

Communicating and managing children and young people with autism and extensive burn injury

KEY WORDS

- ▶ Autism
- ▶ Assessment
- ▶ Burns
- ▶ Children
- ▶ Communication
- ▶ Multidisciplinary Team

Autistic spectrum disorder (ASD) is a lifelong developmental disability that affects the way an individual communicates and relates to their environment and the people around them. Children and young people (0–18 years) with autism find change difficult and can demonstrate challenging behaviours when reacting to new situations. Children with autism can therefore be difficult to manage in paediatric intensive care settings, and this can become even more challenging when these children present with extensive burn injuries. A burns service at one children's hospital in Manchester explored these issues among staff, and the reasons why children with autism have challenging hospital stays. Lack of staff awareness was found to be the key indicator of this, stemming from concerns relating to patient/staff experience, rights, safety and behaviour, management skills and improving clinical effectiveness. To ameliorate this situation and improve care provision, a range of measures have been implemented, including a hospital-wide care standard, an autism training and education strategy, and development of an autism 'champion' role to ensure early intervention. This article outlines the development and implementation of these measures and future action plans.

In the UK, there are an estimated 500,000 individuals with autism; of these, approximately 1% are children (Baird et al, 2006). In 2012 (the most recent data available), it was estimated that 378 children with a diagnosis of autism live in Manchester city centre. As Royal Manchester Children's Hospital (RMCH) is the tertiary provider of acute paediatric burn care in North West England, the increasing numbers of children and young people with autism has a potentially large impact on service provision.

Autism comprises a range of communication problems across a broad spectrum that ultimately impact on social interaction with others (Centers for Disease Control and Prevention, 2012). These range from mild communication problems through to the non-communicative child with repetitive behaviours and limited interest in activities or awareness of their surroundings (Szatmari, 2003). *Figure 1* demonstrates the manifest signs of autism within the first 3 years of the child's life. Children with autism are commonly well known to their local healthcare providers and may have other, often complex, comorbidities. It is not uncommon for clinicians

to encounter individuals with tuberous sclerosis, Tourette's Syndrome, learning disabilities and attention deficit disorders (National Institute of Neurological Disorders, 2013). Children with autism can, therefore, be difficult to manage in the critical care setting and prove even more challenging when presenting with extensive burn injuries, owing to the complex nature of care interventions, sensory communication challenges and the restrictive care routine (Bennett, 1997; van der Walt and Moran, 2001).

The World Health Organization (WHO; 2013) recommends early intervention and treatment for children with autism to improve outcomes in later life. Early intervention in paediatric burn care has also been demonstrated to improve outcomes in later life, as there is a link between cognitive ability and burn injury (Herndon, 2012).

CONTEXT

Burn injuries can impact greatly on the child and their family, with lasting effects (Herndon, 2012). If the child has autism, this impact can be even more profound if not managed appropriately (Hes-

ROB KENNEDY

Education and Development Practitioner, Honorary Senior Lecturer Regional Paediatric Burns Service, Royal Manchester Children's Hospital

FRANCES BINNS

Professional Lead for Therapeutic and Specialised Play Services Therapeutic and Specialised Play Consultant, Autism Project Manager/Lead Northern Play Healthcare, Network & Benchmarking Director, Manchester

lop et al, 2013). However, much of the clinician's paediatric experience may not be effective for the child with autism. 'Normal' procedure may complicate an already challenging care situation, especially during the acute phase of the child's care pathway (Pratt et al, 2012).

When placed into context, it is easy to ascertain the different approaches required in providing compassionate care, but not immediately obvious. In a child, any burn injury greater than 10% total body surface area (TBSA) is classed as a large burn (Herndon, 2013), having many physiological effects. The greater the TBSA, the larger impact upon the child and young person and their family who are experiencing it (Herndon, 2013).

The most common cause of burn injuries in children is a scald, caused by any hot liquid; be that tea, coffee, soup or a bath (Herndon 2013). A 5-year-old child with a superficial or superficial-partial thickness burn not exceeding 10% TBSA (Herndon, 2013) may have a hospital stay of 1 week or less. The 5-year old, being in the pre-operational stages of cognitive development (Wood et al, 2001), will be able to rationalise some aspects of care. The provision of care through play during a dressing change may further contribute to the child's understanding and concordance and subsequent discharge.

If the aforementioned 5-year-old has a diagnosis of autism, the length of treatment and hospital stay may be dramatically increased. The inability of the multidisciplinary team (MDT) to communicate effectively with the 5-year-old due to altered communication processing and cognitive development (Berk, 1991) will have a profound impact on treatment and management strategies. A lack of understanding regarding the child's individual needs, reduced ability to play, inability to communicate through play and rational thought processing all impact on length of hospital stay (Figure 2) (Pratt et al, 2012).

At RMCH Burns Service, it is recognised that care strategies, particularly relating to communication, have to be tailored to each patient. Therefore, a communication and care strategy — incorporating a range of communication skills and approaches — was required to enable all staff to interact effectively with children with autism and their families, ensuring equality in access for children across the autism spectrum (Michael, 2008; WHO, 2013; National Institute for Health and Care Excellence [NICE], 2011).

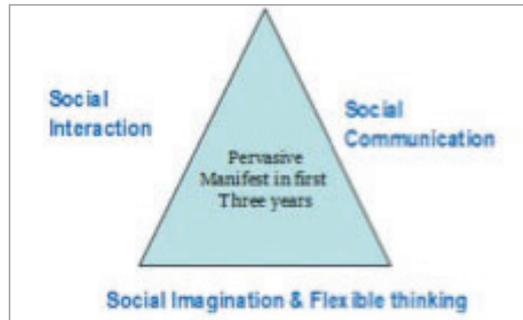


Figure 1. Detection of autism-related behavioral profile is possible within the first three years of life.

INITIAL STEPS

In order to develop a communication and care strategy, as well as understand the emotional impact and needs of staff managing this patient group, a small-scale focus group and an anonymous staff survey were conducted. These explored staff experiences of providing care to children with autism who present with major burns. The key themes that emerged related to a lack of knowledge around autism in general, particularly from more senior team members who had received no autism or communication training in their pre-registration education.

Lack of confidence was another key theme. Concerns were raised about fear, anxiety and 'getting it wrong' or 'making it worse.' Frustration around lack of multiprofessional, evidence-based, patient-centred care pathways for these patients was also apparent. Staff explained that signposted guidance would allay their fears and anxieties (Mencap, 2007; Michael, 2008; NICE, 2011; The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

Staff outlined the challenges they face when working with children with autism. These were:

- ▶▶ An increase in the number of patients with autism
- ▶▶ Difficulty in providing invasive treatments (extensive dressings, blood tests, cannulation and catheterisation)
- ▶▶ Concerns regarding the health and safety of nursing and medical staff
- ▶▶ Risk assessments
- ▶▶ Increased planning meetings to address patient safety
- ▶▶ Lack of appropriate communication methods/tools
- ▶▶ Increased use of sedation
- ▶▶ A need for therapeutic safeholding and safeguarding
- ▶▶ Increase in clinical incidents

“A lack of understanding regarding the child’s individual needs, reduced ability to play, inability to communicate through play and rational thought-processing, all impacts on length of hospital stay.”



Figure 2. Young child with autism that would not receive treatment unless wearing his hat and scarf.

- ▶ Raised parental and professional concerns
- ▶ Complaints
- ▶ Lack of knowledge/ awareness and expertise regarding autism.

A large-scale literature review was undertaken to identify relevant existing evidence, which was then used to support and validate these findings. The literature review provided limited evidence of existing strategies to support or manage care of children with autism and extensive burn injuries.

THE WAY FORWARD

All staff recognised that children with autism are different to other patient groups that the Burns Service encounters (Kumar et al, 2005), although many team members found it difficult to clearly distinguish between autism and attention deficit hyperactivity disorder. To address this confusion and to highlight the complexities of providing care to these children, a comprehensive training programme to support the MDT was developed.

Development of the training programme was undertaken in partnership with the Burns Education and Development Practitioner and the RMCH Therapeutic Play Department Consultant and Professional Lead for Autism. This partnership enabled the development of strategies, tools, teaching and learning resources to

educate the MDT. Monthly education sessions entitled ‘Communicating with Children and Young People with Burns and Autism’ were devised, each with a defined set of measurable learning outcomes. These learning outcomes were:

- ▶▶ What is autism?
- ▶▶ Explain how a hospital play specialist can provide intervention for children with autism
- ▶▶ Discuss how to communicate with a child/young person and family member with autism
- ▶▶ Describe how the child/young person can be prepared for burns treatment/interventions
- ▶▶ List and describe different communication aids and tools that are available to you
- ▶▶ Identify methods to improve the patient/staff experience
- ▶▶ Identify methods to reduce risk to the child, family and staff members
- ▶▶ Demonstrate understanding and knowledge of the child’s/family’s views of coming into hospital as either a planned or emergency admission
- ▶▶ Demonstrate understanding of partnership working and care planning throughout the care pathway, including transition and aftercare
- ▶▶ Raise awareness of the Autism Act (HM Government, 2009) and Health and Social Care Act (HM Government, 2012).

A key concern that arose in focus group sessions was the subject of ‘zero harm’, as well as supporting appropriate and ongoing care. A ‘Communication Do’s and Don’ts’ tool was shared as a starting point to help guide staff in their communication strategies (NICE, 2011). This tool advises on approaches to best support the child and proved a valuable resource to the MDT, particularly in avoiding harm (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

To gain a greater understanding of the individual needs of children with autism, a ‘Person Centred Assessment of Child’s Individual Specific Needs’ form was developed, for completion on admission, in partnership with the child (if possible) and/or parents/guardians (Pratt et al, 2012). This assessment highlights the child’s essential individualised needs, using a traffic light scale. For example, if the child will not interact without holding their favourite toy for security, this will be rated as red; if the child becomes distressed and bites on hearing loud noises, this would also be red; if the child becomes calmer with touch and toys, this

would be indicated in the green section. Used in conjunction with other communication strategies, MDT members can be guided by this information, directing them to the best approaches for care that meets the child's needs at every stage (Miller and Aitken, 2003).

Further essential information is contained within the 'All About Me' handheld records that many children with complex care needs and autism possess (Warner, 2000). This informs MDT members of the best approaches to achieve quality care, maintain interaction, communicate likes/dislikes, and identify behavioural patterns (Warner, 2000). It also helps ensure a smooth transition between different services (NICE, 2011; The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

CARE PATHWAY

To facilitate the smooth transition between services, a care pathway was created to guide the Burns team. As soon as autism is recognised, essential additional resources and communication strategies are put into place to support the child, their family and the staff (Faber and Mazlish, 2001). To support the child undergoing an invasive procedure, such as a burn dressing or placement of a nasogastric tube, a person-centred form, which is completed on admission to highlight specific and individual, needs to indicate reasonable adjustments required (Figure 3). Nind and Hewitt (1995) recognised this as being an essential part of care provision.

COMMUNICATION TOOL

Communication tools are fundamental to the strategies used in the department and have proven to be extremely useful (Figure 4). Used in conjunction with the care pathway, patient passport ('All About Me') and communication do's and don'ts, they are the next 'visual' stage in communicating with the child with autism and burns.

Social storyboards have also been developed in partnership with the RMCH wider therapy teams. Time between the relaying and processing of information is required for these to be successful; this 'think gap' enables the child to process what is happening without being bombarded with excessive information (Nind and Hewitt, 1995; Scarpinato et al, 2010). A 'now and next' or 'then and this' approach is very useful, as 50% of children are best interacted with by explaining each step of treatment as it occurs (Kopecky et al, 2013).

THE CHAMPION ROLE

There are two 'champions' within the Burns Service and the specialist Burns Aftercare Clinic, who are key in ensuring resources are available to support children with autism. This role is paramount in flying the flag through effective leadership (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) and sharing the message that services can be provided in a positive, coordinated way (Autism Act, 2009). These champions work in partnership with other MDTs at RMCH, to roll out processes hospital-wide.

EVALUATION AND FUTURE ACTION PLANS

The communication strategies, together with non-pharmacological pain management distraction techniques, have been extremely useful in managing children with autism and burn injuries. Anecdotal evidence suggests a reduction in distress, anxiety and challenging behaviour, demonstrated by increased compliance of children during interventions such as dressing changes. The authors feel this is directly related to improved professional knowledge and understanding. From a service-user perspective, the parental survey demonstrates a reduction of anxiety and stress experienced by families. Service development has improved MDT team working and appropriate sharing of patients' needs, resulting in consistent standards of care. The standards of care have been ratified for use within the Children's Hospital and Trust to ensure equal access to healthcare for children with autism and to ensure good practice is sustained.

Objectives for the future include the rollout of the care strategy for children and young people with autism hospital-wide, and to share the lessons learned with others locally, nationally and internationally. Communicating through play and the use of electronic tablet devices to support the 'show and tell' processing methodology is also planned, and this will help build the momentum of staff communication training. It is

Figure 3. This form, which is filled in on admission, helps to highlight any child-specific needs.



Figure 4. Digital communication tools have proven to be extremely useful when interacting with autistic children.

the authors' aim to embed autism awareness and communication training into higher education institutions that deliver paediatric health and social care education programmes.

MAINTAINING MOMENTUM

The standards of care for children and young people with autism are measurable and auditable, enabling the quality review process to continue, thereby enhancing patient safety and improving care standards. All new MDT members receive 'Positive About Autism' training and the authors hope to further support this with additional e-learning, teaching and learning resources. Autism champions throughout all RMCH departments have been identified and will receive appropriate training.

CONCLUSION

It is imperative to support staff that care for children and young people with autism. A child or young person with a major burn injury requires a vast amount of technological support and invasive care strategies. However, staff must see past the technological aspects and focus on the child and family, how best to communicate with them and support them. RMCH's care strategy supports the staff in doing this and the improved resources enhance communication between patients and professionals.

Each child has their individual needs assessed and a bespoke pathway planned with MDT collaboration to

improve their hospital experience. The strategy has been shared locally, at conferences, and with NHS England. The authors will continue to develop the service, and focus on service-user evaluations, patient safety, staff training, the patient voice, and equality and inclusion of all children and young people within the service.

WUK

REFERENCES

- Centers for Disease Control and Prevention (2012) Prevalence of autism spectrum disorders-Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *MMWR Surveill Summ* 61(3): 1–19
- Baird G, Simonoff E, Pickles A et al (2006) Comment in *Lancet*. *Lancet* 15: 368(9531): 210–5
- Bennett NR (1997) Provision of Paediatric Intensive care Services. *Br J Hosp Med* 58(8): 368–71
- Berk LE (1991) *Child Development* (2nd edn) Allyn and Bacon, Mexico MO, USA
- Faber A, Mazlish E (2001) *How to Talk so Kids will Listen and Listen so Kids will Talk*. Piccadilly Press, London
- Herndon D (2012) *Total Burn Care* (4th edn) Saunders Elsevier, London
- Heslop P, Blair PS, Fleming PJ et al (2013) Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *Lancet* 383(9920): 889–95
- HM Government (2009) *Autism Act*. Available at: <http://bit.ly/1iUWF1E> (accessed 01.07.2014)
- HM Government (2012) *Health and Social Care Act*. Available at: <http://bit.ly/1dCgQbZ> (accessed 01.07.2014)
- Kopecky K, Broder-Fingert S, Iannuzzi D, Connors S (2013) The needs of hospitalized patients with autism spectrum disorders: a parent survey. *Clin Pediatr (Phila)* 52(7): 652–60
- Kumar P, Wilson G, Ross GL, Shah M (2005) The management of an autistic burns patient, A case for ventilation? *Burns* 31(4): 532–3
- Mencap (2007) *Death by Indifference: Following up the Treat Me Right Report*. Available at: <http://bit.ly/1fEKlUM> (accessed 21.02.2014)
- Michael J (2008) *Healthcare For All: Report of the Independent Inquiry into Access to Healthcare for People With Learning Disabilities*. Aldridge Press, London.
- Miller S, Aitken S (2003) *Personal Communication Passports: Guidelines for Good Practice*. Available at: <http://bit.ly/Nh4lg1> (accessed 21.02.2014)
- National Institute for Health and Clinical Excellence (2011) *Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum*. Available at: <http://www.nice.org.uk/guidance/CG128> (accessed 02.07.2014)
- National Institute of Neurological Disorders (2013) *Autism Fact Sheet*. Available at: <http://1.usa.gov/1fd3oj> (accessed 01.07.2014)
- Nind N, Hewitt D (1995) *Access to Communication – Developing the Basics of Communication with People with Severe Learning Disabilities Through Intensive Interaction*. Tavistock, London
- Pratt K, Baird G, Gringras P (2012) Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme. *Child Care Health Dev* 38(6): 789–97
- Scarpinato N, Bradley J, Kurbjun K et al (2010) Caring for the child with an autism spectrum disorder in the acute care setting. *J Spec Paediatr Nurs* 15(3): 244–54
- Szatmari P (2003) The causes of autism spectrum disorders. *BMJ* 326(7382): 173–4
- The Mid Staffordshire NHS Foundation Trust (2013) *Public Inquiry – Chaired by Robert Francis QC*. Available at: <http://bit.ly/1byNzCi> (20.02.2014)
- Van der Walt JH, Moran C (2001) An audit of perioperative management of autistic children. *Paediatr Anaesth* 11(4): 401–8
- Warner HK (2000) Making the invisible, visible. *J Child Health Care* 4(3): 123–6
- Wood KC, Smith H, Grossniklaus D (2001) Piaget's Stages of Cognitive Development. In: Orey M (ed) *Emerging Perspectives on Learning, Teaching, and Technology*. CreateSpace, Independent Publishing Platform
- World Health Organization (2013) *Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders*. Available at: <http://bit.ly/1vrTLlu> (accessed 01.07.2014)