illnesses then the average population. Such children may also be difficult to examine, due to challenging behaviour, which is often exacerbated by the stress and unpredictability of medical encounters. The United Nations Convention on the Rights of a Child (1989, 1) states that all children should receive effective health care. Regardless of this assertion, limited evidence in current literature demonstrates how this can be achieved when treating children with ASD. If successful, the 'Where does it hurt?' system may provide a simple, cost-effective method of improving services for this group.

Educational Objectives

- Conduct a literature review outlining issues faced when examining children with ASD, and strategies that have been successfully employed to overcome this.
- Gain experience in carrying out basic physical examinations on a challenging population, whilst employing alternative communication methods.
- Observe the role of community paediatrician and understand the importance of multi-disciplinary teams in providing an effective health service of children with ASD.

Background

Autistic Spectrum Disorder (ASD) is a pervasive developmental disorder, often recognised in early childhood. Children with this condition exhibit deficits in three main areas of functioning: repetitive behaviours and restricted interests, failure to form effective social relationships and abnormal communication skills (2). The prevalence of ASD in the United Kingdom is currently between 1-2%, a figure, which may rise with increased awareness and detection rates (3). Consequently, it is likely that most physicians will encounter individuals with autism, and it is essential that they are adequately equipped to cope with the challenges this population may present.

Although ASD is characterised primarily by cognitive abnormalities, it has been associated with an increased rate of medical conditions. This is particularly true of gastro-intestinal disorders (4-6), which have been demonstrated to be over 4 times more common in this group compared to in unaffected siblings (4). Other associated

medical co-morbidities include epilepsy, visual and hearing deficits (6). These findings emphasise a need to offer efficient medical examinations for children with ASD, allowing for early detection and treatment of illness.

Medical conditions in children can have a negative impact on quality of life and educational performance, regardless of their developmental trajectory. Children with ASD may however encounter a more complicated array of challenges due to their sensory and communication deficits (2). This has been illustrated in a longitudinal study considering the association between health problems and behavioural issues in autism (7). Deteriorations in health were observed to coincide with higher levels of maternal burden, due to increases in challenging behaviour such as aggression, self-harm and autistic-like behaviours. Such manifestations of pain may be attributed to the child's diagnosis of autism, thereby overlooking treatable health issues that may be at their root.

A barrier that may potentially affect health care provided to children with ASD may be how they are percieved by health care professionals. Interviews with such individuals suggest that treating patients with autism is often viewed as frustrating, with communication issues highlighted as a key difficulty in forming effective therapeutic relationships (8). This opinion is emphasised further by extreme methods, such as sedation (9, 10) and adult restraint (10), which have been advocated in attempts to calm children with ASD for anaesthesia administration. Evidently, there is a requirement for validated behavioural alternatives to such methods, suitable for use by all physicians.

Physical illnesses may be difficult to detect in children with ASD, due to the nature of the emergency department setting. This often unpredictable, hectic environment can serve to exacerbate anxiety, thereby aggravating challenging behaviour (11, 12). Suggestions to overcome such issues include the use of quiet rooms, and visual communication systems where appropriate (12, 13). Furthermore, treatment in a familiar place, such as a school medical room may help to reduce distress caused by acute medical events, thereby increasing child cooperation to procedures required.

A limited number of alternative studies have considered how compliance to medical examinations may be increased in children with ASD (14-16). In one study considering 35 children with autism, 31% were found to have specific phobias

relating to such scenarios (14). Following graded exposure, employed in individual settings over a 25 week period, many children showed neutral or positive reactions to feared equipment. Whilst this technique may offer a promising intervention to assist physicians, it is highly intensive and requires staff training for successful implementation. With resources allocated to children with ASD often being sparse, this method does not offer a practical solution to overcome the issues faced, and a more cost-effective system would be required to assist with medical examinations.

An alternative successful intervention when assisting with both medical (15) and dental (16) examinations on children with ASD has also been outlined, in the form of an intensive training schedule. 9 week teaching programmes using DVDs, escape prevention and visual prompts were demonstrated to increase compliance of children with ASD when experiencing such encounters. Although successful, this technique would not be practical for implementation on a large scale, due to its time consuming nature. Moreover, the study only included 6 children, and no follow-up test was conducted, so it is unclear whether positive results would be extinguished with time.

Promising results have also been obtained from a high-probability response procedure, in which commands that children are unlikely to perform were infrequently interspersed with more attainable ones (17). This procedure was found to greatly increase compliance to basic physical examinations. Such a method would however have limited efficacy when considering wide-scale implementation, as prior training for health-professionals would be necessary for its employment. Therefore, whilst such evidence indicates that children with ASD can be taught to cooperate with basic medical examinations, a practical, cost-effective system suitable for application into classrooms would be beneficial to achieve this.

A tool that is frequently employed to assist children with ASD to communicate is that of picture exchange communication systems (PECS). Training with this has been found to increase spontaneous verbal and picture communication for instrumental means (18). The use of similar system, combined with reinforcement has been trialled in simulated medical examinations on children with ASD (19). This intervention was found to useful, although the children had received no prior training. Evidently, it would be advantageous to observe if classroom based teaching,

combined with and use of a visual system within examinations would further improve the compliance of children with autism to the medical encounter.

The present study aims to evaluate the efficacy of a visual tool in assisting with medical examinations on children with ASD. The 'Show Me Where™'* pain communication system has been incorporated into classrooms in a specialist school for children with ASD. These children will receive a simulated physical examination, the success of which will be assessed, and compared with examinations received by an unexposed group, where the intervention will not be used. The results will be reported with a view to outlining which factors may affect the successful use of the system, further highlighting whether it is suitable for implementation in additional settings.

METHOD

Ethical Considerations

Ethical approval was obtained from the Cardiff University Research Ethics Committee prior to study commencement. Issues raised included confidentiality, follow-up of abnormalities found during examination, abandoning procedures in cases of child distress and only including participants for who informed parental/guardian consent was obtained in writing.

Participants

This study included participants aged 5-12 years, attending two specialist schools for children with ASD. The intervention group was obtained from The Hollies School, Cardiff. Inclusion criteria for this group was previous exposure and training with the 'Show Me Where™' system. Control group participants were obtained from Ashgrove School, Cardiff and had not been previously exposed to the 'Show Me Where™'* communication system. Children over 12 years were excluded from both groups.

Additional information relating to all participants was obtained from teachers, and cross-referenced with medical and educational documentation. This included special educational needs, sensory processing issues and communication skills possessed.

'Where does it hurt?' Picture communication system

The 'Show Me Where™'* picture communication system was pioneered by Irene Hammond, a nurse at the Hollies school. The tool includes large posters, depicting the back and front of a boy/girl, with smaller illustrations of different parts of the body. Children have been taught to retrieve appropriate symbols if they are experiencing pain, and comply with examinations when presented with a picture. The intervention group received regular classroom training with this system prior to the study commencement. It is available in a variety of formats, including magnetic books, smart board programs and wall charts.

SCORING SYSTEM

Each examination was scored using a single rating of success, the criteria of which are outlined in table 1.

Table 1: **Possible examination grading and the criteria used to achieve this.**

Score	Criteria
Very successful	Participant successfully compliant to all areas of the examination.
Complete with difficulties	Participant compliant. Attempts made in all aspect of the examination although these may be inadequate.
Partially complete	Limited participant compliance. Unable to complete all areas of the examination.
Unsuccessful Procedure	No compliance observed.

The study took place in the medical room of the school attended, with the assistance of a nurse. In the intervention group, children entered the room and were asked to sit on the bed. Utilising the 'Where does it hurt'* system, they were first shown the throat symbol, and the examiner attempted to inspect the tonsils. Verbal commands to open their mouth were also given. Next, the chest symbol was presented and the participant's shirt was lifted, allowing for front and back auscultation of the heart and

lung fields. Finally, the children were shown the tummy picture, and asked to lie on their backs to allow for abdominal palpation. This was conducted whilst standing/sitting if incompliant. All verbal commands were simple and specific, with additional adult support provided if required. In the control group, an identical procedure was implemented, omitting the use of the '6KRZ0H□KHUH' picture communication system. Examinations were conducted with the use of verbal commands and imitation. All examinations were scored immediately for success by the examiner.

Detailed notes were documented throughout by an observer to allow for additional qualitative analysis. Statistical analysis of results was deemed inappropriate due to the size and unmatched nature of the sample.

The main data collection issue was failing to gain written parental consent for many eligible participants in the control group, thereby resulting in their excluding them from the study. No participants were excluded from the study following examinations.

RESULTS

Participant demographics

The present study included 22 participants aged 5-12 years, 12 in the intervention group, (11 male, one female, mean age 7.9 years) and 10 in the control group (10 males, mean age 6.6 years). Additional information indicated that fewer children in the intervention group had severe learning disabilities, compared to the control group (3 vs. 5). The intervention group had a less frequent use of picture communication, although none possessed normal verbal communication skills, whereas this was the case for 2 children in the control group. Individual details, including examination success scores are outlined in table 2 (intervention group) and 3 (control group).

Table 2: **Ability level, sensory processing, aggression and communication skills of individual children in the intervention group**

Child No	Learning disability	Sensory processing	Aggression	Functional verbal communication	PECS use	Success Score
1	None	Defensive	Frequent	Limited	Occasional	1
2	Moderate	None	Rare	Limited	Occasional	1
3	Mild	Both	Rare	None	Occasional	2
4	None	Both	None	Limited	Occasional	2
5	Moderate	Defensive	None	Limited	Occasional	2
6	Moderate	None	None	None	Frequent	2
7	Severe	None	None	Limited	Frequent	3
8	Severe	Both	Rare	None	Occasional	3
9	Moderate	Both	Rare	None	Occasional	2
10	Moderate	Both	Rare	Limited	Frequent	1
11	Moderate	Seeking	Rare	Limited	Frequent	1
12	Severe	Both	None	None	Occasional	1

Table 3: **Ability level, sensory processing, aggression and communication skills of individual children in the control group**

Child No	Learning disability	Sensory processing	Aggression	Functional verbal communication	PECS use	Success Score
1	Severe	Seeking	None	None	Frequent	2
2	Mild	Seeking	None	Limited	Frequent	2
3	Mild	Seeking	None	None	Occasional	3
4	Severe	Defensive	Rare	Limited	Frequent	3
5	None	Defensive	Frequent	Normal	None	1
6	Moderate	Seeking	None	Normal	None	1
7	Severe	Defensive	Rare	Limited	Frequent	4
8	Severe	Defensive	Rare	None	Occasional	3
9	Severe	Both	Rare	None	Occasional	4
10	Moderate	Defensive	Rare	Limited	Frequent	3

Examination success:
Very successful = 1, Complete with difficulties = 2, Partially complete = 3, Unsuccessful = 4

OVERALL SUCCESS

Scores indicate that more participants in the intervention group received completely successful examinations compared to the control group (5 vs. 2). A higher number of complete examinations with difficulties were awarded in the intervention group, and no examinations were scored as unsuccessful. Partially complete examinations were more common in the control group, where 2 examinations were also scored as being unsuccessful. These results are illustrated in Figure 1.

Further analysis of results also demonstrates that examinations scored as incomplete in the intervention group, and unsuccessful in the control group, were received by participants possessing severe learning disabilities. Very successful ratings were obtained in the control group for high functioning children with normal verbal communication skills only.

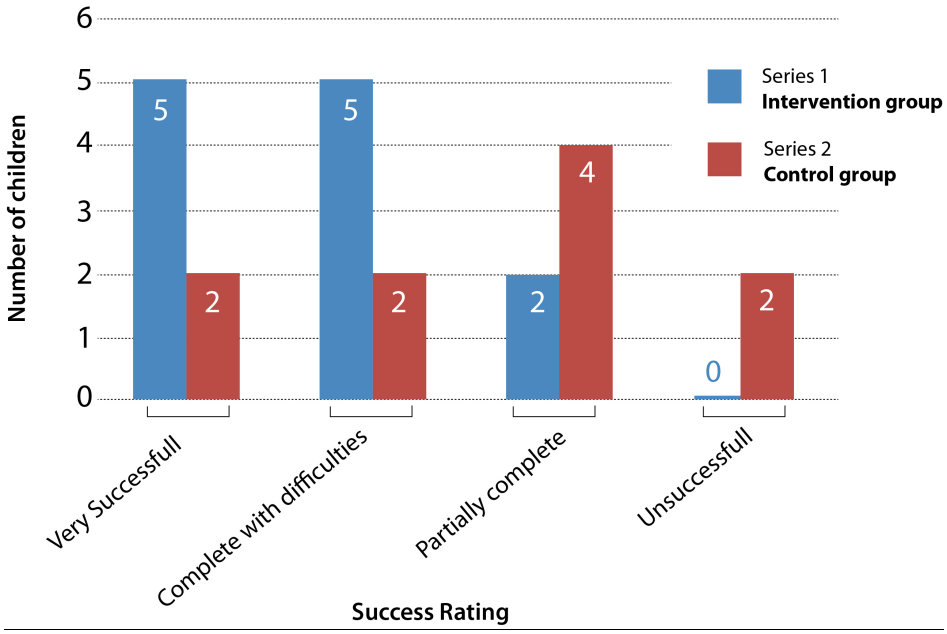

Figure 1: **A graph illustrating the success ratings of medical examinations in the intervention compared to control group**

DESCRIPTIVE ANALYSIS

When conducting examinations, the intervention group were found to be more compliant with commands compared to the control group. When the 'Show Me Where™'* tool was used, a sense of control was maintained by the examiner. Participants often pre-empted elements of the procedure before receiving verbal commands. All children attempted every request in the intervention group, with partially complete scores being awarded due to an inability to complete tasks, as opposed to incompliance. Conversely, responses from participants in the control group were often limited, with children exhibiting increased activity and unpredictable behaviour. This is emphasised by a key difference observed, in which children in the intervention group consistently lay flat for abdominal palpation. This was a skill that the control group found difficult to achieve.

Another consistent difficulty common to all participants was that of mouth opening for inspection. This was performed poorly in many cases in the intervention group, however was often not attempted in the control group. In both groups, one participant was distressed prior to examination commencement. Despite this, the child in the intervention group attempted to comply with all aspects of the examination. In the control group however, the participant refused to enter the room, and exhibited aggression and self-harm, leading to the procedure being abandoned.

Example participants are provided in table 4 below.

Table 4: **Descriptions of typical consultations in the control and intervention groups.**

Group	Examination description
Intervention group	Henry entered the room and sat on the bed as requested. When shown the picture of the throat he opened his mouth saying 'ah', causing him to gag and allowing for a brief view of his tonsils. When given the picture of the chest Henry said 'chest', and remained quiet with his shirt lifted, so the heart and lung fields could be auscultated. Finally Henry was shown the picture of an abdomen, which he held and lay down to allow palpation. He did however make groaning noises and adopted an odd posture, pushing the examiners hand softly. Henry then left the room and returned to class.
Control group	Joe entered the room with an assistant. He was asked to open his mouth, but did not do so, saying 'ah' quietly and staring into the examination light. When examining the chest Joe stood up, and during auscultation he firmly pushed the stethoscope away and laughed. Whilst being examined, Joe was fidgety and noisy. He was asked to lie down to have his abdomen palpated. Joe lay on his side and immediately sat up again. Attempts were made to continue this whilst sitting, however palpation was not tolerated and he left the room.

False names are included to maintain participant confidentiality.

DISCUSSION

The results of the present study indicate the 'Show Me Where™'* pain communication system is beneficial when assisting with medical examination on children with ASD. In the intervention group 5 children received very successful examinations, compared to 2 in the control group. Where the tool was used, no examinations were rated as unsuccessful, whereas 2 obtained this score when it was omitted.

The qualitative results obtained further elucidate the positive influence of the 'Show Me Where™'* system on conducting medical examinations. Children were calmer and more compliant in the intervention group, with fewer participants requiring

additional adult support, supplementary to the nurse present. This was not however the case in the control group, where children were often fidgety, making no attempt to engage with the examiner and carry out tasks required of them. Furthermore, where the communication device was not employed, 8 participants required the assistance of two adult helpers (nurse and teacher) during the encounter. Such findings emphasise the difficulties faced when conducting the examinations without a visual communication system.

A difference demonstrated between the two groups was reaction of children to anxiety. This appeared to have a highly detrimental impact on control group examinations. The starkest example is offered by one participant who refused to enter the room, exhibiting aggression and self-harm. In the intervention group however, the child experiencing the highest level of distress displayed no such actions, and attempted all commands requested. Such findings are supportive of previous evidence (18), indicating that the use of a visual system during examinations decreased irritability levels of children with ASD. It is possible that the benefits observed may be due to the 'Show Me Where™'* system offering a visual framework on which the children can base their actions. This would provide routine to an otherwise incomprehensible situation, thereby dissipating the anxiety present. A factor that may mediate successful use of the 'Where does it hurt?'* communication system is the degree of learning disability present. This is highlighted in the intervention group, where all children receiving partially successful scores also possessed severe learning disabilities. This was also the case in the control group for participant whose examinations were rated as unsuccessful. Although an increased level of learning disability may result in a more challenging consultation, it appears that the 'Show Me Where™'* system does provide some benefit, as no children received unsuccessful scores when it was used. It is however possible that, with a combination of severe learning disabilities and ASD, the purpose of the communication tool may not be understood, rendering it ineffective.

An additional factor influencing successful use of the system may be the level of communication skills a child possess. In the control group, the only participants to attain very successful scores were those with normal verbal language ability. It is likely that, in the absence of distress, these proficiencies would negate the need for a picture communication system. It would have been beneficial to observe if matching

children on the basis of communication usage would have affected the success of examinations.

Past research has indicated the positive impact of both preparatory training (13, 14) and implementation of techniques during medical encounters (16, 18) when assisting children with ASD to cope with physical examinations. The procedure employed in the present study differs from these interventions, as children were both taught to use 'Show Me Where™'* communication aid as part of their classroom routine, and it was also incorporated into the examinations themselves. Although it is unclear which element of the method may have the biggest influence on compliance, previous studies outlined would suggest that both components are beneficial.

Unlike previous techniques offered (14-16), the current study does not include an intensive training programme. The 'Show Me Where™'* system would be highly suitable for inclusion in classroom teaching regimens, where its use may become routine as a result of regular exposure and open access to it. Furthermore, due to its simplicity, minimal training would be required by healthcare professionals. This therefore offers a cost-effective, practical approach to increase compliance of children with ASD during medical examinations.

The results outlined by the present study must be considered in light of its methodological limitations. Due to practical restraints, only a small number of participants were recruited. Controlling for levels of learning disability, communication skill and sensory issues was not possible, and such differences may have had influenced findings obtained. An example of this can be observed in the control group, where more children possessed severe learning disabilities compared to the intervention group. Future participant matching may elucidate how successful the system is in assisting with medical examinations, and in which group the largest benefit is likely to be obtained.

A further issue relates to the environment in which the data was collected. The school included in the intervention group benefitted from a consistent medical presence, as a familiar nurse was permanently based there. Moreover, the examination room had a central position, making it recognisable to all children. This was not the case in the school attended by children in the control group. Here, the medical room was in a discrete location within the school, and a nurse had only

recently been recruited on a temporary basis. As routine is integral in the lives of children with ASD, the latter environment may not have been conducive to the achievement of successful examinations.

It must be emphasised that none of the participants recruited in the present study were acutely unwell. Children may associate medical encounters with illness and so this may have led to the purpose of the examinations not being understood, explaining why limited numbers of very successful scores were achieved in both groups. Regardless of this, the 'Show Me Where™'* system still appeared to offer some benefit, producing increased participant compliance. Future research may focus on conducting a similar procedure within an emergency department setting, with unwell children. This would illustrate if the intervention assisted with examinations in this circumstance and whether children with ASD could employ it to identify the location of pain experienced.

The present study could also be expanded to include a large closely matched sample. Additionally, obtaining video recordings for scoring of examinations by impartial observers would produce a robust evaluation of the 'Show Me Where™'* tool, allowing for statistical analysis. Furthermore, a longitudinal study could be undertaken, by assessing the success of physical examinations before and after its incorporation into classroom teaching. This would offer a direct and detailed demonstration of success.

In conclusion, the use of the 'Show Me Where™'* pain communication system appears to be helpful in assisting with medical examinations for children with ASD. When it was used, increased compliance was observed, resulting in a higher number of children receiving very successful scores. This system may function by dissipating anxiety, offering a degree of predictability to the medical encounter. Furthermore, the 'Show Me Where™'* tool would be suitable for application to a wide population, enabling more children to enjoy its benefits.

* Previously known as 'Where does it hurt?' (Copyright Cardiff and Vale University Health Board 2011)

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