Results There were 115,443 children 2-21 years old, accounting for a total of 157,902 visits. The top three reasons for visiting the ED for children with and without ASD were acute upper respiratory infections, viral infections and otitis media. Children with ASD had on average 0.26 more ED visits annually than children without ASD ($p < 0.01$) and were 2.6 % points more likely to have nonurgent visits; $p < 0.01$). Their visits were also less likely to result in hospital admissions (OR 0. 61; $p < 0.01$). Conclusions Examination of predisposing, enabling, and reinforcing factors suggest that children with ASD were more likely to visit the ED and for nonurgent reasons.

Journal Subset: Continental Europe; Core Nursing; Europe; Nursing; Peer Reviewed; USA

ISSN: 1092-7875

MEDLINE Info: *NLM UID:* 9715672

Entry Date: 20160203

Revision Date: 20170131

DOI: 10.1007/s10995-015-1830-y

Accession Number: 112693319

Database: CINAHL Plus with Full Text

Record: 37

Title: Learning disability nurse provision in children’s hospitals: hospital staff perceptions of whether it makes a difference

Authors: Kate Oulton
Jo Wray
Angela Hassiotis
Charlotte Kenten
Jessica Russell
Irene Tuffrey-Wijne
Mark Whiting
Faith Gibson

Source: BMC Pediatrics, Vol 19, Iss 1, Pp 1-11 (2019)

Publisher Information: BMC, 2019.

Publication Year: 2019

Collection: LCC:Pediatrics

Subject Terms: Learning disability nurse provision
Intellectual disability
Workforce planning
Mixed methods
Health services research
Pediatrics
RJ1-570

Description: Abstract Background In response to multiple United Kingdom investigations and inquiries into the care of adults with learning disabilities, Mencap produced the Getting it Right Charter which campaigned for the appointment of a Learning Disability Liaison Nurse in every hospital. More recent best practice guidelines from the Care Quality Commission included the need for all children's units to have access to a senior learning disability nurse who can support staff and help them manage difficult situations. However, little evidence exists of the extent of learning disability nurse provision in children's hospitals or the nature and impact of this role. Here we report selected findings from a national mixed methods study of hospital care for children and young people with and without learning disabilities in England. The extent of learning disability nurse provision in children's hospitals is described and perceptions of staff working in hospitals with and without such provision is compared. Methods Semi-structured interviews were conducted with senior staff across 15 children's hospitals and an anonymous survey was sent to clinical and non-clinical staff with patient (children and young people) contact within these hospitals. The survey focused on six different elements of care for those with and without learning disability, with additional questions concerning identifying and tracking those with learning disabilities and two open-ended questions. Results Forty-eight senior staff took part in interviews, which included a subset of nine nurses and one allied health professional employed in a dedicted learning disability nurse role, or similar. Surveys were completed by 1681, of whom 752 worked in a hospital with dedicated learning disability nurse provision. We found evidence of limited and varied learning disability nurse provision which was valued by hospital staff and shown to positively impact their perceptions of being capable to care for children and young people with learning disabilities, but not shown to increase staff perceptions of capacity or confidence, or how children and young people are valued within the hospital, their safety or access to appointments. Conclusion Further consideration must be given to how learning disability nurse roles within children's hospitals are best operationalised in practice to have the greatest impact on staff and families, as well as how we monitor and evaluate them to ensure they are being utilised effectively and efficiently. Trial registration The study has been registered on the NIHR CRN portfolio 20,461 (Phase 1), 31,336 (Phases 2–4).

Document Type: article

File Description: electronic resource

Language: English

ISSN: 1471-2431

Relation: http://link.springer.com/article/10.1186/s12887-019-1547-y; https://doaj.org/toc/1471-2431

DOI: 10.1186/s12887-019-1547-y

Access URL: https://doaj.org/article/0398e57cbb484018b9ce7f673981bcec

Accession Number: edsdoj.0398e57cbb484018b9ce7f673981bcec

Database: Directory of Open Access Journals

Record: 38

Title: Patterns of Contact with Hospital for Children with an Autism Spectrum Disorder: A Danish Register-Based Study.

Authors: Atladóttir, Hjördis
Schendel, Diana
Lauritsen, Marlene
Henriksen, Tine
Parner, Erik

Source: Journal of Autism & Developmental Disorders. Aug2012, Vol. 42 Issue 8, p1717-1728. 12p. 6 Charts.

Document Type: Article

Subjects: Attention-deficit hyperactivity disorder
Psychiatric diagnosis
Diagnosis of autism
Autism risk factors
Siblings
Confidence intervals
Longitudinal method
Medical care use
Preventive health services
Research funding
Sex distribution

Proportional hazards models
Data analysis software
Descriptive statistics

Geographic Terms: Denmark

Abstract: The aim of this study was to study patterns of contact with hospital for children with autism spectrum disorder (ASD) using Danish population based register data. We included all children born in Denmark from 1994 through 2002. We found that children diagnosed with ASD had an increased rate of contact with hospital, almost regardless of the cause for the hospital contact. Given the overall association between hospital contact for various causes and ASD observed in these data, hospital data should be used cautiously in future studies searching for associations between a specific disease and ASD. If the increased rate of hospital contact overall for children with ASD is not considered, then misleading over interpretations might be made of observed associations between specific diseases and ASD. [ABSTRACT FROM AUTHOR]

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Title: Challenges hindering family involvement in the hospital nursing care of a child with autism.

Authors: Williams NA; Department of Nursing, Faculty of Health Sciences, Durban University of Technology, Durban, South Africa.; Department of Health, King Edward VIII Campus of the Kwa-Zulu Natal College of Nursing, Durban, South Africa.
Sokhela DG; Department of Nursing, Faculty of Health Sciences, Durban University of Technology, Durban, South Africa.
Ngxongo TSP; Department of Nursing, Faculty of Health Sciences, Durban University of Technology, Durban, South Africa.

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Abstract: **Competing Interests:** The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article.

Background: Family involvement is crucial in a child's treatment; however, many professional nurses still neglect to involve families in their child's care. Studies have indicated that the perceived lack of family involvement in hospitalised children with autism spectrum disorder (ASD) is a problem in many countries. Few studies have been conducted in Africa with none relating to family involvement, highlighting the need for further research.

Aim: To develop in-depth insights into the challenges regarding family involvement in hospital nursing care of children with ASD, in the South African context.

Setting: Paediatric wards at selected private hospitals and family homes in the eThekwini District of KwaZulu-Natal.

Methods: An interpretative phenomenological analysis method was used. A sample of 10 professional nurses and 10 family members was achieved by purposive sampling. Data were collected from participants using semi-structured in-depth interviews.

Results: The following challenges were identified by the participants: the lack of knowledge of nurses regarding ASD, nurses not listening to family, uncaring attitude of nurses, nurses' lack of time and shortage of nursing staff.

Conclusion: Nurses play a pivotal role in overcoming the challenges to family involvement, in the hospital nursing care, of a child with ASD. Making nurses aware of the challenges will help improve family involvement in hospitals nursing for the child with ASD.

Contribution: This study added to the body of knowledge by identifying the challenges to the involvement of families in the hospital nursing care of a child with ASD.

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Title: Frequency and correlates of augmentative and alternative communication use in an autistic inpatient sample.

Authors: DeLucia EA; Department of Psychology, Virginia Polytechnic Institute & State University, Williams Hall, 24061, Blacksburg, VA, USA. lizdelucia@vt.edu.
McFayden TC; Department of Psychology, Virginia Polytechnic Institute & State University, Williams Hall, 24061, Blacksburg, VA, USA.
Fok M; Department of Psychology, Virginia Polytechnic Institute & State University, Williams Hall, 24061, Blacksburg, VA, USA.
Andrzejewski TM; Department of Psychology, University of Wyoming, Laramie, USA.

Scarpa A; Department of Psychology, Virginia Polytechnic Institute & State University, Williams Hall, 24061, Blacksburg, VA, USA.
McDonnell CG; Department of Psychology, University of Wyoming, Laramie, USA.

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Abstract: Although augmentative and alternative communication (AAC) strategies are often used by autistic youth, little is known about the use of AAC in inpatient psychiatric settings. This study evaluated how demographic and clinical factors (e.g., language level, IQ) related to AAC use in a well-characterized sample of 527 autistic youth (78.7% male, mean age 12.94) who participated in the Autism Inpatient Collection. AAC use was common, with 42.5% of caregivers reporting at least one form of AAC. White children were more likely to use AAC than non-white children at the bivariate level. In regression analyses, young children were more likely to use AAC than older children. These results suggest the importance of provider training and improved equitable access to AAC.

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Frequency and correlates of augmentative and alternative communication use in an autistic inpatient sample

Although augmentative and alternative communication (AAC) strategies are often used by autistic youth, little is known about the use of AAC in inpatient psychiatric settings. This study evaluated how demographic and clinical factors (e.g., language level, IQ) related to AAC use in a well-characterized sample of 527 autistic youth (78.7% male, mean age 12.94) who participated in the Autism Inpatient Collection. AAC use was common, with 42.5% of caregivers reporting at least one form of AAC. White children were more likely to use AAC than non-white children at the bivariate level. In regression analyses, young children were more likely to use AAC than older children. These results suggest the importance of provider training and improved equitable access to AAC.

Keywords: Augmentative and alternative communication; Autism; Hospitals; Inpatient; Psychiatry

Autism spectrum disorder (ASD) has historically been defined as a neurodevelopmental disorder with heterogeneous language presentations, including autistic individuals who identify as non-speaking or partially-verbal (American Psychiatric Association, [2])[1]. Estimates suggest approximately 30% of autistic youth do not use more than five words daily by age 9 (Anderson et al., [3]). These non-speaking and partially verbal groups of autistic youth are often omitted from autism research and have been referred to as the "neglected end of the spectrum" (Tager-Flusberg & Kasari, [43]). Research suggests communication in autistic youth is related to numerous outcomes including academic, behavioral, and post-secondary engagement (Branson & Demchak, [10]; Hamm & Mirenda, [27]; Mayo et al., [37]). Guided by these findings, recent efforts have promoted speech/language interventions for autistic youth with diverse language levels, with many utilizing augmentative and alternative communication (AAC) strategies for autistic youth with complex communication needs, including but not limited to youth who are non-speaking or partially-verbal (Tager-Flusberg & Kasari, [43]). However, little is known about AAC use in high-needs service settings nor how demographic factors relate to use. The current study seeks to address these gaps by evaluating the use of AAC in relation to demographic and clinical factors in a well-characterized sample of autistic youth in a psychiatric inpatient setting.

The efficacy of many AAC approaches for autistic people with varying language levels has been well-established in the literature (Ganz, [17]), including manual sign language (van der Meer et al., [44]), exchange-based communication systems (PECS; Flippin et al., [14]; Frost & Bondy, [16]), speech-generating devices, and hand-held devices and tablets

(Flores et al., [15]; Ganz, Boles, et al., [18]; Gevarter et al., [26]). AAC implementation has been studied most often in single case designs or case studies (Ganz, Rispoli et al., [24]), as feasibility approaches (e.g., Ganz [17]), in educational settings (Ganz, Rispoli, et al., [24]), with young children (Ganz, [17]; Ganz, Earles-Vollrath, et al., [20]; Holyfield et al., [28]), and with males/boys (Aydin & Diken, [4]). Furthermore, although autism is diagnosed at higher rates in males than females (~ 4:1, APA, 2013), recent demographics from a 2020 meta-analysis on 30 studies of AAC use in autistic youth included only 11 females, representing a ratio that is far from that of the male:female diagnostic discrepancy (Aydin & Diken, [4]). Indeed, research involving AAC implementation across an array of methodological designs, contexts, communicative partners, and client demographics is limited (Ganz & Hong, [22]).

Strikingly little published work has investigated AAC use for autistic youth in inpatient hospital settings, despite estimates suggesting that autistic youth are 9 times as likely to experience psychiatric emergency department visits than their non-autistic peers (Kalb et al., [29]), and an estimated 11% of autistic youth experience psychiatric hospitalization (Mandell, [35]). For families with autistic children who have undergone inpatient hospitalizations, parents reported their top area of concern was in the domain of communication, underscoring that autistic youth often have unique ways of conveying pain (Kopecky et al., [31]). In fact, use of AAC strategies in inpatient settings may provide several advantages. Assistive communication strategies in the context of hospitalization and intensive care have the potential to improve patient-provider communication (Carruthers et al., [11]; Garrett et al., [25]) and assist with pain management for non-speaking patients and those with communication needs in general (Koszalinski et al., [32]). Of note, up to 7% of all individuals receiving hospital inpatient services may be candidates for AAC (Zubow & Hurtig, [45]). However, the prevalence and correlates of AAC use and its potential benefits have not been evaluated in autistic youth receiving inpatient services specifically. In addition to improving communicative needs, AAC approaches are also moderately effective at addressing behaviors requiring significant support (e.g., self-injury), which are likely to occur at a higher frequency in inpatient settings (Ganz, Davis, et al., [19]; Ganz, Earles-Vollrath, et al., [20]). Further research into AAC use for autistic youth receiving psychiatric inpatient services is imperative for providers and families to further their understanding of communication strategies utilized by this population.

Characteristics Associated with AAC use

Within the empirical evidence suggesting positive communicative outcomes for autistic youth using AAC technologies, research has identified participant characteristics that have been linked to AAC implementation, including age, spoken language use, intellectual abilities, co-occurring conditions, and socioeconomic status (SES). Younger children have been reported to outperform older children in their adaptation and use of AAC, likely due to their ability to learn a novel communication system more quickly (Ganz et al., [21]). Autistic youth with some spoken language have better reported outcomes than autistic youth who identify as entirely non-speaking (Ganz, Mason, et al., [23]). However, little work has investigated how expressive and receptive language skills may differentially impact AAC use in autistic youth. Direct associations with nonverbal intelligence levels have not been evaluated. Although some studies have indicated that youth with co-occurring concerns may demonstrate less AAC progress (Ganz et al., [21]), few studies have investigated specific domains of co-occurring concerns such as irritability or self-injurious behaviors, which may significantly impact access to AAC intervention. Importantly, the studies reviewed here offer a helpful investigation of AAC implementation *outcomes*; however, little is known about characteristics associated with the *likelihood of access* to AAC, which the current study seeks to evaluate as an important first step in the implementation process. In addition to characteristics at the child level that may impact individuals' ability to access appropriate AAC, external characteristics are also likely to play a role. Environmental factors such as provider attitudes and intervention philosophy play an important role in facilitating access to AAC; providers who view AAC as facilitating communication rather than impeding spoken language may be more likely to facilitate the use of AAC (Donato et al., [12]; Moorcroft et al., [38]). In addition, some studies have suggested that low socioeconomic status (SES) may serve as a barrier to access to AAC (Moorcroft et al., [38]), although household income as a proxy for SES has not been systematically evaluated in relation to AAC use in autistic youth.

Current study

The current study seeks to address these demographic (e.g., age, sex, income, parental education), clinical (IQ, receptive and expressive language), and contextual (e.g., type of setting) gaps in the autism AAC literature with three distinct aims: (1) to characterize AAC use for autistic youth in inpatient settings, (2) to explore bivariate associations between

child characteristics and demographic characteristics and AAC use, and (3) to investigate whether demographic characteristics moderate the association between expressive language and AAC use. We aimed to understand characteristics associated with AAC use for this population rather than AAC performance specifically, and therefore we hypothesized that child cognitive/language characteristics (e.g., NVIQ, expressive and receptive language) would be negatively associated with AAC use, given that AAC may more frequently be accessed by those with lower levels of spoken language. We further hypothesized that age would be negatively associated with AAC use, consistent with prior research showing that AAC tends to be more effective for younger children than older children (Ganz et al., [21]). Based on existing research (Kulkarni & Parmar, [33]; Moorcroft et al., [38]), we hypothesized a negative association between demographic characteristics such as non-white race and lower SES with AAC use, although these hypotheses were highly exploratory in nature given that research on these issues is still emerging. Finally, based on findings that youth with co-occurring conditions may have more difficulty with AAC use (Ganz et al., [21]), we developed an exploratory hypothesis that child characteristics including self-injury, level of autism traits, and irritability would be negatively associated with AAC use. We also conducted exploratory moderation analyses, to consider the possibility that demographic factors may differentially relate to AAC use across different levels of clinical variables.

Method

Participants and Procedure

Participants in this study were 527 autistic individuals ages 4–20 years. The mean participant age was 12.94 years (*SD* = 3.39). The sample was predominantly white (79.0%) and male (78.7%), and the majority of participating caregivers reported a high school education or less. See Table 1 for full demographic information. This sample was derived from the Autism Inpatient Collection (AIC) at the Interactive Autism Network (Siegel et al., [41]). Participants were recruited from a multi-site collaboration from six child and adolescent inpatient psychiatric units between 2014 and 2016. Inclusion criteria required that participants were not on probation or house arrest and had at least one parent or caregiver who knew the child at 4–5 years of age and was proficient in English. Participants' autism diagnoses were confirmed by clinical cutoffs on the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2; Lord et al., [34]) per *DSM*-5 criteria by research-reliable clinicians. Informed consent was obtained from the child participants' legal guardians to include their children's data in the AIC and monitored by the Institutional Review Boards (IRB) at each data collection site. Consent was also obtained to share de-identified data with a searchable online data portal (SFARI Base). The current study obtained permission through SFARI Base and the Virginia Tech IRB to access the deidentified AIC dataset. Children and caregivers were administered a wide range of measures at admission, during their hospitalization, at discharge and at follow-up. For a detailed review of the AIC study methods, see Siegel et al., ([41]).

Table 1 Demographic Characteristics

Variable	n	M (SD) or %
Child age	527	12.94 (3.38)
Child sex	527	
Male	415	78.7%
Child race	517	
American Indian or Alaskan Native	14	2.7%
Native Hawaiian or Other Pacific Islander	0	0%
Black or African American	57	11.0%
Asian	17	3.3%

Variable	n	M (SD) or %
White	418	80.9%
Other	11	2.1%
Child Ethnicity	464	
Hispanic/Latino	26	5.6%
First Parent/Guardian Education	460	
Less than high school	28	5.7%
High school or some college	265	57.6%
Bachelor's degree or higher	169	36.7%
Second Parent/Guardian Education	397	
Less than high school	34	8.6%
High school or some college	219	55.2%
Bachelor's degree or higher	144	36.3%
Total household income (USD)	438	
<$20,000-$35,000	174	39.7%
$36,000–65,000	108	24.7%
$66,000-$100,000	64	14.6
$101,000+	92	21.0%

Measures

AAC Use Survey

Caregivers were asked, either as part of the admission process or through a specific AAC survey, whether their children utilized any AAC. The AAC survey was only administered during one study phase; children who received the AAC survey (n = 137) did not differ from children who did not receive the AAC survey on household income, caregiver education, age, sex, or expressive language level. A significantly higher proportion of caregivers of white than non-white children received the supplementary AAC survey, χ^2[1, 527] = 14.14, p <.001; however, AAC use data was available for all 527 participants either from intake information or the AAC survey. AAC use was coded as a binary yes/no variable. We classified AAC use as present if caregivers endorsed the current use of any AAC (i.e., sign language, sight board, voice generating devices, PECS, photos, text, etc.) either on the intake demographics form or the separate AAC survey.

Leiter International Performance Scale, Third Edition (Leiter-3; Roid et al., 2013)

The Leiter-3 is an assessment of estimated nonverbal cognitive ability (i.e., NVIQ) developed for individuals 3–75 years old. The measure produces standard scores with a mean of 100 and standard deviation of 15. The average NVIQ score in the current sample was 74.81 (*SD* = 29.24, Range = 30–145).

ADOS-2 (Lord et al., 2012)

The ADOS-2 is a semi-structured behavioral observation of an individual's autistic traits and produces two domain scores (Social Affect and Restricted, Repetitive Behaviors) and a comparison score (CS) to compare across ADOS modules, which are based on language and developmental level. In the current study, 201 participants were administered module 1, 67 module 2, 206 module 3, and 53 module 4.

Repetitive behavior scale-revised (RBS-R; Bodfish et al., 2000)

The RBS-R is a 43-item parent-report measure of restricted and repetitive behaviors across six subscales that measures the presence of behavior (dichotomously: does vs. does not occur) and the severity level of present behaviors: 1 (*mild problem*), 2 (*moderate problem*), 3 (*severe problem*). For the current study, a subset of caregivers (n = 120) completed the Self-injurious Behaviors (SIB) subscale (8-item). The mean number of endorsed SIB at admission was 3.97 (SD = 2.41) and the mean SIB total score was 7.68 (SD = 5.69).

Aberrant behavior Checklist Community (ABC; Aman et al., 1985)

The ABC is a 58-item parent-report measure, originally designed to assess treatment-related changes in psychiatric service settings. Each item is scored on a four-point Likert-type scale: 0 (*not at all a problem*), 1 (*slight problem*), 2 (*moderately serious*), and 3 (*severe*). The Irritability subscale of the ABC, which measures aggression, mood lability, and agitation, was utilized in the current study. The average score on the ABC Irritability subscale at admission was 27.56 (SD = 9.36).

Vineland Adaptive Behavior Scales, 2nd Edition (Vineland-II; Sparrow et al., 2005)

The Vineland-II parent/caregiver survey form is a measure of a child's adaptive behaviors that yields Domain level standard scores and Subdomain level v-scale scores (M = 15, SD = 3). The frequency of behaviors is assessed on a three-point Likert scale: 0 (*never*), 1 (*sometimes*), 2 (*usually*). The current study examined participant's abilities in the Expressive subdomain within the Communication domain (M = 6.77, SD = 4.33). The Expressive subdomain refers to the extent to which an individual uses spoken words and sentences to communicate and has demonstrated excellent convergent validity with other standardized measures of expressive language (e.g., Bayley Scales; Scattone et al., [40]).

Peabody Picture Vocabulary Test-4th Edition (PPVT-4; Dunn & Dunn 2007)

The PPVT-4 is an assessment of receptive vocabulary comprising 228 items (i.e., nouns, verbs, adjectives across 20 different topics) that provides age-normed standard scores (M = 100, SD = 15). One subset of children in the current sample (n = 110) received the PPVT-4. Receptive vocabulary levels were relatively low, though range in the sample was substantial (M = 67.66, SD = 33.76).

Analytic Plan

First, we described overall reported use and types of AAC in the sample. Next, we analyzed correlations between AAC use and relevant child-level and demographic characteristics. Point-biserial correlations, which provide the correlation between a continuous and a binary variable, were conducted given that AAC use was coded as binary. We also conducted bivariate analyses (e.g., Chi-square tests) to further understand associations between demographic characteristics and AAC use. Finally, we conducted hierarchical logistic regression to evaluate whether demographic characteristics with a significant main effect on AAC use moderated this association.

Results

Descriptive statistics

Of total youth in the AIC sample, 42.5% used at least one AAC method. In the subsample that received the AAC survey that included additional information about types of AAC methods (n = 137), 24.1% of children used sign language, 43.3% used PECS, 44.2% used photos, 51.3% used some form of symbol, 28.1% used a voice generating device, and

34.1% used text.

Child characteristic analyses

AAC use was negatively associated with NVIQ, $r = -.35$, p <.001, $df = 410$, receptive language, $r = -.22$, $p = .02$, $df = 108$ and caregiver-reported expressive language, $r = -.44$, $p < .001$, $df = 385$. There was a moderate positive correlation between AAC use and caregiver-reported self-injury on the RBS-R, $r = .23$, $p < .001$, $df = 314$. AAC use was not associated at the bivariate level with the overall autism comparison score on the ADOS-2 nor the Irritability subscale of the ABC. See Table 2 for all correlation analyses.

Table 2 Correlations between study variables

	1	2	3	4	5	6	7	8	9	10
1. AAC Use	--									
2. White Race	--	--								
3. Income	− 0.03	0.08	--							
4. Age	0.04	− 0.02	0.14**	--						
5. NVIQ	− 0.35***	0.14**	0.10	− 0.27***	--					
6. Receptive Language	− 0.22*	0.00	0.00	− 0.47***	0.80***	--				
7. ADOS Comparison Score	− 0.00	− 0.00	0.01	0.10*	0.04	− 0.18	--			
8. Child Sex	--	--	− 0.02	− 0.00	− 0.03	− 0.06	0.01	--		
9. Expressive Language	− 0.44***	0.14**	0.04	− 0.36***	0.69***	0.74***	− 0.07	− 0.04	--	
10. Self Injurious Behavior	0.23***	0.05	− 0.15*	− 0.01	− 0.25***	--	0.04	0.08	− 0.24***	--
11. ABC Irritability	0.05	0.35	− 0.14**	− 0.19***	− 0.12*	0.15	− 0.09	0.16***	− 0.09	0.55***

Note. *<0.05 **<0.01 ***<0.001. **Bolded = statistically significant.** Correlations between a categorical and a continuous variable are point-biserial; correlations between two continuous variables are Pearson's correlations. Correlations between two binary variables (race, AAC use, sex) are not reported

Demographic analyses

We conducted chi-square analyses to investigate differences in AAC use between race and sex. Pearson chi-square analyses revealed no differences in AAC use between males and females $\chi^2[1, 527] = 0.09$, $p = .764$, but significant differences within race, $\chi^2[1, 527] = 9.72$, $p = .002$, such that white children (45.93%) were more likely to use an AAC device than non-white children (29.36%). Point-biserial correlations (see Table 2) showed that AAC use was not associated with child age, $r = .04$, $p = .42$, $df = 525$, nor household income, $r = -.03$, $p = .48$, $df = 436$. Similarly, there was no correlation between AAC use and first caregiver education, $r = -.04$, $p = .36$, $df = 458$, nor second caregiver education, $r = -.02$, $p = .66$, $df = 395$.

At the multivariate level, hierarchical logistic regression analyses were used to consider whether demographic characteristics (income, age, sex, race) independently associated with AAC use or moderated the association between AAC use and expressive language. Step one of our hierarchical model included demographic characteristics; we also included NVIQ in step one in order to account for the association between NVIQ and verbal expression. Step two of the model added verbal expression to identify whether verbal expression was associated with AAC use even when accounting for estimated nonverbal cognitive ability. Receptive language was excluded from the model to maximize power

due to its strong association (collinearity) with other included variables (e.g., correlation of 0.80 between receptive language and NVIQ). In step three of the hierarchical model, we examined whether expressive language moderated the association between AAC use and significant demographic predictors.

Age was significantly associated with AAC use when controlling for other individual characteristics with an odds ratio of 0.61, indicating that older children are less likely to use AAC. There was no interaction effect between age and expressive language. Other demographic characteristics did not demonstrate a main effect on AAC use in regression analyses, and thus were not included in moderation analyses. NVIQ (OR = 0.62) and expressive communication (OR = 0.43) both significantly predicted AAC use even when controlling for demographic characteristics such that children with higher NVIQ or expressive language were less likely to use AAC. Post-hoc power analyses indicated that the sample was adequately powered to detect medium effect sizes. See Table 3 for full regression results.

Table 3 Hierarchical Logistic Regression Predicting AAC Use

	Cox & Snell R^2	**B(SE)**	**Wald**	**p**	**Odds Ratio**
Block 1	0.16***				
Nonverbal IQ		− 0.93(0.15)	38.60	< 0.001***	0.40
Household Income		0.01(0.14)	0.01	0.919	1.01
Age		− 0.32(0.14)	5.12	0.024*	0.73
Female Sex		− 0.04(0.31)	0.01	0.912	0.97
White Race		− 0.26(0.41)	0.41	0.520	0.77
Block 2	0.20***				
Nonverbal IQ		− 0.48(0.18)	6.90	0.009**	0.62
Household Income		0.07(0.14)	0.27	0.604	1.08
Age		− 0.50(0.16)	10.23	0.001***	0.61
Female Sex		− 0.02(0.32)	0.002	0.964	0.99
White Race		− 0.19(0.41)	0.22	0.643	0.83
Expressive Language		− 0.84(0.21)	15.83	< 0.001***	0.43
Block 3	0.22***				
Nonverbal IQ		− 0.48(0.18)	7.05	0.008**	0.62
Household Income		0.07(0.14)	0.22	0.64	1.07
Age		− 0.50(0.16)	10.48	0.001***	0.61
Female Sex		− 0.04(0.32)	0.01	0.913	0.97
White Race		− 0.17(0.41)	0.17	0.681	0.84
Expressive Language		− 0.87(0.22)	16.31	< 0.001***	0.42
EL*Age		0.14(0.17)	0.66	0.415	1.15

Note. *<0.05 **<0.01 ***<0.001. **Bolded = statistically significant.** EL = expressive language

Discussion

The results of the current study suggest several important findings regarding AAC use in an inpatient sample. Overall, these findings suggest high relative frequency of AAC use in inpatient autistic youth (i.e., 42.5%), which has implications for future research and clinical practice. Furthermore, our results suggest important correlates of AAC use across child and family characteristics including child verbal expression, NVIQ, and non-white race. Given the substantial proportion of autistic people who seek psychiatric care, the results presented here highlight the importance of ensuring access to inclusive communication strategies across mental health settings for youth with a variety of communication needs. Further, the range of AAC strategies reported by families in the current study suggest the importance of provider familiarity with multiple types of AAC in order to facilitate their use.

Frequency of AAC use

Approximately 42.5% of surveyed caregivers reported that their child used at least one form of AAC. Considering that many autistic youth will experience a psychiatric hospitalization at some point in their lifetime, this high level of AAC use has important implications for inpatient psychiatric settings, as well as future research at the provider level. Future work should consider levels of comfort with AAC devices for psychiatric unit staff members and providers. Furthermore, from a clinical perspective, AAC device use should be considered within treatment planning for patients. While the current study did not investigate provider knowledge of AAC use or accessibility of care, future work should consider whether offering providers training in the use of a range of AAC strategies may make psychiatric care more accessible for autistic youth. Future descriptive work evaluating levels of AAC use that occur during inpatient stays would be beneficial in informing these applied questions. Furthermore, the frequency of AAC use in this sample provides some initial indication that providers may benefit from consultation with AAC experts such as speech language pathologists as part of the interdisciplinary treatment team. When possible, families of children who currently utilize AAC strategies may benefit from inquiring about how AAC is integrated into various hospital contexts. Overall, this line of work will be critical in improving the accessibility of the inpatient setting for autistic patients. As this line of research progresses, it will be important for policymakers and administrators to provide updated guidance for providers on integrating AAC use into the inpatient setting.

Child characteristics Associated with AAC use

Level of autistic traits was not associated with AAC use in this sample. This suggests that provider knowledge and comfort with AAC devices is critical across a range of settings and with youth with a range of autistic traits. Other child characteristics were associated with AAC use, including NVIQ, receptive language, and expressive communication. Lower levels of NVIQ and expressive communication were associated with increased likelihood of AAC use even when accounting for other factors in logistic regression. Given that AAC devices are more likely to be accessed by youth with lower levels of spoken language, these associations are as hypothesized. Providers in inpatient settings with high rates of non-speaking autistic patients should therefore be particularly mindful of how AAC use may best be integrated into treatment within the hospital setting, although supporting communication through AAC and/or other methods is also critically needed with autistic youth with varying language levels. Improved integration of AAC in psychiatric care is of particular importance given that AAC demonstrates effectiveness in improving provider-patient communication in other hospital settings (Carruthers et al., [11]). For autistic youth with complex communication needs who do not utilize AAC systems, clinicians may consider recommending follow-ups with speech language pathologists or other AAC specialists upon discharge.

Demographic factors

Significantly more white youth were reported to use AAC than non-white youth in Chi-square analyses, although there was no association for race in logistic regression analyses when accounting for other characteristics. Importantly, it should be noted that the relatively small sample size of non-white participants may have played a role in these results. This finding may highlight the multiple barriers to supports experienced by youth who identify with non-white racial groups, and highlights the need for improved access to AAC among these youth. Future research should investigate potential barriers to AAC for non-white populations, as well as consider potential interventions to ameliorate such barriers. As one potential example, some families identify that it is difficult to access AAC in their primary language, which limits its usefulness (Kulkarni & Parmar, [33]). While caregivers in the current study were required to be proficient in English, it is critical that future research evaluate AAC across a variety of languages to determine how family primary language

may play a role. Furthermore, focus groups have suggested that modifications to AAC protocols may be necessary to make them accessible to marginalized ethnic groups (Binger et al., [5]). Given that our findings are in line with previous literature, further investigation is warranted. However, because race was significantly associated with AAC use at the bivariate level, but not in multiple regression analysis, future research should consider why this finding is not robust when accounting for other clinical factors.

While age and AAC use were not related in binary analyses, there was a significant association of age with AAC use when accounting for other factors, particularly NVIQ and expressive language, such that younger children were more likely to use an AAC. This is consistent with past findings that younger children adapt more easily to using AAC (Ganz et al., [21]); however, it also indicates a need to consider how AAC can continue to be an effective tool as children age. Providers who work with young children may encounter AAC with the most frequency; this suggests that improved comfort with AAC should be a priority for this subset of providers, although providers for youth across developmental stages would likely benefit from increased familiarity with these communication strategies. Given the substantial age range in this study, these results may also reflect improvements in AAC accessibility in recent years. Furthermore, attitudes toward AAC among autism professionals such as early intervention providers have changed significantly in recent years, such as an increased emphasis on interdisciplinary approaches that encourage AAC use (Marks, [36]). These shifting attitudes may also facilitate AAC use among younger children in this sample; future research should thoroughly consider the effects of such attitude shifts.

Significant associations for AAC use with sex and household income were not detected in this sample. The nonsignificant sex finding may suggest that AAC use is common for autistic youth of both sexes; however, more work in this area is needed given that this was a predominantly male sample. It is interesting that family income (as a proxy for SES) was not associated with AAC use; future research should further investigate this association, perhaps considering non-linear models to account for socioeconomic concerns such as insurance coverage gaps.

Limitations

Several important limitations of the current study should be noted. The sample was predominantly white, which may have limited our ability to conduct analyses related to racial or ethnic identity differences. In particular, the small sample size of non-white participants may have impacted our ability to capture racial or ethnic differences in AAC use. It is essential to recognize this limitation particularly in the context of our findings that race was associated with AAC use at the bivariate, but not the multivariate, level. This finding may suggest that other factors account for the bivariate association between race and AAC use, or may be an indication of low power. However, we hope that the pilot data presented here may inform future research questions related to racial disparities in AAC use. In addition, we were not able to examine communicative intent of AAC use to better understand participants' reasons for using AAC, and we did not have access to information about how AAC was used during the inpatient stay itself. Furthermore, our data was based on parent self-report; future research using behavioral data on AAC use will prove beneficial in further understanding AAC use in this population. The analyses presented here also did not allow for exploration of how AAC use may be related to treatment and quality of life outcomes either during inpatient hospitalization or at follow-up.

Future research and conclusion

The research presented here suggests several important future directions in the field of AAC among autistic youth. While this study offers an understanding of characteristics associated with AAC use in an inpatient setting, future work would benefit from examining such characteristics in an outpatient population who may be experiencing lower levels of clinical distress. Furthermore, additional research in this area should consider how AAC is implemented within inpatient settings, as well as how AAC use may influence treatment planning and treatment outcomes for autistic individuals in the inpatient setting. Improving our understanding of multiple facets of AAC use should be considered a key goal of future research. Applied studies can examine intervention strategies such as training for inpatient staff on AAC use and investigate systematic integration of AAC systems into inpatient settings. Furthermore, it will be important for future work to further investigate race differences in AAC use; should our findings be replicated, it will be critical to identify strategies for reducing disparities in access to or use of AAC.

The results presented here provide an important foundation of knowledge regarding AAC use in an inpatient psychiatric setting and suggest the importance of this topic for clinical practice in acute settings broadly. Considering the variety of settings in which autistic youth may receive healthcare, it is critical to better understand avenues for enhancing communication across settings and communication methods, including AAC. This line of research has the potential to build on our knowledge of the experiences of autistic individuals, as well as improve clinical services for individuals who utilize AAC devices as communication tools.

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Declarations

Conflict of interest

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Footnotes

Identity-first language (e.g., "autistic") is used instead of person-first language (e.g., "person with autism") to be consistent with clinical and research recommendations (Bottema-Beutel et al., [8]; Kenny et al., [30]). We also utilized language recommendations utilized in this paper including "non-speaking" or "partially verbal" instead of "minimally verbal," and "co-occurring" instead of "comorbid" (Bottema-Beutel et al., [8]; Botha et al., [7]; Bradshaw et al., [9]).

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By Elizabeth A. DeLucia; Tyler C. McFayden; Megan Fok; Theresa M. Andrzejewski; Angela Scarpa and Christina G. McDonnell

Reported by Author; Author; Author; Author; Author; Author
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Source: Journal of autism and developmental disorders, 2024 May, Vol. 54 Issue 5, p2060

Item: 35796911

Record: 41

Title: Caring for the Child With an Autism Spectrum Disorder in the Acute Care Setting

Authors: Scarpinato, Nina
Bradley, Jana
Kurbjun, Kay
Bateman, Xenia
Holtzer, Brenda
Ely, Beth

Source: *Journal for Specialists in Pediatric Nursing*. Jul 01, 2010 15(3):244-254

Publication Year: 2010

Description: PURPOSE.: This article explores the challenges that patients with autistic spectrum disorders (ASDs) face when hospitalized and provides assessment strategies and plan-of-care suggestions for nursing caregivers. CONCLUSIONS.: With a high prevalence rate of medical comorbidities among this population, such as gastrointestinal complaints and seizures, nurses are likely to care for hospitalized patients with an ASD. PRACTICE IMPLICATIONS.: For a child with an ASD, hospitalization can be an overwhelming sensory and cognitive experience. Nurses equipped with an understanding of the unique needs of a child with ASD can tailor the plan of care to reduce patient and family anxiety, optimize treatment goals, and reduce the stress of hospitalization.

Language: English

Author Affiliations: 1The Children’s Hospital of Philadelphia, Philadelphia, Pennsylvania, USA.

ISSN: 1539-0136

DOI: 10.1111/j.1744-6155.2010.00244.x

Availability: http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=fulltext&D=ovft&CSC=Y&NEWS=N&SEARCH=01253237-201007000-00009.an

Accession Number: edsovi.01253237.201007000.00009

Database: Journals@OVID

Record: 42

Title: Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals.

Authors: Muskat, Barbara
Burnham Riosa, Priscilla
Nicholas, David B
Roberts, Wendy
Stoddart, Kevin P
Zwaigenbaum, Lonnie

Source: Autism: The International Journal of Research & Practice; May2015, Vol. 19 Issue 4, p482-490, 9p

Publication Year: 2015

Subject Terms: CHILDREN
TEENAGERS
TREATMENT of autism
AUTISM
COMMUNICATION
HOSPITALS
INTERVIEWING
MEDICAL care
MEDICAL cooperation
MEDICAL personnel
PARENTS
PATIENTS
PEDIATRICS
RESEARCH
RESEARCH funding
SENSORIMOTOR integration
QUALITATIVE research
JUDGMENT sampling
DATA analysis software

DESCRIPTIVE statistics
DISEASE complications

Geographic Terms: CANADA

Author-Supplied Keywords: autism spectrum disorder
health care
hospital
medical
paediatric
qualitative methods

NAICS/Industry Codes: NAICS/Industry Codes 622110 General Medical and Surgical Hospitals
622111 General (except paediatric) hospitals

Document Type: Article

Abstract: Youth with autism spectrum disorder are a vulnerable, often poorly understood patient group, who may experience periodic and chronic health challenges, in addition to their primary developmental social and communication problems. Developmental and behavioural challenges can complicate management of acute health-care needs. To date, there is an absence of empirical research exploring the hospital experiences of children and youth with autism spectrum disorder, their families and their health-care providers. Therefore, the purpose of this study was to understand these experiences in order to inform hospital-based care. A total of 42 participants were interviewed (youth with autism spectrum disorder, their parents and health-care providers) at one of two Canadian paediatric hospitals, representing 20 distinct cases of patients with autism spectrum disorder. Results from the qualitative analyses indicated that patients with autism spectrum disorder faced several challenges in the context of health-care delivery in the hospital setting, as did their families and health-care provider team. Problems identified included communication and sensory challenges, and the degree of flexibility of health-care providers and the hospital organization. Supportive health-care providers were those who acknowledged parents as experts, inquired about the requirements of patients with autism spectrum disorder and implemented strategies that accommodated the unique clinical presentation of the individual patient. These recommendations have wide-reaching utility for hospital and health-care practices involving this patient group. [ABSTRACT FROM PUBLISHER]

ISSN: 13623613

DOI: 10.1177/1362361314531341

Accession Number: 102085882

Database: Complementary Index

Record: 43

Title: Providing Inpatient Medical Care to Children With Autism Spectrum Disorder.

Authors: Thom, Robyn P.
Hazen, Melissa M.
McDougle, Christopher J.
Hazen, Eric P.

Source: Hospital Pediatrics; Oct2020, Vol. 10 Issue 10, p918-924, 7p

Publication Year: 2020

Document Type: Article

ISSN: 21541663

DOI: 10.1542/hpeds.2020-0140

Accession Number: 146322598

Database: Complementary Index

Record: 44

Title: Children with learning disabilities in the paediatric clinic, Hospital Tuanku Ja'afar Seremban: an overview.

Authors: Mariana AM; Department of Paediatrics, Hospital Tuanku Ja'afar Seremban, Jalan Rasah, 70300 Seremban, Malaysia.
aina.mariana@ns.moh.gov.my
Wong SL

Source: The Medical journal of Malaysia [Med J Malaysia] 2011 Dec; Vol. 66 (5), pp. 487-90.

Publication Type: Journal Article

Language: English

Journal Info: *Publisher:* Malaysian Medical Association *Country of Publication:* Malaysia *NLM ID:* 0361547 *Publication Model:* Print *Cited Medium:* Print *ISSN:* 0300-5283 (Print) *Linking ISSN:* 03005283 *NLM ISO Abbreviation:* Med J Malaysia *Subsets:* MEDLINE

Imprint Name(s): *Original Publication*: Kuala Lumpur : Malaysian Medical Association

MeSH Terms: Learning Disabilities/*epidemiology
Child ; Child, Preschool ; Cross-Sectional Studies ; Female ; Hospitals, Pediatric ; Humans ; Malaysia/epidemiology ; Male ; Prevalence

Abstract: The aim of the study was to document the prevalence of learning disability among the children attending the Paediatric Clinic in Hospital Tuanku Ja'afar Seremban. The demographic distribution of these patients; the age of detection of the problem; the associated medical conditions and types of intervention received by these patients were documented. Patients who were between the ages of five to twelve years were included in the study. Learning disability was divided into three categories: speech and articulation problems, academic skills disorder and other categories which included developmental delay. Children with cerebral palsy were excluded from the study. Out of 1320 patients screened, 355 were found to have learning disorders. Majority were Malays, with the male to female ratio of 1.9:1. Most of the patients stayed in Seremban. The learning problem was most commonly detected at the age of 4 years and below. The commonest type of learning disorder was developmental delay, followed by academic skills disorder, speech and academic skills problems and speech disorders. Problems that were detected early were speech problems and developmental delay. Majority of the children had associated medical conditions. Most of the patients received some form of intervention but 11.3% did not attend any intervention program at all. A strategy should be formulated and implemented to help this group of children.

Entry Date(s): *Date Created:* 20120307 *Date Completed:* 20120405 *Latest Revision:* 20191210

Update Code: 20250114

PMID: 22390107

Database: MEDLINE Complete

Record: 45

Title: Equal access to hospital care for children with learning disabilities and their families: a mixed-methods study.

Authors: Oulton, Kate
Wray, Jo
Kenten, Charlotte
Russell, Jessica
Carr, Lucinda
Hassiotis, Angela
Jewitt, Carey
Kelly, Paula
Kerry, Sam

Tuffrey-Wijne, Irene
Whiting, Mark
Gibson, Faith

Source: Health & Social Care Delivery Research (HSDR); 6/21/2022, Vol. 10 Issue 13/14, pv-167, 169p

Publication Year: 2022

Document Type: Article

ISSN: 27550060

DOI: 10.3310/NWKT5206

Accession Number: 157882969

Database: Complementary Index

Record: 46

Title: Pay More Attention: a national mixed methods study to identify the barriers and facilitators to ensuring equal access to high-quality hospital care and services for children and young people with and without learning disabilities and their families.

Authors: Oulton, Kate
Wray, Jo
Carr, Lucinda
Hassiotis, Angela
Jewitt, Carey
Kerry, Sam
Tuffrey-Wijne, Irene
Gibson, Faith

Source: BMJ Open; 12/9/2016, Vol. 6 Issue 12, p1-11, 11p

Publication Year: 2016

Document Type: Article

Abstract: Introduction: Despite evidence of health inequalities for adults with intellectual disability (ID) there has yet to be a comprehensive review of how well hospital services are meeting the needs of children and young people (CYP) with ID and their families. We do not know how relevant existing recommendations and guidelines are to CYP, whether these are being applied in the paediatric setting or what difference they are making. Evidence of parental dissatisfaction with the quality, safety and accessibility of hospital care for CYP with ID exists.

However, the extent to which their experience differs from parents of CYP without ID is not known and the views and experiences of CYP with ID have not been investigated. We will compare how services are delivered to, and experienced by CYP aged 5-15 years with and without ID and their families to see what inequalities exist, for whom, why and under what circumstances. Methods and analysis: We will use a transformative, mixed methods case study design to collect data over four consecutive phases. We will involve CYP, parents and hospital staff using a range of methods; interviews, parental electronic diary, hospital and community staff questionnaire, patient and parent satisfaction questionnaire, content analysis of hospital documents and a retrospective mapping of patient hospital activity. Qualitative data will be managed and analysed using NVivo and quantitative data will be analysed using parametric and non-parametric descriptive statistics. Ethics and dissemination: The study will run from December 2015 to November 2018. We have Health Authority Approval (IRAS project ID: 193932) for phase 1 involving staff only and ethical and Health Authority Approval for phases 2-4 (IRAS project ID: 178525). We will disseminate widely to relevant stakeholders, using a range of accessible formats, including social media. We will publish in international peer-reviewed journals and present to professional, academic and lay audiences through national and international conferences. [ABSTRACT FROM AUTHOR]

ISSN: 20446055

DOI: 10.1136/bmjopen-2016-012333

Accession Number: 120214289

Database: Complementary Index

Record: 47

Title: Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform.

Authors: Williamson EJ; London School of Hygiene and Tropical Medicine, London, UK.
McDonald HI; London School of Hygiene and Tropical Medicine, London, UK.; National Institute for Health Research (NIHR) Health Protection Research Unit in Vaccines and Immunisation, London, UK.
Bhaskaran K; London School of Hygiene and Tropical Medicine, London, UK.
Walker AJ; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Bacon S; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.

Davy S; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Schultze A; London School of Hygiene and Tropical Medicine, London, UK.
Tomlinson L; London School of Hygiene and Tropical Medicine, London, UK.
Bates C; TPP, TPP House, Horsforth, Leeds, UK.
Ramsay M; National Institute for Health Research (NIHR) Health Protection Research Unit in Vaccines and Immunisation, London, UK.; Public Health England, London, UK.
Curtis HJ; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Forbes H; University of Bristol, Bristol, UK.
Wing K; London School of Hygiene and Tropical Medicine, London, UK.
Minassian C; London School of Hygiene and Tropical Medicine, London, UK.
Tazare J; London School of Hygiene and Tropical Medicine, London, UK.
Morton CE; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Nightingale E; London School of Hygiene and Tropical Medicine, London, UK.
Mehrkar A; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Evans D; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Inglesby P; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
MacKenna B; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Cockburn J; TPP, TPP House, Horsforth, Leeds, UK.
Rentsch CT; London School of Hygiene and Tropical Medicine, London, UK.
Mathur R; London School of Hygiene and Tropical Medicine, London, UK.
Wong AYS; London School of Hygiene and Tropical Medicine, London, UK.
Eggo RM; London School of Hygiene and Tropical Medicine, London, UK.
Hulme W; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Croker R; The DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.
Parry J; TPP, TPP House, Horsforth, Leeds, UK.
Hester F; TPP, TPP House, Horsforth, Leeds, UK.
Harper S; TPP, TPP House, Horsforth, Leeds, UK.
Douglas IJ; London School of Hygiene and Tropical Medicine, London, UK.
Evans SJW; London School of Hygiene and Tropical Medicine, London, UK.
Smeeth L; London School of Hygiene and Tropical Medicine, London, UK.

Goldacre B; National Institute for Health Research (NIHR) Health Protection Research Unit in Vaccines and Immunisation, London, UK.
Kuper H; London School of Hygiene and Tropical Medicine, London, UK.

Source: BMJ (Clinical research ed.) [BMJ] 2021 Jul 14; Vol. 374, pp. n1592. *Date of Electronic Publication:* 2021 Jul 14.

Publication Type: Journal Article; Research Support, Non-U.S. Gov't

Language: English

Journal Info: *Publisher:* British Medical Association *Country of Publication:* England *NLM ID:* 8900488 *Publication Model:* Electronic *Cited Medium:* Internet *ISSN:* 1756-1833 (Electronic) *Linking ISSN:* 09598138 *NLM ISO Abbreviation:* BMJ *Subsets:* MEDLINE

Imprint Name(s): *Original Publication*: London : British Medical Association

MeSH Terms: COVID-19/*epidemiology
Hospitalization/*statistics & numerical data
Learning Disabilities/*epidemiology
Adolescent ; Adult ; Aged ; Aged, 80 and over ; Cerebral Palsy/epidemiology ; Cohort Studies ; Persons with Disabilities ; Down Syndrome/epidemiology ; England/epidemiology ; Female ; Humans ; Male ; Middle Aged ; Young Adult

Abstract: **Competing Interests:** Competing interests: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare the following: support from the Medical Research Council, TPP, NIHR Oxford Biomedical Research Centre, NIHR Applied Research Collaboration Oxford and Thames Valley, Mohn-Westlake Foundation, NHS England, NIHR Health Protection Research Unit in Vaccines and Immunisation, the Foreign, Commonwealth and Development Office, and the Health Foundation for the submitted work. EJW has received payments from AstraZeneca for providing training, unrelated to the submitted work. BG has received research funding from the Laura and John Arnold Foundation, the NHS National Institute for Health Research (NIHR), the NIHR School of Primary Care Research, the NIHR Oxford Biomedical Research Centre, the Mohn-Westlake Foundation, NIHR Applied Research Collaboration Oxford and Thames Valley, the Wellcome Trust, the Good Thinking Foundation, Health Data Research UK (HDRUK), the Health Foundation, and the World Health Organization; he also receives personal income from speaking and writing for lay audiences on the misuse of science. IJD has received unrestricted research grants and holds shares in GlaxoSmithKline (GSK) and holds grants from NIHR. LS reports grants from Wellcome, MRC, NIHR, UK Research and Innovation (UKRI), British Council, GSK, British Heart Foundation, and Diabetes UK outside this work. AS is employed by the London School of Hygiene and Tropical Medicine (LSHTM) on a fellowship sponsored by GSK. KB holds a Sir Henry Dale fellowship jointly funded by Wellcome and the Royal Society. AYSW holds a fellowship from BHF. RM holds a Sir Henry Wellcome Fellowship funded by the Wellcome Trust. HF holds a UKRI fellowship. RME is funded by HDRUK and the MRC.

Objective: To assess the association between learning disability and risk of hospital admission and death from covid-19 in England among adults and children.

Design: Population based cohort study on behalf of NHS England using the OpenSAFELY platform.
Setting: Patient level data were obtained for more than 17 million people registered with a general practice in England that uses TPP software. Electronic health records were linked with death data from the Office for National Statistics and hospital admission data from NHS Secondary Uses Service.
Participants: Adults (aged 16-105 years) and children (<16 years) from two cohorts: wave 1 (registered with a TPP practice as of 1 March 2020 and followed until 31 August 2020); and wave 2 (registered 1 September 2020 and followed until 8 February 2021). The main exposure group consisted of people on a general practice learning disability register; a subgroup was defined as those having profound or severe learning disability. People with Down's syndrome and cerebral palsy were identified (whether or not they were on the learning disability register).
Main Outcome Measure: Covid-19 related hospital admission and covid-19 related death. Non-covid-19 deaths were also explored.
Results: For wave 1, 14 312 023 adults aged ≥16 years were included, and 90 307 (0.63%) were on the learning disability register. Among adults on the register, 538 (0.6%) had a covid-19 related hospital admission; there were 222 (0.25%) covid-19 related deaths and 602 (0.7%) non-covid deaths. Among adults not on the register, 29 781 (0.2%) had a covid-19 related hospital admission; there were 13 737 (0.1%) covid-19 related deaths and 69 837 (0.5%) non-covid deaths. Wave 1 hazard ratios for adults on the learning disability register (adjusted for age, sex, ethnicity, and geographical location) were 5.3 (95% confidence interval 4.9 to 5.8) for covid-19 related hospital admission and 8.2 (7.2 to 9.4) for covid-19 related death. Wave 2 produced similar estimates. Associations were stronger among those classified as having severe to profound learning disability, and among those in residential care. For both waves, Down's syndrome and cerebral palsy were associated with increased hazards for both events; Down's syndrome to a greater extent. Hazard ratios for non-covid deaths followed similar patterns with weaker associations. Similar patterns of increased relative risk were seen for children, but covid-19 related deaths and hospital admissions were rare, reflecting low event rates among children.
Conclusions: People with learning disability have markedly increased risks of hospital admission and death from covid-19, over and above the risks observed for non-covid causes of death. Prompt access to covid-19 testing and healthcare is warranted for this vulnerable group, and prioritisation for covid-19 vaccination and other targeted preventive measures should be considered.

References: Wellcome Open Res. 2021 Apr 27;6:90. (PMID: 34471703)
Ir J Psychol Med. 2020 Sep;37(3):231-236. (PMID: 32404232)
Kidney Int. 2016 Nov;90(5):943-949. (PMID: 27317356)
BMC Public Health. 2021 Mar 11;21(1):484. (PMID: 33706738)
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MMWR Morb Mortal Wkly Rep. 2021 Jan 01;69(5152):1657-1660. (PMID: 33382671)
Disabil Health J. 2020 Oct;13(4):100969. (PMID: 32600948)
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Ann Intern Med. 2021 Apr;174(4):572-576. (PMID: 33085509)
Int J Epidemiol. 2019 Aug 1;48(4):1294-1304. (PMID: 30879056)
Br J Gen Pract. 2020 Nov 26;70(701):e890-e898. (PMID: 33077508)
J Epidemiol Community Health. 2022 Jun;76(6):550-555. (PMID: 35232778)
Lancet Reg Health Eur. 2021 Jul;6:100109. (PMID: 33997835)
BMJ Open. 2018 Feb 5;8(2):e018292. (PMID: 29431619)
Semin Immunopathol. 2020 Oct;42(5):635-645. (PMID: 32705346)
BMJ. 2020 Aug 27;370:m3249. (PMID: 32960186)
BMJ Open. 2018 Feb 28;8(2):e020738. (PMID: 29490968)
Br J Gen Pract. 2011 Jul;61(588):438-9. (PMID: 21722461)
BJPsych Open. 2020 Oct 16;6(6):e123. (PMID: 33059790)
Eur J Hum Genet. 2020 Nov;28(11):1477-1478. (PMID: 32686759)
Lancet. 2014 Mar 8;383(9920):889-95. (PMID: 24332307)
Int J Equity Health. 2016 Jan 20;15:11. (PMID: 26791808)
Disabil Health J. 2020 Jul;13(3):100942. (PMID: 32473875)

Grant Information: MC_PC_20058 United Kingdom MRC_ Medical Research Council; MR/V015737/1 United Kingdom MRC_ Medical Research Council; MR/S003940/1 United Kingdom MRC_ Medical Research Council; MR/S01442X/1 United Kingdom MRC_ Medical Research Council; MR/S003975/1 United Kingdom MRC_ Medical Research Council

Entry Date(s): *Date Created:* 20210715 *Date Completed:* 20210726 *Latest Revision:* 20250530

Update Code: 20250530

PubMed Central ID: PMC8278652

DOI: 10.1136/bmj.n1592

PMID: 34261639

Database: MEDLINE Complete

Record: 48

Title: Development and Evaluation of an Educational Initiative to Improve Hospital Personnel Preparedness to Care for Children with Autism Spectrum Disorder.

Authors: Lucarelli, Jennifer
Welchons, Leah
Sideridis, Georgios
Sullivan, Nancy R.
Chan, Eugenia
Weissman, Laura

Source: Journal of Developmental & Behavioral Pediatrics; Jun2018, Vol. 39 Issue 5, p358-364, 7p

Publication Year: 2018

Document Type: journal article

ISSN: 0196206X

DOI: 10.1097/DBP.0000000000000580

Accession Number: 130265937

Database: Complementary Index

Record: 49

Title: [Autism spectrum disorder: the impact of an online training strategy on the knowledge of the healthcare staff of a tertiary care hospital].

Transliterated Title: Trastorno del espectro autista: impacto de una estrategia de formación en línea en los conocimientos del personal sanitario de un hospital de tercer nivel.

Authors: Alonzo-Castillo T; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.
Lugo-Marín J; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.
Robles M; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.
Rossich R; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.
Gallego L; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.
González M; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.
Setién-Ramos I; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.
Martínez-Ramírez M; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.

Ramos-Quiroga JA; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.
Gisbert-Gustemps L; Hospital Universitari Vall d'Hebron, 08035 Barcelona, España.

Source: Revista de neurologia [Rev Neurol] 2024 Jan 01; Vol. 78 (1), pp. 1-7.

Publication Type: English Abstract; Journal Article

Language: Spanish; Castilian

Journal Info: *Publisher:* IMR Press *Country of Publication:* Spain *NLM ID:* 7706841 *Publication Model:* Print *Cited Medium:* Internet *ISSN:* 1576-6578 (Electronic) *Linking ISSN:* 02100010 *NLM ISO Abbreviation:* Rev Neurol *Subsets:* MEDLINE

Imprint Name(s): *Publication*: 2024- : Singapore : IMR Press
Original Publication: Barcelona [Centro de Orientacion Escolar? 1973?]-

MeSH Terms: Autism Spectrum Disorder*/therapy
Autism Spectrum Disorder*/diagnosis
Humans ; Child ; Prospective Studies ; Tertiary Care Centers ; Health Personnel ; Health Knowledge, Attitudes, Practice

Abstract: **Introduction:** Autism spectrum disorder (ASD) often presents related medical disorders that require specialised healthcare. Professionals in the health sector therefore face difficulties that require specific training in the healthcare needs of this population.
Aim: The aim of this study is to quantify paediatric healthcare professionals' knowledge about ASD and to assess the impact of online training.
Subjects and Methods: It is a quasi-experimental, longitudinal, prospective before-and-after study; study subjects: health professionals; independent variable: online training in ASD; dependent variable: knowledge about ASD. An online training course was held for paediatric professionals to address the core characteristics of diagnosis, as well as the needs they present in the hospital context and the adaptations it is recommended that should be carried out. Fifty-eight healthcare professionals took part.
Results: An increase in knowledge about ASD was observed at the end of the intervention (from 73.9% to 85% according to the ASD background knowledge questionnaire), which showed that more than 90% of the participants had the highest level of knowledge about ASD.
Conclusions: Online training courses are a useful and effective way to increase knowledge about ASD and the adaptations that are recommended in the hospital setting. More training in ASD should be made available in these settings.

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Child Care Health Dev. 2010 Nov;36(6):753-5. (PMID: 21039752)

J Autism Dev Disord. 2005 Jun;35(3):323-30. (PMID: 16119473)
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An Pediatr (Barc). 2017 Jun;86(6):329-336. (PMID: 27325257)
J Autism Dev Disord. 2015 Jul;45(7):2209-17. (PMID: 25724445)
Autism Res Treat. 2012;2012:685053. (PMID: 22934179)
Korean J Pediatr. 2015 Jan;58(1):8-14. (PMID: 25729393)
J Autism Dev Disord. 2015 Dec;45(12):4002-14. (PMID: 26334872)
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Contributed Indexing: *Local Abstract:* [Publisher, Spanish; Castilian] Trastorno del espectro autista: impacto de una estrategia de formación en línea en los conocimientos del personal sanitario de un hospital de tercer nivel. [Publisher, Spanish; Castilian] Introducción. El trastorno del espectro autista (TEA) frecuentemente presenta trastornos médicos relacionados que requieren una atención sanitaria especializada. En este sentido, los profesionales del ámbito sanitario se enfrentan a dificultades que precisan una formación específica en las necesidades sanitarias que presenta esta población. Objetivo. Cuantificar los conocimientos sobre el TEA de los profesionales sanitarios del área pediátrica y valorar el impacto de una formación en línea. Sujetos y métodos. Estudio cuasi experimental del antes y después, longitudinal y prospectivo; sujetos a estudio: profesionales sanitarios; variable independiente: formación en línea en TEA; variable dependiente: conocimiento sobre el TEA. Se llevó a cabo una formación en línea para profesionales del área de pediatría en la que se abordaron las características nucleares del diagnóstico, así como las necesidades que presentan en el contexto hospitalario y las adaptaciones que se recomiendan llevar a cabo. Participaron 58 profesionales sanitarios. Resultados. Se observó un aumento en el conocimiento sobre el TEA al finalizar la intervención (del 73,9 al 85% según el cuestionario de conocimientos previos del TEA), que mostró que más del 90% de los participantes tenía el grado máximo de conocimiento sobre el TEA. Conclusiones. Las formaciones en línea son un método para ampliar conocimiento útil y eficaz para aumentar el conocimiento sobre el TEA y las adaptaciones que se recomiendan en el ámbito hospitalario. Se recomienda aumentar la disponibilidad de formación sobre TEA en estos entornos.

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PubMed Central ID: PMC11064939

DOI: 10.33588/rn.7801.2023244

PMID: 38112651

Database: MEDLINE Complete

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Title: A Pilot Study of Autism-Specific Care Plans During Hospital Admission.

Authors: Broder-Fingert, Sarabeth[1,2,3] *sarabeth.broder-fingert@bmc.org*

Shui, Amy[4]

Ferrone, Christine[3]

Iannuzzi, Dorothea[3]

Cheng, Erika R.[2]

Giauque, Ann[3]

Connors, Susan[3]

McDougle, Christopher J.[3]

Donelan, Karen[5]

Neumeyer, Ann[3]

Kuhlthau, Karen[2]

Source: Pediatrics. Feb2016 Supplement, Vol. 137, pS196-S204. 9p.

Document Type: Article

Subject Terms: *AUTISM

*CHI-squared test

*EXPERIENCE

*FAMILIES

*FISHER exact test

*LENGTH of stay in hospitals

*HOSPITAL admission & discharge

*MEDICAL protocols

*MULTIVARIATE analysis

*PARENTS

*PATIENTS

*QUALITY assurance
*QUESTIONNAIRES
*REGRESSION analysis
*RESEARCH funding
*PILOT projects
*RETROSPECTIVE studies
*DATA analysis software

Abstract: BACKGROUND AND OBJECTIVE: Hospital admissions can be difficult for patients with autism spectrum disorder (ASD). We created an autism-specific care plan (ACP) to help improve the hospital experience for patients with ASD, and we tested feasibility and acceptability and compared the experience of care for children with and without an ACP. METHODS: We performed a nonrandomized, retrospective chart review of all patients with ASD and a hospital admission from January 2013 to December 2013 (n = 142) to determine feasibility of the intervention. We then mailed surveys to all 142 families to measure experience with the ACP and to compare experience of care in those who did and did not have an ACP. Using multivariable linear regression we assessed the association of experience of care with ACP use while adjusting for covariates. RESULTS: The ACP was well tolerated by parents and used frequently by staff. Compared with parents who did not use the ACP, parents who used the ACP reported a better experience relating to their general hospital experience (B = 1.48, P < .001) and staff attention to their child's ASD-specific needs (B = 3.07, P < .001). CONCLUSIONS: According to this pilot study, care plans are feasible and hold promise to improve the experience of care for children with ASD and their families in the hospital setting. [ABSTRACT FROM AUTHOR]

Author Affiliations: [1]Boston Medical Center, Division of General Pediatrics, Boston University School of Medicine, Boston, Massachusetts
[2]Division of General Academic Pediatrics, MassGeneral Hospital for Children, Department of Pediatrics, Harvard Medical School, Boston, Massachusetts
[3]Lurie Center for Autism, MassGeneral Hospital, Harvard Medical School, Lexington, Massachusetts
[4]Biostatistics Center, Boston, Massachusetts
[5]Mongan Institute for Health Policy, MassGeneral Hospital, Boston, Massachusetts

ISSN: 0031-4005

DOI: 10.1542/peds.2015-2851R

Accession Number: 112739914

Database: Academic Search Index

Record: 51

Title: Improving the care of children with learning disabilities in hospital.

Authors: Glasper A

Source: British journal of nursing (Mark Allen Publishing) [Br J Nurs] 2017 Feb 23; Vol. 26 (4), pp. 246-247.

Publication Type: Journal Article

Language: English

Journal Info: *Publisher:* MA Healthcare *Country of Publication:* England *NLM ID:* 9212059 *Publication Model:* Print *Cited Medium:* Print *ISSN:* 0966-0461 (Print) *Linking ISSN:* 09660461 *NLM ISO Abbreviation:* Br J Nurs

Imprint Name(s): *Publication*: London : MA Healthcare
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MeSH Terms: Hospitalization*
Pediatric Nursing*
Quality Improvement*
Autistic Disorder/*nursing
Learning Disabilities/*nursing
Adolescent ; Child ; Humans ; Inpatients

Abstract: Emeritus Professor Alan Glasper, from the University of Southampton, discusses care delivery for children with learning disabilities or autism who require a hospital stay, prompted by the recent Lenehan report.

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DOI: 10.12968/bjon.2017.26.4.246

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Title: Many Hands Working Together: Adapting Hospital Care to Support Autistic Children's Mental Health.

Authors: Mahoney WJ; Wanda J. Mahoney, PhD, OTR/L, is Associate Professor of Occupational Therapy and Medicine, Program in Occupational Therapy, School of Medicine, Washington University in St. Louis, St. Louis, MO; wmahoney@wustl.edu.
Abraham G; Gifty Abraham, OTD, OTR/L, is Associate Professor, Department of Occupational Therapy, Midwestern University, Downers Grove, IL.
Villacrusis M; Minerva Villacrusis, MOT, OTR/L, is Occupational Therapist, Special Education Department, Community Consolidated School District 59, Elk Grove, IL.

Source: The American journal of occupational therapy : official publication of the American Occupational Therapy Association [Am J Occup Ther] 2023 Mar 01; Vol. 77 (2).

Publication Type: Journal Article

Language: English

Journal Info: *Publisher:* Published For The American Occupational Therapy Association By AJOT Pub. Co *Country of Publication:* United States *NLM ID:* 7705978 *Publication Model:* Print *Cited Medium:* Print *ISSN:* 0272-9490 (Print) *Linking ISSN:* 02729490 *NLM ISO Abbreviation:* Am J Occup Ther *Subsets:* MEDLINE

Imprint Name(s): *Publication*: Rockville, MD : Published For The American Occupational Therapy Association By AJOT Pub. Co
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MeSH Terms: Mental Health*
Autistic Disorder*
Humans ; Child ; Hospitals ; Child Health ; Program Evaluation

Abstract: **Importance:** Hospitals pose a threat to autistic children's mental health. Adapting hospitals to meet children's needs can address this issue.
Objective: To determine the impact of an interprofessional program (Adaptive Care) to support autistic children's mental health on nursing staff's knowledge, efficacy, and confidence.
Design: Pretest-posttest, quasi-experimental design.
Setting: Large pediatric hospital.
Participants: Nursing staff were the first participants in the program implementation. Approximately 300 nursing staff received training through the program, and 107 completed program evaluation surveys. Of these, 18 nursing staff completed both the pretest and posttest surveys approximately 1 yr apart.
Intervention: Occupational therapy practitioners and other professionals developed and implemented the program, which consists of staff training and resources to adapt hospital physical and social environments and to ultimately improve patients' hospital experiences.
Outcomes and Measures: Researcher-developed, pilot-tested, online survey to assess knowledge, perceived effectiveness, confidence, and strategies that staff used while caring for autistic children in the hospital.

Results: Respondents had increased effectiveness and confidence working with autistic children in the hospital after program implementation. Respondents reported significantly more strategies to care for autistic children.

Conclusions and Relevance: Interprofessional collaboration and programming can positively affect social environments in the hospital by enhancing nursing staff's self-efficacy, confidence, and strategies to support mental health and to enhance health care for autistic children. What This Article Adds: The Adaptive Care program is an example of occupational therapy practitioners and other interprofessional team members adapting physical and social health care environments to support autistic children's mental health. This program was effective at increasing nursing staff's self-efficacy, confidence, and strategies while caring for autistic children in the hospital. Positionality Statement: This article uses the identity-first language autistic people. This nonableist language describes their strengths and abilities and is a conscious decision. This language is favored by autistic communities and self-advocates and has been adopted by health care professionals and researchers (Bottema-Beutel et al., 2021; Kenny et al., 2016).

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DOI: 10.5014/ajot.2023.050032

PMID: 37040105

Database: MEDLINE Complete

Record: 53

Title: Young people's perceptions of the accessibility of general NHS hospital services: a follow-up study; Nobody had ever consulted young people with learning disabilities on their experiences of attending hospital in a systematic way, so Elizabeth Scott and colleagues decided to plug this important research gap. Here they present some of the main themes to emerge from their study

Authors: Scott, Elizabeth
Wharton, Sarah
Hames, Annette

Source: Learning Disability Practice. November, 2005, Vol. 8 Issue 9, p28, 6 p.

Publisher Information: Royal College of Nursing Publishing Company (RCN), 2005.

Publication Year: 2005

Subject Terms: Hospitals -- Central service department
Learning disabilities -- Care and treatment
Mentally ill -- Care and treatment

Interpersonal communication
United Kingdom. National Health Service -- Services

Subject Geographic: United Kingdom

Description: Keywords * Outpatient's department * carers * communication These keywords are based on the subject headings from the British Nursing Index. This article has been subject to a double-blind review. [...]

Language: English

ISSN: 1465-8712

Accession Number: edsgcl.139260608

Database: Gale OneFile: Health and Medicine

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Title: Simulation-Based Education for Staff Managing Aggression and Externalizing Behaviors in Children With Autism Spectrum Disorder in the Hospital Setting: Pilot and Feasibility Study Protocol for a Cluster Randomized Controlled Trial.

Authors: Mitchell, Marijke Jane
Newall, Fiona Helen
Sokol, Jennifer
Williams, Katrina Jane

Source: Journal of medical Internet research Jun2020; Vol. 22 (6).

Language: English

Journal Info: *Publisher:* JMIR Publications Inc. *ISSN:* 1439-4456

Contributed Indexing: *Keywords:* adolescent; aggression; autism spectrum disorder; child; feasibility studies; high-fidelity simulation training; intellectual disability; pediatric nursing

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Database: MEDLINE Complete

Simulation-Based Education for Staff Managing Aggression and Externalizing Behaviors in Children With Autism Spectrum Disorder in the Hospital Setting: Pilot and Feasibility Study Protocol for a Cluster Randomized Controlled Trial

Keywords: feasibility studies; autism spectrum disorder; intellectual disability; high-fidelity simulation training; pediatric nursing; child; adolescent; aggression

Introduction

Background and Rationale

Autism spectrum disorder (ASD), a neurodevelopmental disorder identified in childhood, is characterized by persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behavior or interests [[1]]. Children diagnosed with ASD, with or without an intellectual disability, have an increased risk of hospitalization [[2]-[5]]. They also have longer and more frequent outpatient visits and medications prescribed than children in general [[6]]. Intellectual disability, one of the most prevalent comorbidities occurring in approximately 40%-70% of individuals with ASD [[7]-[9]], has been associated with greater autism symptomology with increased difficulties in communication and social functioning [[10]].

Exposure to the hospital environment can provide a sensory overload to children with ASD as it is often noisy and brightly lit, with people moving quickly, many unfamiliar people, and long wait times [[11]]. The surroundings are unfamiliar and usual home routines are not able to be maintained. The hospital environment necessitates that children must communicate with many more people, mostly unfamiliar, than usual. This is particularly challenging and stressful for children with ASD as they innately prefer less social interaction and have more difficulty identifying social cues and understanding the expressed emotions of others. Externalizing behaviors are common in children with ASD when exposed to these stressors and can result in difficult or delayed treatment, increased anxiety for the parent and child, prolonged procedure times, increased health care costs, and poorer health outcomes [[2], [6], [11]].

The Code Grey procedure is one of a series of emergency response codes used in some Australian hospitals. Code Grey refers to *unarmed aggression* and is called when an individual fails to respond to initial defusing mechanisms undertaken by staff [[13]]. At The Royal Children's Hospital (RCH) Melbourne, the numbers of Code Grey activations are rising each year. In 2016, there were 611 recorded Code Grey activations, 1050 in 2018, and 1682 in 2019. In 2016-2017, 36% of Code Grey activations were due to aggression demonstrated by children and young people with ASD, with or without an intellectual disability [[14]].

Need for a Trial

Staff training programs designed to teach best practice principles in the management of clinical aggression in pediatric acute care settings is warranted; however, evidence on training effects in general hospital settings is scant [[15]]. There are a number of reviews of aggression management training programs in psychiatric and mental health settings [[16]]; however, the results cannot be generalized to the acute setting or further extrapolated to the pediatric setting due to the different types of care provided in each facility and prior training of staff [[18]]. In addition, aggression management training programs designed for nursing staff working with children with neurodisabilities are rarely described in the literature. Simulation training may be an effective educational tool to practice de-escalation skills in a high-fidelity situation. Simulation-based education for communication skills has been shown to improve patient safety in a number of studies [[20]-[22]]. There is a paucity of literature in the use of simulation-based education to teach de-escalation communication techniques to staff working with children and young people, particularly those with ASD, in the acute care setting.

Choice of Comparator

A purpose-designed and purpose-built web-based learning package for working with children and young people with ASD and aggression or externalizing behaviors was chosen as the comparator. An online learning package was chosen as it is convenient and flexible in time to complete, yet provides consistent information and allows self-paced learning. The online resource includes an opportunity for learner-determined revision of concepts, promotion of active and independent learning, and ability to link to and explore relevant resources.

Study Purpose and Trial Design

The purpose of this study is to conduct a pilot and feasibility cluster randomized controlled trial (RCT) to evaluate the effectiveness of simulation-based education for staff in managing aggression and externalizing behaviors of children with ASD in the hospital setting.

This study has a mixed design, with between-group and within-participant comparisons to explore the acceptability and feasibility of delivering a large-scale cluster RCT and to assess trial processes, including recruitment, completion rates, contamination, and outcome measures. Randomization of two hospital wards will be performed with 1:1 sample size per cluster.

Study Objectives

Primary Objective

The study objectives are to conduct a pilot and feasibility study and assess features of the acceptability and feasibility of our pilot design.

Population, Intervention, and Comparator

Our study population will include clinical nurses working in an acute care pediatric hospital. The study intervention will be comprised of simulation-based education plus web-based education resources on the management of clinical aggression and externalizing behaviors in children with ASD, with or without an intellectual disability. The study comparator will be web-based educational materials on the management of clinical aggression and externalizing behaviors in children with autism.

Outcomes

The following criteria will have to be met to indicate that an RCT is feasible and acceptable as planned:

- Randomization: more than 10% recruitment rate from ward staff. A total of 160 staff members from the two selected wards will be eligible to participate in the study. We aim to recruit 10 staff members to each arm of the study.
- Completion: less than 20% attrition rate with survey completion rate of at least 80%; focus group participation rate of at least 50% of total participants.
- Acceptability: high acceptability of the intervention among participants as indicated by 80% of scores being 4 (good) out of 5 or higher in survey data.
- Data collection: follow-up survey response rate of at least 30% with acceptability and confidence levels maintained; ward data-collection rate of at least 80% of total shifts during study time in each ward.

- Low contamination from intervention participants as evidenced by participant report.

Secondary Objectives

The secondary objectives and their outcomes are as follows:

- Confidence and competence: 80% of participants reporting increased confidence levels and positive qualitative comments.

- Data collection: 80% reporting of the number of Code Grey activations and the number of successful de-escalation episodes not requiring a Code Grey activation with description of context and outcome for each incident; participant use of de-escalation skills during simulations using the English Modified version of the De-escalating Aggressive Behaviour Scale (EMDABS).

Summary

In summary, the aim of this study is to conduct a pilot and feasibility cluster RCT to evaluate the effectiveness of simulation-based education for acute care hospital staff in managing aggression and externalizing behaviors of children with ASD. We hypothesize that a multisite cluster RCT to evaluate this training format is feasible.

Methods

Participants, Interventions, and Outcomes

Study Setting

The study setting is a tertiary pediatric hospital, the RCH Melbourne, Australia. Recruitment will be performed from nursing staff from one general medical ward and one general surgical ward, both of similar size and patient complexity. Hospital data indicate that children and young people with autism, with or without intellectual disability, are admitted with similar frequency to these wards. The two included wards also experience similar numbers of aggressive incidents per year requiring a hospital Code Grey response.

Eligibility Criteria

Clinical nurses who work in the general medical and surgical wards will be invited to participate in the study. Eligible nurses will be those who are responsible for providing direct clinical care for ward patients. Nurses from these wards are excluded if they are not responsible for direct patient care (eg, care coordinators, advanced practice nurses, and nurses in charge of the shift).

Interventions

Overview

The training intervention will consist of two components:

- A web-based learning package, developed using Articulate software (Articulate Global), for the management of aggression and externalizing behaviors in children and young people with autism, with or without intellectual disability, in the hospital setting as prereading.

- Prereading will be followed by a 1.5-hour simulation-based group education session to manage aggression and externalizing behaviors in an adolescent with autism; this will include two separate simulation exercises, each followed by a facilitated reflective debrief, which explores what the participants did well, what the challenges were, and what they will do differently next time. The first scenario involves an adolescent with autism and aggressive and externalizing behaviors. The second scenario increases in complexity and involves a nonverbal adolescent who has autism and intellectual disability who also demonstrates aggressive and externalizing behaviors. The training will be conducted in the Simulation Centre, conducted by the Simulation Faculty and Code Grey Coordinator, with an actor playing the role of the patient. The parent role in each of the scenarios will be played by a member of the Simulation Faculty. The simulation exercises will be recorded using Sportstec (also known as Studiocode) software.

Web-Based Education: Comparator

A web-based learning package is being developed using Articulate software. Content will be written by a study investigator with significant experience working with children with ASD and intellectual disability and their families. The content will be reviewed by autism experts within the Department of Neurodevelopment and Disability, RCH; the Murdoch Children's Research Institute; and the Department of Paediatrics, University of Melbourne. A consumer representative will also review the content. Modifications will be made from the feedback received. The content will be succinct and will be designed for the learner to complete within 30 minutes. A small number of short multiple-choice questions will be included in the education package to test understanding and application of knowledge.

Simulation-Based Education: Training Intervention

A 1.5-hour simulation-based education session, focusing on managing aggression and externalizing behaviors exhibited by a young person with autism in the inpatient setting, is being developed by the study investigators in conjunction with the Simulation Faculty. The RCH Simulation Program curriculum and simulation sessions are designed according to the concepts described by Dieckmann et al [[23]], utilizing the debriefing framework by Rudolph et al [[24]]. The simulation scenarios will be reviewed and trialed by members of the Simulation Faculty, with modifications to improve the learning experience made prior to conducting the sessions. The training sessions will be delivered by the Simulation Faculty in the Simulation Centre with assistance from the Code Grey Coordinator. Two separate simulation exercises will be delivered within this 1.5-hour simulation training session.

Participants will be required to complete pre- and posttraining surveys and a follow-up survey 3 months posttraining. Each participant will be asked to create a unique identifier for use in all the surveys, using the first three letters of their first street name followed by the first two numbers of their mother's birth date.

Nurses randomized in the ward to receive the training intervention will receive the simulation-based training intervention plus web-based training resources. They will be sent an email with instructions on how to access the surveys and the training and the requirements of the study. Participants in this arm will be instructed to complete the web-based training prior to attending the simulation-based education.

Nurses working in the ward randomized to receive the comparator will receive the web-based training resources only. They also will receive an email outlining the requirements of the study with links to the surveys and the training materials.

The intervention arm will be sent an electronic link to reserve their place in one of two simulation training sessions. Each session will have capacity for 5 participants. The comparator arm will be sent a link to access the web-based training. It is expected that the participants will confirm with their Nurse Unit Manager (NUM) whether they are able to be released from ward duties for the duration of the training. Participants will also be instructed via email to complete the pretraining survey prior to commencing the training. The time commitment to complete the web-based education will be 30 minutes, with the simulation education involving a 1.5-hour commitment within working hours.

Staff will complete the simulation training during double staff time; during this time, there are more nurses available to attend training while not compromising patient care. The principal investigator will liaise with the relevant nurse education team members to ensure that nurses have the capacity to complete the simulation-based training and the online training during double staff time. This is the time that education is often scheduled for nurses working on wards. The training was scheduled for late Spring 2019, when it was anticipated that ward activity levels would be lower than during the winter period. The nursing executive and the NUMs of the study wards have agreed to support this study, as have the RCH Simulation Program and the Department of Neurodevelopment and Disability.

Training Intervention

A researcher who is not involved with this study will explain the study design to the participants prior to commencement of the prebrief to the simulation training. The researcher will explain that participants will complete a short electronic survey at the completion of the simulation education program. The survey will be completed anonymously with no personal details recorded. The researcher will explain that the simulation sessions will be recorded to enable researchers to view the recordings at a later date to assess the impact of the training on participants' performances in de-escalating aggressive situations. Only the study investigators will have access to the recordings, which will be deleted once analyzed. The assessment of the recordings will not include any participant identification details. Participants in the simulation-based education intervention will be asked to maintain and hold confidential all information regarding the performance of specific individuals and the details of the specific scenarios. The researcher will check that all participants have completed the pretraining survey. For those who have not, time will be provided for them to complete it in a nearby room with computer access prior to commencing the simulation training.

The Simulation Faculty member facilitating the simulation session will then brief the participants on the objectives of the two simulation exercises. The roles and expectations of both the participants and the instructors will be discussed. The structure of the session and the purpose of the postsimulation debrief will be explained. The participants will be informed that the same professional actor will play the role of the patient in each of the simulation exercises. The second simulation scenario will be more complex than the first, giving the participants the opportunity to extend their skills and build on knowledge learned from the first scenario. Participants will be asked to volunteer for the different roles in each simulation scenario. The Simulation Faculty technologist will orient the participants to the Simulation Centre and simulation equipment prior to commencement of the first simulation scenario.

Outcomes

The primary and secondary outcome measures for assessing the acceptability and feasibility of conducting the training intervention are detailed in the Study Objectives section above.

Two simulation scenarios involving an adolescent with autism, intellectual disability, aggression, and externalizing behaviors will be assessed. Study participants will be asked to complete three surveys: a pretraining survey, a posttraining survey, and a follow-up survey.

The purpose of the pretraining survey is to determine participants' self-perceptions of confidence and competence in managing aggressive and externalizing behaviors in a young person with autism. The pretraining survey incorporates the Confidence in Coping with Patient Aggression Instrument [[25]], short-answer questions, and free text to assess self-perceived levels of confidence and competence in managing aggression in a young person with autism and intellectual disability as well as acceptability of the simulation- and web-based education. The Confidence in Coping with Patient Aggression Instrument is a one-dimensional, 10-item instrument demonstrating a high degree of internal consistency (Cronbach alpha=.92) and precision (SE 1.5) [[25]].

The purpose of the posttraining survey is to determine if the training had an impact on participants' self-perceptions of confidence and competence in managing aggression and externalizing behaviors in a young person with autism. The posttraining survey also incorporates the Confidence in Coping with Patient Aggression Instrument [[25]], short-answer

questions, and free text to assess self-perceived levels of confidence and competence in managing aggression and externalizing behaviors in a young person with autism and intellectual disability as well as acceptability of the simulation- and web-based education. The purpose of the follow-up survey is to determine if the training had a continued impact on participants' self-perceptions of confidence and competence in managing aggression in young people with ASD.

Each of the simulation training scenarios will be recorded. The recordings will be analyzed by two clinicians, who are experienced in clinical aggression management, using the EMDABS to assess the influence the training had on participants' performances in de-escalating aggressive situations. A study investigator will train the clinicians in the use of the tool using the training materials provided by Mavandadi et al [[26]], providing a clear definition of terms and items and the scoring system. Both clinicians will use the tool on a recording of a practice simulation involving only members of the Simulation Faculty and the study investigator and will discuss decision-making processes to ensure consistency and interrater reliability [[27]].

Knowledge retention by study participants 3 months posttraining, as well as continued confidence and exposure to clinical aggression, will be assessed via surveys similar in content to the pre- and posttraining surveys. Results from the pretraining, posttraining, and follow-up surveys will be linked using the unique identifiers that the participants created prior to completing the pretraining survey.

Data will be collected at the ward level at each shift for the duration of the study to assess the number of aggressive incidents and rates of successful de-escalations for patients with ASD. A short survey will be emailed to Associate Nurse Unit Managers (ANUMs), as well as to any additional nurses who acted in the roles of ANUM or *nurse in charge of shift*, at the completion of the study to explore the enablers and barriers to collecting this data.

Total change in Code Grey activations will also be assessed in total and at the ward level. We will also record rates of data collection.

Participant Timeline

Figure 1 shows the study design flowchart, including participant recruitment and allocation, intervention components, and follow-up.

Graph: Figure 1. Study design. EMDABS: English Modified version of the De-escalating Aggressive Behaviours Scale; RN: registered nurse.

Sample Size

We plan to recruit 10 staff members to each arm of the study. This sample size, based on our experiences in an earlier study we conducted, is a good size for a pilot and feasibility study to assess recruitment, contamination, and data collection.

Recruitment

A study investigator will provide ward-based education about the study, providing clinical nursing staff with information about the study and an opportunity for questions during the double staff time in each ward two times in a 2-3-week period prior to commencement of the study. Hard copies of the study information will also be provided. Following face-to-face information sharing, study information and a request to participate in the study will be forwarded via email to each nurse in the ward by a study investigator. This email will describe the study and outline the participant requirements. It will include a participant information statement and consent form. Two reminder emails will be sent 1 week apart to potential participants to remind them to respond.

The first 10 nurses from each ward who agree to participate in the study and return the consent form will be accepted into the study. Following randomization, participants from each arm of the study will be sent an information email, specific to the group to which they have been randomized, with all the information they require to participate in the study. This email will include links to the relevant resources and surveys as well as links for securing a position into the simulation training and the focus group interviews. Then, 3

months posttraining, all participants will receive an email reminding them to complete the follow-up survey. This email will be resent two times as a reminder to participants. At the completion of the study, participants will receive a letter that provides a summary of the main study findings and thanks them for their participation in the study.

Assignment of Groups

Allocation

A researcher who is not associated with this study and is not based at the study site will use a coin toss to randomize the wards included in the study to either the training intervention or the comparison group. This will occur once recruitment is complete. The first coin toss will identify which ward is being considered (ie, heads for one ward and tails for the other). The second coin toss will decide whether the selected ward is assigned to the intervention arm or to the comparator arm. Once the wards have been allocated, the study investigator will be unblinded and will individually notify participants via email regarding the arm of the study to which they have been allocated.

Blinding

Blinding for the study investigators and participants will not be possible. To reduce bias, once data are exported to Microsoft Excel, a researcher who is not involved with the study will code the intervention and comparator groups and remove data columns that relate to the intervention group only, so the person conducting the analysis will be blind to group allocation.

Data Collection, Management, and Analysis

Overview

The Kirkpatrick Four-Level Model

The Kirkpatrick Model will be used to measure the impact of the training. This four-level model evaluates training according to (1) reaction, (2) learning, (3) behavior, and (4) results [[28]-[30]].

1. Pre- and Posttraining Survey (Kirkpatrick Level 1)

A link to a short, electronic REDCap (Research Electronic Data Capture) survey will be administered to participants' before and after simulation training, incorporating the Confidence in Coping with Patient Aggression Instrument [[25]], short-answer questions, and free text. These will be used to assess self-perceived levels of confidence and competence in managing aggression as well as the acceptability of the simulation and web-based training.

2. Follow-Up Survey: 3 Months Posttraining (Kirkpatrick Level 1)

A link to a short, electronic REDCap survey will be emailed to participants 3 months after simulation training incorporating the Confidence in Coping with Patient Aggression Instrument [[25]], short-answer questions, and free text. These will assess self-perceived levels of confidence and competence in managing aggression as well as the acceptability of the simulation and web-based training.

3. Observer Evaluation of Use of De-escalation Skills Within the Simulation (Kirkpatrick Leve...

The simulation exercises will be recorded using Sportstec software. Sportstec is video analysis software designed for use in medical simulation research that allows users to interpret and code the multifaceted elements of video while identifying patterns that form a comprehensive picture. The video recordings are securely held on RCH servers and the software license includes use for research purposes. Two clinicians with expertise in the management of clinical aggression will assess the participants' recorded performances for each scenario using the EMDABS [[27], [31]]. The EMDABS is a one-dimensional, seven-item scale combined with a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5

(*strongly agree*). Performance will be represented by the means of the seven items. The original German-language scale (De-escalating Aggressive Behaviour Scale, DABS) was enhanced and validated by Mavandadi et al [[26]] to create the EMDABS. This tool demonstrated good interrater reliability (intraclass correlation coefficient=.752) and strong internal consistency (Cronbach alpha=.901). Training materials have been provided by the authors of the EMDABS tool and will be used to train the clinicians in the use of the tool.

4. Ward Patient Aggression Record (Kirkpatrick Level 3)

Episodes of clinical aggression from patients with ASD will be recorded during each shift in participating wards 1 month prior to and 3 months after the training intervention. Numbers of successful de-escalation interactions will be recorded. A short, electronic REDCap survey will be emailed to ANUMs, and to any additional nurses who acted in the role of ANUM, at the completion of the study to explore the enablers and barriers to collecting this data.

5. Code Grey Activations (Kirkpatrick Level 4)

We will conduct a review of numbers and context of Code Grey activations in participating wards for 1 month prior to and 3 months after the training intervention. Strategies to be used by the study team to promote participant retention and completion of follow-up surveys are described in the Recruitment section.

Data Management

Participant confidentiality will be strictly held in trust by the study investigators and the sponsoring institutions. All surveys are anonymous so no personal details will be stored. The data from the EMDABS will be entered into a password-protected REDCap account by an administrative assistant. All survey data will be entered directly by participants into the secure REDCap web-based application. Sportstec recordings of the simulation-based education will be deleted once analysis is complete. All data for this study will be stored on a password-protected computer located in the Department of Neurodevelopment and Disability for 5 years. After 5 years, the data will be deleted.

Statistical Methods

Primary Outcomes

Percentages will be calculated to estimate recruitment, retention, outcomes, survey response rate, focus group participation, and the precision of those estimates. We will treat the Likert-scale scores as categories and dichotomize the 11- and 5-point scale responses. Changes in confidence and competence will be compared statistically with a chi-square test using before-and-after data to compare the proportion of those who have high confidence between the two arms at baseline and at follow-up.

Secondary Outcomes

The Code Grey data and daily aggression data will be analyzed using descriptive statistics, including descriptions of the clinical journey for children and young people who trigger more than one Code Grey response. We will report whether aggression de-escalation attempts were recorded during each shift on each ward as planned. The EMDABS data will be analyzed using mean values and SDs to understand the variation in performance of individuals who undertake the training.

Monitoring

A Data Monitoring Committee is not required, as this is a feasibility and pilot study of short duration and minimal risk. Due to the realism of simulation-based education, participants could potentially become distressed during, or at the completion of, a simulation scenario or the debrief for many reasons. If a member of the Simulation Faculty observes distress in a participant, they will offer them the option to leave the scenario or debrief and will support them both at the time they leave, as well as follow up with them through the following week. In addition, they will be offered the counsel of the RCH Employees' Assistance Program. In a previous pilot study conducted prior to this work by the authors, distress following simulation-based education was minimal. Immediate support from the Simulation Faculty posttraining was sufficient to reassure a small number of participants who verbalized concern about their performance. No participants required referral to the RCH Employees' Assistance Program for continued support or follow-up.

It is not expected that the focus groups will cause participants any anxiety or distress. If participants do not feel comfortable answering any of the questions in the focus group, they do not need to answer them. Auditing of data is not required, as this is a feasibility and pilot study of short duration.

Ethics and Dissemination

Research Ethics Approval

The study received ethical approval from the RCH Melbourne Human Research Ethics Committee (HREC) on November 1, 2019 (HREC reference number: 56684).

Protocol Amendments

There are no anticipated amendments to the protocol for this pilot and feasibility study.

Consent

Participation will be voluntary and consistent with the National Statement on Ethical Conduct of Human Research Section 2.2.9: no coercion or pressure to participate will occur between the study investigators and potential participants [[32]].

A study investigator will email the participant information statement and consent form to all potential study participants. Nurses in the study wards will be asked within this email to return the consent form to the nominated study investigator if they would like to participate in the study.

All participants will be required to read the participant information statement and sign and return the consent form via email before participating in the study.

Participants in both arms of the study will be required to (1) complete the training intervention, (2) complete the pre- and posttraining surveys, (3) complete the follow-up survey, and (4) participate in a 1-hour focus group interview at the completion of the training.

Confidentiality

Overview

Participant confidentiality will be strictly held in trust by the study investigators and the sponsoring institutions. Participants in the simulation-based training will be asked to maintain and hold confidential all information regarding the performance of specific individuals and the details of the specific scenarios. Only study investigators will have access to the trial data.

Surveys

All surveys are anonymous and will be completed electronically using a web link to the REDCap survey sent to participants via email. While no personal details will be recorded, it is possible that years of clinical experience may potentially identify some participants. Participants will be asked to create their own unique identifier to be used for each survey, so that pretraining, posttraining, and follow-up survey results can be linked. Data stored in the secure REDCap database will be deleted following completion of data analysis.

Sportstec Recordings of the Simulation-Based Education

Confidentiality will be maintained by the assessors; no identifying participant information will be kept and the recordings will be deleted once analysis is complete.

Ward Patient Aggression Record

Completed daily ward patient aggression records will be stored in a locked filing cabinet in the ward nursing offices and collected daily on weekdays by a study investigator, who will then store the record sheets in a locked filing cabinet in the Department of Neurodevelopment and Disability. No patient names will be recorded on these records, which will only be identified by the patient Medical Record Number (MRN). This information is reidentifiable; however, only the study investigator (MJM) will have access to the data during the study period. The nurse in charge of the shift who completes the record will have access to the record sheets completed that day and will store them in a locked filing cabinet on the ward until they are collected by a study investigator (MJM). This investigator, who is an RCH clinician and works with this population, will access the medical records to locate the aggressive incident. No personal information will be recorded in REDCap; instead, what will be recorded is whether a de-escalation episode was found or not, to check the validity of the reported data as part of the pilot and feasibility study. Data, excluding the patient MRN, will be entered into the secure REDCap database and will be deleted following completion of data analysis. Written records will be shredded and disposed of securely once data has been entered into REDCap.

Dissemination Policy

The results of this study will be disseminated to study participants, staff of the study site, and health care professionals through the dissemination plan in Table 1.

Table 1. Dissemination plan.

Domain	Activities	Approach	Time frame	Responsibility	Budget
Dissemination objectives	Goal is to present main findings to participants, staff at study site, hospital executive, health care professionals, and consumers	Dissemination options are detailed below for each group	Within 6 months following completion of study	Study investigators	Nil
Identify target audience	Inform study participants	Letter summarizing the main findings	1 month following completion of study	Study investigators	Nil
	Inform staff at study site	Presentation at research forums, department meetings, and ward education session	Within 6 months following completion of study	Study investigators	Nil
	Inform hospital executive	Face-to-face meeting with Executive Director of Nursing and Allied Health and a written summary of findings	Within 2 months following completion of study	Study investigators	Nil
	Inform health care professionals	Publication in relevant journals, presentation at relevant local and international conferences, and	Within 1 year following	Study investigators	Funding will be sought from relevant

Domain	Activities	Approach	Time frame	Responsibility	Budget
		webinar about the study and findings for the Department of Neurodevelopment and Disability	completion of study		scholarships and funding sources
	Inform consumers	Blog of main findings presented in plain English on department website	Within 2 months following completion of study	Study investigators	Nil
Key messages	Determine key messages for each target group following completion of study	Adapt content as appropriate	1 month following completion of study	Study investigators	Nil
Sensitivities	Determine sensitivities for each target group following completion of study	Adapt content as appropriate	1 month following completion of study	Study investigators	Nil
Evaluation plan	Evaluate the effect of the different strategies	Analyze click and open rates for web-based resources and note implementation strategies at the study site following dissemination of results	Within 1 year following completion of study	Study investigators	Nil

Graph

Results

This study gained ethical approval from the RCH Melbourne HREC on November 1, 2019 (HREC reference number: 56684). Data collection was completed in February 2020. Data analysis is due to commence with results anticipated by August 2020.

Discussion

Aggression demonstrated by children and young people with autism, with or without intellectual disability, is increasing in acute care pediatric hospitals. Nursing staff often feel underequipped to successfully de-escalate or prevent aggression or externalizing behaviors in this population. It is important that acute care nurses working with children with ASD are confident in managing aggression demonstrated by patients in their workplace. This study aims to develop and pilot test a simulation-based training program to upskill pediatric nursing staff who work with children and young people with autism who display aggression and externalizing behaviors.

Acknowledgments

The authors would like to acknowledge the RCH Simulation Faculty as well as staff from the Department of Neurodevelopment and Disability, RCH; the Autism Research Team, University of Melbourne; and the Murdoch Children's Research Institute for their assistance in the development of the simulation scenarios and the content of the web-based

learning package. We would also like to thank all our reviewers for their helpful comments and suggestions.

This study fulfils part of the requirements for MJM's PhD candidature and is funded in part by an Australian Government Research Training Program Scholarship and the Elizabeth and Vernon Puzey Scholarship. The funders have no input into the planning or conduct of this study or the interpretation or publication of the study results.

Authors' Contributions

MJM developed the training materials for this study with input from all authors. MJM wrote the draft of this manuscript. All authors have been involved in revising the manuscript and approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1

HREC Pre submission peer review.

DOCX File , 136 KB

Abbreviations

ANUM: Associate Nurse Unit Manager
ASD: autism spectrum disorder
DABS: De-escalating Aggressive Behaviour Scale
EMDABS: English Modified version of the De-escalating Aggressive Behaviour Scale
HREC: Human Research Ethics Committee
MRN: Medical Record Number
NUM: Nurse Unit Manager
RCH: Royal Children's Hospital
RCT: randomized controlled trial
REDCap: Research Electronic Data Capture

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By Marijke Jane Mitchell; Fiona Helen Newall; Jennifer Sokol and Katrina Jane Williams

Reported by Author; Author; Author; Author

Record: 55

Title: Mapping staff perspectives towards the delivery of hospital care for children and young people with and without learning disabilities in England: a mixed methods national study.

Authors: Oulton, Kate; [1]Gibson, Faith; [1,2]Carr, Lucinda; [3]Hassiotis, Angela; [4]Jewitt, Carey; [5]Kenten, Charlotte; [1]Russell, Jessica; [1]Whiting, Mark; [6]Tuffrey-Wijne, Irene; [7]Wray, Jo[1]

Affiliation: [1]Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID)Great Ormond Street Hospital for Children NHS Foundation TrustLevel 4, Barclay House, 37 Queen SquareWC1N 3BHLondonUK
[2]School of Health Sciences, Faculty of Health and Medical SciencesUniversity of SurreyGU2 7XHGuildfordSurreyUK
[3]Great Ormond Street Hospital for Children NHS Foundation TrustWC1N 3JHLondonUK
[4]UCL Division of Psychiatry6th Floor, Maple House, 149 Tottenham Court RoadW1T 7NFLondonUK
[5]UCL Knowledge LabInstitute of Education23-29 Emerald StreetWC1N 3QSLondonUK
[6]Health Research BuildingUniversity of HertfordshireCollege Lane CampusAL10 9ABHatfieldHertfordshireUK
[7]Faculty of Health, Social Care and EducationKingston University and St George's University of London6th floor Hunter Wing, Cranmer TerraceSW17 0RELondonUK

Source: BMC Health Services Research (BMC HEALTH SERV RES), 3/23/2018; 18: 1-1. (1p)
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Publication Type: Journal Article - research

Language: English

Major Subjects: Child Health Services -- Administration
Healthcare Disparities
Learning Disorders -- Epidemiology
Personnel, Health Facility -- Psychosocial Factors
Attitude of Health Personnel

Minor Subjects: England; Qualitative Studies; Human; Health Services Research; Child; Surveys; Health Services Needs and Demand; Quality of Health Care; Validation Studies; Comparative Studies; Evaluation Research; Multicenter Studies; Arthritis Impact Measurement Scales; Ferrans and Powers Quality of Life Index; Impact of Events Scale; Scales

Abstract: Background: Children and young people (CYP) with learning disabilities (LD) are a vulnerable population with increased risk of abuse and accidental injury and whose parents have reported concerns about the quality, safety and accessibility of their hospital care. The Care Quality Commission's (CQC) view of best practice for this group of patients includes: access to senior LD nurse provision; a clearly visible flagging system for identifying them; the use of hospital passports; and defined communication strategies (Glasper, Comp Child Adolesc Nurs 40:63-67, 2017). What remains unclear is whether these recommendations are being applied and if so, what difference they are making. Furthermore, what we do not know is whether parental concerns of CYP with LD differ from parents of other children with long-term conditions. The aims of this study were to 1) describe the organisational context for healthcare delivery to CYP with LD and their families and 2) compare staff perceptions of their ability to identify the needs of CYP with and without LD and their families and provide high quality care to effectively meet these needs.Methods: Individual interviews (n = 65) and anonymised online survey (n = 2261) were conducted with hospital staff working with CYP in 15 children's and 9 non-children's hospitals in England. The majority of interviews were conducted over the telephone and recorded and transcribed verbatim. Health Research Authority was obtained and verbal or written consent for data collection was obtained from all interview participants.Results: The nature and extent of organisational policies, systems and practices in place within hospitals to support the care of CYP with LD differs across England and some uncertainty exists within and across hospitals as to what is currently available and accessed. Staff perceived that those with LD were included less, valued less, and less safe than CYP without LD. They also reported having less confidence, capability and capacity to meet the needs of this population compared to those without LD.Conclusion: Findings indicate inequality with regards the provision of high quality hospital care to children and young people with LD that meets their needs. There is a pressing need to understand the impact this has on them and their families.Trial Registration: The study has been registered on the NIHR CRN portfolio 20461 (Phase 1), 31336 (Phases 2-4).

Journal Subset: Biomedical; Europe; Peer Reviewed; UK & Ireland

Instrumentation:

Arthritis Impact Measurement Scale (AIMS) (Meenan)
Learning and Study Strategies Inventory (LASSI)
Perceived Stress Scale (PSS) (Cohen et al)
Impact of Events Scale (IES)
Ferrans and Powers Quality of Life Index

ISSN: 1472-6963

MEDLINE Info: *PMID:* NLM29566681 *NLM UID:* 101088677

Grant Information: HS&DR/14/21/45/DH_/Department of Health/United Kingdom; 14/21/45//Health Services and Delivery Research Programme/International

Entry Date: 20180324

Revision Date: 20210111

DOI: 10.1186/s12913-018-2970-8

Accession Number: 128628845

Database: CINAHL Plus with Full Text

Record: 56

Title: Helping children on the autism spectrum deal with hospital admissions.

Authors: Povey C

Source: Archives of disease in childhood [Arch Dis Child] 2016 Dec; Vol. 101 (12), pp. 1081. *Date of Electronic Publication:* 2016 Aug 19.

Publication Type: Editorial; Comment

Language: English

Journal Info: *Publisher:* BMJ Pub. Group [etc.] *Country of Publication:* England *NLM ID:* 0372434 *Publication Model:* Print-Electronic *Cited Medium:* Internet *ISSN:* 1468-2044 (Electronic) *Linking ISSN:* 00039888 *NLM ISO Abbreviation:* Arch Dis Child *Subsets:* MEDLINE

Imprint Name(s): *Publication*: London :, BMJ Pub. Group [etc.]
Original Publication: London : British Medical Association

MeSH Terms: Autistic Disorder*
Hospitalization*
Child ; Child Development Disorders, Pervasive ; Humans

Comments: Comment on: Arch Dis Child. 2016 Dec;101(12):1090-1094. doi: 10.1136/archdischild-2016-310814. (PMID: 27226525)

Contributed Indexing: *Keywords:* Autism; Paediatric Surgery

Entry Date(s): *Date Created:* 20160821 *Date Completed:* 20180808 *Latest Revision:* 20181202

Update Code: 20250114

DOI: 10.1136/archdischild-2016-311299

PMID: 27543507

Database: MEDLINE Complete

Record: 57

Title: Children with autism need better hospital care, says RCN.

Source: Nursing Children & Young People. Jun2017, Vol. 29 Issue 5, p6-6. 2/3p.

Document Type: Article

Subject Terms: *AUTISM in children
*PEDIATRICS

Geographic Terms: UNITED Kingdom

Abstract: The article focuses on the call by nurses in Great Britain for improvements to the care of children with autism in hospitals and the community.

ISSN: 2046-2336

DOI: 10.7748/ncyp.29.5.6.s2

Accession Number: 123551793

Database: Academic Search Index

Record: 58

Title: Exploring the value of the learning disability nurse role in children's hospitals.

Authors: Atkinson, Dave

Source: Learning Disability Practice; 7/30/2019, Vol. 22 Issue 4, p10-10, 1p

Publication Year: 2019

Subject Terms: OCCUPATIONAL roles
ATTITUDE (Psychology)

CHILDREN'S hospitals
MEDICAL personnel
NURSES
PEOPLE with intellectual disabilities

Geographic Terms: ENGLAND

NAICS/Industry Codes: NAICS/Industry Codes 622110 General Medical and Surgical Hospitals
622112 Paediatric hospitals
622310 Specialty (except Psychiatric and Substance Abuse) Hospitals

Document Type: Article

Abstract: This study explores the nature and extent of learning disability nurse provision in children's hospitals in England and the perceptions of staff. [ABSTRACT FROM AUTHOR]

ISSN: 14658712

DOI: 10.7748/ldp.22.4.10.s9

Accession Number: 148704373

Database: Complementary Index

Record: 59

Title: [Level of training in autistic spectrum disorders among hospital paediatricians].

Transliterated Title: Nivel formativo sobre trastornos del espectro autista (TEA) entre los pediatras de atención hospitalaria.

Authors: Martínez-Cayuelas E; Servicio de Neuropediatría, Hospital Universitario de Móstoles, Móstoles, Madrid, España. Electronic address: elenamartinezcayuelas@gmail.com.
Ibáñez-Micó S; Servicio de Neuropediatría, Hospital Clínico Universitario Virgen de la Arrixaca, Murcia, España.
Ceán-Cabrera L; Servicio de Neuropediatría, Hospital Universitario de Torrevieja, Torrevieja, Alicante, España.
Domingo-Jiménez R; Servicio de Neuropediatría, Hospital Clínico Universitario Virgen de la Arrixaca, Murcia, España.

Alarcón-Martínez H; Servicio de Neuropediatría, Hospital Clínico Universitario Virgen de la Arrixaca, Murcia, España.
Martínez-Salcedo E; Servicio de Neuropediatría, Hospital Clínico Universitario Virgen de la Arrixaca, Murcia, España.

Source: Anales de pediatria (Barcelona, Spain : 2003) [An Pediatr (Barc)] 2017 Jun; Vol. 86 (6), pp. 329-336. *Date of Electronic Publication:* 2016 Jun 17.

Publication Type: Journal Article; Multicenter Study

Language: Spanish; Castilian

Journal Info: *Publisher:* Elsevier España *Country of Publication:* Spain *NLM ID:* 101162596 *Publication Model:* Print-Electronic *Cited Medium:* Internet *ISSN:* 1695-9531 (Electronic) *Linking ISSN:* 16954033 *NLM ISO Abbreviation:* An Pediatr (Barc) *Subsets:* MEDLINE

Imprint Name(s): *Publication*: Madrid : Elsevier España
Original Publication: Barcelona : Ediciones Doyma, SL, c2003-

MeSH Terms: Autism Spectrum Disorder*
Clinical Competence*
Health Knowledge, Attitudes, Practice*
Medical Staff, Hospital*
Pediatrics/*education
Adult ; Child ; Female ; Hospitals ; Humans ; Male ; Middle Aged ; Spain ; Young Adult

Abstract: **Background:** Training in autistic spectrum disorders is crucial in order to achieve an early diagnosis. However, the number of papers describing this training is limited. This study describes this level of knowledge among paediatricians from tertiary care hospitals in different regions of Spain and detects areas that need improvement.
Material and Method: A total of one hundred and fifty-seven (157) paediatricians working in tertiary healthcare hospitals located in three different regions in Spain consented to complete an online questionnaire divided in three sections (socio-demographic, knowledge about childhood autism, and opinion). Data were analysed using SPSS version 15.
Results: The total mean score of participating paediatricians in the questionnaire was 20.34 (± 2.43 SD) out of a total possible score of 23. Approximately two-thirds (65%) of paediatricians scored more or equal to the mean score. The knowledge gap was found to be higher with symptoms of repetitive behaviour patterns, concept of autism, and comorbidity, with no statistical significance. There were no differences in paediatrician scores within different socio-demographic groups. Just under two-thirds (64%) of paediatricians subscribed to the opinion that their own knowledge about autism is limited, and there is a significant lack of knowledge about facilities in every region.
Conclusions: There is a sufficient level of knowledge about autism among paediatricians in tertiary healthcare, although a lack of awareness about the management of these patients, with poor coordination between the different specialists that are involved in their

treatment. Efforts should focus on achieving a better coordination between these specialists, and update the knowledge gaps identified.

Contributed Indexing: *Keywords:* Autistic disorder; Child psychiatry; Conocimiento; Encuesta de salud; Health surveys; Knowledge; Paediatrics; Pediatría; Psiquiatría infantil; Terapéutica; Therapeutics; Trastorno autístico

Entry Date(s): *Date Created:* 20160622 *Date Completed:* 20180524 *Latest Revision:* 20180524

Update Code: 20250114

DOI: 10.1016/j.anpedi.2016.05.005

PMID: 27325257

Database: MEDLINE Complete

Record: 60

Title: Charmaine Champ has developed a set of materials that aim to put children with learning disabilities or special needs at ease before they go into hospital

Source: Learning Disability Practice. July, 2007, Vol. 10 Issue 6, p10, 1 p.

Publisher Information: Royal College of Nursing Publishing Company (RCN), 2007.

Publication Year: 2007

Subject Terms: Hospitals -- United Kingdom -- Equipment and supplies -- Services
Hospital administrators -- Works -- Equipment and supplies -- Methods
Children's services -- Methods -- Equipment and supplies -- Services

Subject Person: Champ, Charmaine -- Works

Subject Geographic: United Kingdom

Description: Charmaine Champ, a Chelmsford-based community nurse specialist, Ms Champ, who is employed by North East Essex Primary Care Trust (PCT), is using the materials at Broomfield Hospital and St John's [...]

Document Type: Brief article

Language: English

ISSN: 1465-8712

Rights:

Accession Number: edsgcl.166995421

Database: Gale OneFile: Health and Medicine

Record: 61

Title: Specialist nursing input improves hospital care for children with learning disabilities.

Authors: Atkinson, Dave

Source: Learning Disability Practice. 7/19/2018, Vol. 21 Issue 4, p11-11. 1p.

Document Type: Article

Abstract: Challenges persist in ensuring consistent approaches that fully respect people's rights and which ensure full inclusion and engagement of people and families. [ABSTRACT FROM AUTHOR]

ISSN: 1465-8712

DOI: 10.7748/ldp.21.4.11.s11

Accession Number: 173634922

Database: Academic Search Index

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Title: Challenges of autism in the inpatient setting.

Authors: Sakai C; Department of Pediatrics, Tufts New England Medical Center, The Floating Hospital for Children, Boston, MA; †Department of Pediatrics, Boston Medical Center, Boston, MA.
Miller K
Brussa AK
MacPherson C
Augustyn M

Source: Journal of developmental and behavioral pediatrics : JDBP [J Dev Behav Pediatr] 2014 Jan; Vol. 35 (1), pp. 82-4.

Publication Type: Case Reports; Journal Article

Language: English

Journal Info: *Publisher:* Lippincott Williams & Wilkins *Country of Publication:* United States *NLM ID:* 8006933 *Publication Model:* Print *Cited Medium:* Internet *ISSN:* 1536-7312 (Electronic) *Linking ISSN:* 0196206X *NLM ISO Abbreviation:* J Dev Behav Pediatr *Subsets:* MEDLINE

Imprint Name(s): *Publication*: <2000->: Hagerstown, MD : Lippincott Williams & Wilkins
Original Publication: [Baltimore, Md.] : Williams & Wilkins, [1980-

MeSH Terms: Child Development Disorders, Pervasive/*psychology
Child, Hospitalized/*psychology
Precursor Cell Lymphoblastic Leukemia-Lymphoma/*drug therapy
Child Development Disorders, Pervasive/epidemiology ; Child Development Disorders, Pervasive/rehabilitation ; Child, Preschool ; Comorbidity ; Female ; Humans ; Patient Care Team ; Precursor Cell Lymphoblastic Leukemia-Lymphoma/epidemiology

Abstract: **Case:** Julie is a 4-year-old girl with autism spectrum disorder (ASD) who presented to the emergency room with severe unilateral hip pain and limping. Initial evaluation indicated increased inflammatory markers and blasts on a blood smear. A bone marrow biopsy revealed acute lymphoblastic leukemia (ALL), and Julie was admitted for induction chemotherapy. Julie was diagnosed with ASD 1 year before this presentation. Her parents, who had immigrated to the United States from China before her birth, indicated that it took them some time to accept the diagnosis of ASD but they were feeling more confident in addressing her behavior challenges and comfortable with the progress she had been making. They now expressed concerns about the possible loss of services in the setting of her hospitalization. At the time of diagnosis, Julie had been receiving in-home behavioral therapy (applied behavioral analysis), speech therapy, and occupational therapy at a hospital-based center. In addition, she had an individualized education plan and was enrolled in a specialized preschool classroom for children with ASD.As Julie's hospital stay became more prolonged, her medical care team started reporting more challenges communicating with Julie without the presence of 1 of her parents, difficulty conducting routine care (e.g., obtaining vitals), sleep disruption, and safety concerns (e.g., Julie would frequently climb on the window sill increasing her fall risk). As her primary care clinician, you are called by the hospital team to help bridge the communication and behavioral divide that has widened--what would you do next?

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