Development and qualitative evaluation of a communication tool for children with autism spectrum disorders and other communication difficulties

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Abstract

Effective communication is essential to establish rapport, explain procedures and give advice on preventing oral disease. Therefore children with communication impairments face potential barriers to receiving optimal dental care.

Aims and objectives: To describe the development and qualitative evaluation of a child-centred chairside augmentative and alternative communication (AAC) tool; to observe its impact on delivery of treatment and gain the perspectives of children, parents and operators.

Methodology: A draft paper-based AAC tool was developed using text and symbols (Widgit Health®). The content and format were amended during an iterative process in response to feedback from children, their parents and operators. A convenience sample of children with significant communication impairments attending a specialist paediatric dentistry community clinic used the tool during dental visits. Data were collected by making contemporaneous field notes of observations and by documenting verbatim comments from parents and operators. Data were subjected to thematic content analysis. The tool was further revised prior to publication.

Results: Twenty children (17 boys, 3 girls) aged 3-14 years used one to four pages of the AAC tool. Known communication impairments (>1 may apply) included autism spectrum disorders (75%; n=15) and learning difficulties (35%; n=7). Forty percent had other medical conditions (n=8). The tool encouraged verbal communication, improved children's cooperation with treatment and enhanced operator experience. Parents commented on its usefulness for their child, appropriateness of the format and the value of knowing the dental procedure sequence.

Conclusions: This new child-centred AAC tool improved children's communication and cooperation. Further evaluation is needed to determine whether its use may be applicable in other settings and with other patient groups.

Key words: *Child, autism spectrum disorder, learning disability, communication, patient information, special care dentistry*

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Background

Effective communication between the dental team, children and parents is an essential requirement for provision of dental care. It is used to establish rapport with children, to explain dental procedures, to convey information to assist in decision making and to give advice on preventing oral disease. It also has an important role in allaying children's anxiety and improving cooperation with treatment (American Academy of Pediatric Dentistry, 2013).

Communication may be adversely affected by communication impairments, for example due to autism spectrum disorders (ASD) or learning difficulties (LD). In the dental setting this creates a potential barrier to provision of optimal dental care. A number of different approaches have been advocated to enhance communication in such circumstances (Charles, 2010; British Society for Disability & Oral Health and Faculty of Dental Surgery of the Royal College of Surgeons of England, 2012). These include both pre-appointment methods such as seeking information about the child's preferences (Golding and East Elmbrige & Mid-Surrey Community Dental Service, 2005), providing information or devising an individualised description (such as a Social Story™) for parent or carer-led use (Bellis, 2010; Charles, 2010) and in-surgery or 'chairside' methods for use during the dental visit.

Children with communication impairments may already be familiar with a range of augmentative and alternative communication (AAC) systems, encompassing both formal sign systems and high-tech and low-tech communication aids, such as speech generating electronic devices or paper-based picture or symbol books or charts (Clarke and Price, 2012). Some of these systems have been utilised to provide published communication tools for chairside use in dentistry (Homefirst Community Trust, 1999; British Society for Disability & Oral Health and Faculty of Dental Surgery of the Royal College of Surgeons of England, 2012). Others can be tailored specifically for the setting or individual patient, such as incorporating symbols into a 'Velcro® timeline' (laminated symbol cards attached to the surgery wall with fabric hook-and-loop fastener), a type of visual schedule. All formats have some limitations, whether the scope of dental treatments illustrated, the difficulties ensuring concurrent cross-infection control or the amount of time required to construct individually-tailored tools.

As implementation of evidence-based practice guidance progresses, there is unprecedented consensus in the UK regarding the preventive procedures that should be offered to children with additional needs or at high risk of dental disease (Department of Health and British Association for the Study of Community Dentistry, 2009). Therefore development of a single, standardised communication tool for commonly-encountered contemporary dental procedures would be timely and might assist providers of paediatric dentistry to reduce barriers to dental care for children with communication disorders.

Guidance on developing healthcare services and patient information for children indicates that they should have input to the process and their perspectives should be included in evaluation (Gilchrist *et al.*, 2013). This presents a potential challenge for clinicians and researchers when working with those with learning difficulties. However some authors have argued convincingly that interpretive methods of data collection can be successfully employed to capture patients' views (Booth and Booth, 1996; Owens, 2007), for example by observing behaviour and collecting field notes (Franklin and Sloper, 2009; Yesudian *et al.*, 2012), the influence of the researchers' interpretation of their own observations being explicit and acknowledged as a legitimate part of the process.

The aims of this paper are to:

- Describe the development of a new AAC tool for chairside use with children with significant communication impairments, developed with input from children and focussed on common dental procedures, in order to support implementation of national guidance on preventive care
- Report a qualitative evaluation of its use. The aims of the evaluation were (i) to observe use of the communication tool and its impact on delivery of dental care and (ii) to gain the perspectives of children, their parents and the dental team.

Material and method

Development of the AAC tool

Initial draft materials were prepared using text, commercially available symbol software (Widgit Software, 2013) (Communicate: In Print 2, Widgit Software, Leamington Spa) and photographs. The tool mirrored a format already developed by the local children's hospital using an AAC symbol system (Widgit Software and Sheffield Children's NHS Foundation Trust, 2010), selected as a result of a parental survey in local educational settings (Short, 2013). Feedback on the initial draft was obtained from five dentist and dental nurse colleagues, all experienced in special care paediatric dentistry. The tool was amended in response to their suggestions prior to its use and evaluation in the clinical setting. Further development followed an iterative process, in response to observations and patient, parent and dental team feedback.

Evaluation of the AAC tool

Setting

The evaluation was conducted in a specialist paediatric dental service in a salaried primary care community dental clinic, staffed by a single dentist assisted by one of several dental nurses. No adjustment was made to usual appointment duration or staffing. The same dental surgery was used throughout. Undergraduate dental students or postgraduate trainees were occasionally present but took no active part in provision of treatment or data collection.

Sampling

A convenience sample was taken of consecutive child patients with significant and disabling communication impairments, referred for specialist dental care. Both new

patients and those attending a subsequent visit were included.

Data collection

Data were collected by a single observer, the operator (JCH), who made field notes of observations of the child using the communication tool (*Figure 1*) and of its impact on delivery of dental care. Effort was made to capture children's perspectives in these observations and also by using the parent as a proxy. Views of parents themselves were sought by informal questioning at the time of the visit and documented verbatim when possible. Dental team perspectives were captured by documenting reflective discussions throughout the evaluation period on an *ad hoc* basis.

The field notes were recorded immediately after the dental visit, as soon as clinical record-keeping was complete. The following were also noted: age of child, sex, main reason/s for communication impairment, significant medical diagnosis, type of dental visit (first or subsequent visit to our surgery) and type of school attended. Available medical history was only that reported previously by parents or referring health professionals; no attempt was made to retrieve additional detail solely for the purposes of the study nor to categorise the impairment according to internationally agreed diagnostic criteria, such as DSM, ICD-10 or ICF-CY. Further observations were recorded if a child attended on a second occasion within the evaluation period. Data collection continued until saturation was reached.

The project was designated as 'service review' and as such, in accordance with the host NHS Trust policy, was required to follow ethical principles laid down in local guidance but did not require formal ethical approval. On arrival for the dental visit, parents were made aware of the use of a new communication tool and gave their verbal consent to participation. In order to ensure confidentiality, consecutive study numbers were allocated in field notes and no patient-identifiable information was recorded.

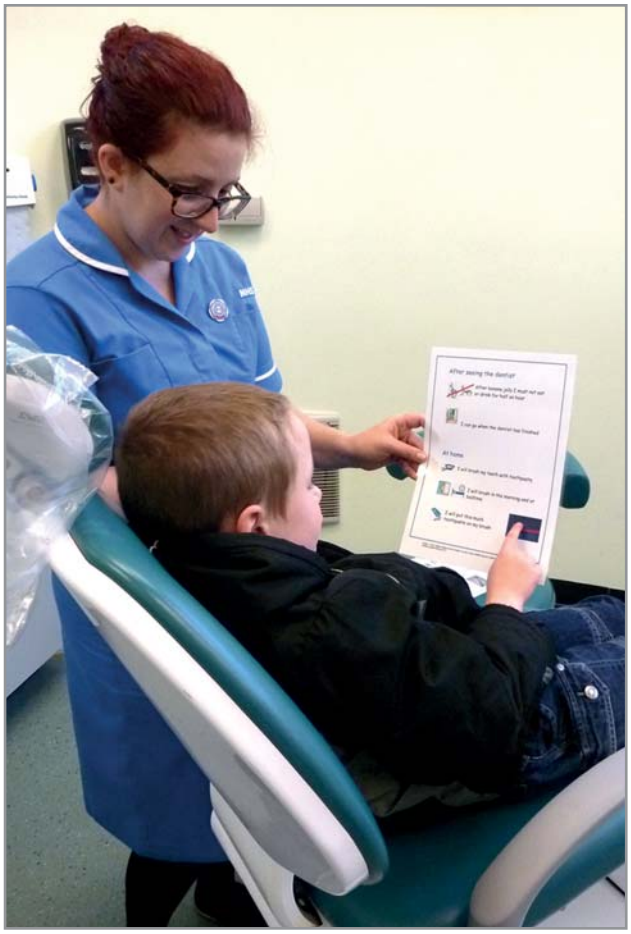
Data analysis

Field notes were typed and subjected to thematic content analysis by two investigators (JCH, ZM). The investigators analysed the data independently then, following discussion, described the emergent themes and relationships between these themes.

Results

Twenty five children and young people used one to four pages of the AAC tool over a 14 month period. Data were excluded for five children due to insufficiently detailed field notes for analysis. Observations were thus available for 20 individuals (17 boys, 3 girls) aged 3 years 8 months to 14 years 6 months (mean 9 years 2 months). Known parent-reported communication impairment diagnoses and other comorbid medical conditions (CMC), where more than one may apply, are shown in *Table 1* (overleaf). For four children (20%) it was their first visit to our surgery and for 15 (75%) a subsequent dental visit (data missing, n=1). Schools attended were special education primary school (n=8, 40%), special education secondary school (n=6, 30%), and mainstream school with educational support (n=3, 15%). School data was missing for one secondary school aged child. For two children, with English as a second language to which they had little exposure due to young age and not yet attending school, the AAC tool was used in addition to the services of a language interpreter.

Figure 1: Dental nurse with child using a draft version of the AAC tool in the dental surgery.



Development of the AAC tool

The initial draft AAC tool consisted of two folded A4 sheets with accompanying flashcards. The first sheet, entitled 'My visit to the dentist', described a routine visit for examination, tooth brushing advice and fluoride varnish application with after-care advice, and the second, 'My silver tooth', described a visit in which a Hall-technique preformed metal crown was placed.

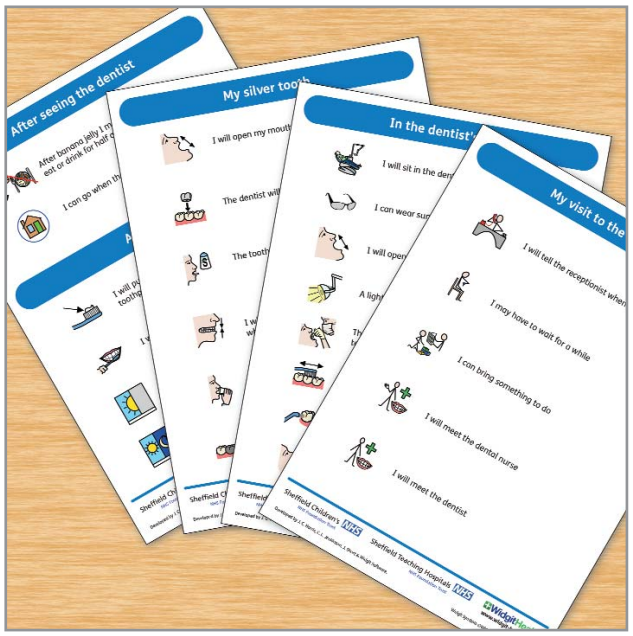
In response to observations and feedback, at an early stage of the development process the format of the first sheet was changed and the information was divided onto three separate A4 sheets: 'My visit to the dentist', 'In the dentist's room' and 'After seeing the dentist'. Use of flashcards was discontinued. On completion of the evaluation, final revisions, including design of some new symbols, were undertaken with the assistance of the symbol software supplier prior to online open-access publication (Harris *et al.*, 2013) (*Figure 2*).

Table 1: Children's (n=20) parent-reported communication and medical diagnoses*

Communication impairments	No. of children	Medical comorbidity	No. of children
All communication impairments	20 (100%)	All medical conditions	8 (40%)
Autism spectrum disorder	15 (75%)	Mental health condition (anxiety, conduct disorder, attention deficit hyperactivity disorder)	4
Learning difficulties (LD) (moderate or severe)	7 (35%)	Cerebral palsy	1
Non-English speaking pre-school children	2	Congenital heart defect	1
Hearing impairment	1	Diabetes – type 1	1
Other (social and communication difficulties with Asperger's traits)	1	Epilepsy Juvenile arthritis Repaired cleft palate	1 1 1

* more than one impairment/condition may apply

Figure 2: Final version of the four-page AAC tool.
Image used with permission: Widgit Symbols ©Widgit Software 2002 – 2014 www.widgit.com (Tool available for free download at: http://www.widgit-health.com/downloads/dental-procedures.htm).



Evaluation of the AAC tool

Observations of AAC tool impact on delivery of dental care

Changes were observed in children's behaviour and the nature of their communication when using the AAC tool. The themes that emerged from the dentist's field notes were that the tool 'unlocked' communication, it focussed the child's attention by providing a sequence to follow and consequently it improved cooperation with dental treatment.

Children who had not previously been known to use verbal communication in the dental surgery were observed speaking for the first time. Others appeared prompted to express feelings that they had never previously communicated to the dental team, using verbal or non-verbal vocalisation.

> *Making noises, not full speech. Sat in the dental chair. We gave him the sheet and he read it all out loud, we were unaware he could do so.*
> Operator observations: boy, age 7, ASD/LD/CMC, subsequent visit.

> *…the child was quiet on arrival but spoke when handed the sheet as if given permission to talk or the means to do so.*
> Operator observations: boy, age 8, ASD/CMC, subsequent visit.

> *Doesn't really need it but we gave it to him – it appeared to encourage him to express his dislike of fluoride varnish; that was helpful so we could discuss it openly.*
> Operator observations: boy, age 11, ASD/LD, subsequent visit.

The tool seemed to focus children's attention. They were observed following the sequence of procedures. Some showed reading ability which the dental team had not expected.

> *Wouldn't open when asked kept lips tight, showed laminated page read out step by step and* [he] *opened* [his] *mouth as soon as got to that stage.*
> Operator observations: boy, age 8, ASD, subsequent visit.

> *He read through all the steps, mentally 'ticking off' what he had done.*
> Operator observations: boy, age 7, ASD, subsequent visit.

Improvement in cooperation was noted in many cases, albeit on occasions from a low baseline. Some children coped with treatment that they had previously found difficult or impossible. Signs of anxiety were observed to reduce and use of the tool appeared to improve children's experience.

> *At the end of the visit* [his mother] *said, "That's the best he's ever done".*
> Operator observations of parent feedback: boy, age 7, other communication impairment, first visit (dental examination and application of fluoride varnish to a single tooth was completed).

Reluctant to have fluoride varnish. …Did not speak but quietly refusing. Gave laminated sheet and reviewed what had to be done. …Continued and finally successfully applied [fluoride varnish].
Operator observations: girl, age 3, non-English speaking, subsequent visit.

Very anxious and tearful. Tried to sit in the dental chair and could not cope. Sat in an ordinary chair and [we] *gave the symbol sheet. He read through and I asked him which of these things he had done before? He replied, "All those." This gave us the opportunity for verbal reinforcement (praise). He calmed down, sat back in the chair and we completed an examination using the operating light, dental mirror and air syringe.*
Operator observations: boy, age 14, ASD/CMC, subsequent visit.

Parent perspectives

The main themes from the parents' perspectives were related to the usefulness of the AAC tool for their child, the familiarity of the symbol system, the precise sequencing of steps and the format of the tool. No negative comments were received.

"He is better if things are wrote down for him, he understands a lot more."
Mother of boy, age 12, ASD, visit type not known (missing data).

"He likes to know what order things are coming in."
Mother of boy, age 7, other communication impairment, first visit.

Parents corrected the sequence of steps in early drafts of the AAC tool, emphasising that it was essential to get them in the correct order.

"The sunglasses should come before the light. Otherwise all good."
Mother of boy, age 14, LD/CMC, subsequent visit.

"The amount of toothpaste needs to go at start of 'At home' section in the order that it is done."
Father of boy, age 11, ASD/LD, subsequent visit.

Parents, acting as proxy for their children, expressed a preference for individual A4 sheets rather than all information combined in a folded leaflet. Some commented on the need for a large font size due to their child's visual impairment or other reason. A combination of symbols and photographs was perceived as better than either alone.

Dental team perspectives

Analysis of the data from the dental team identified the following themes: more treatment was achieved than expected; the AAC tool proved useful in a wider range of situations than anticipated; the tool helped clinicians identify children's anxiety and preferences that might otherwise have been overlooked, thus assisting the team to take action to improve children's experience; and use of the tool improved the clinicians' experience, confidence and job satisfaction.

"Sometime these symbol sheets, I'm amazed!"
Dental nurse

"I always remember the time when we got the Widgit symbols out and that child who had never spoken to us ever started like that [makes hand gesture to indicate rapid speech]. *I just thought that was a wonderful moment."*
Dental nurse

"He wasn't speaking until you showed him the Widgit sheet. It's true; he didn't say anything except when he read it out."
Undergraduate dental student observer

"I was talking about it and saying how impressed I was at the results we were getting. They then commented about a patient that they've got and they were struggling with. This is only a pilot but it has been hard to keep them to ourselves because it is so good. You always get a positive response to it and, if nothing else it is a good distraction technique."
Dental nurse

"I only have these at one workplace but now I find I look for them automatically when I'm elsewhere and feel lost without them. That has never happened with any other communication tool."
Dentist

Discussion

Early dental referral has been advocated as soon as developmental disabilities and communication disorders are diagnosed (British Association for Community Child Health, 2000; Department of Health, 2007). Although there is conflicting evidence whether affected children have higher levels of dental disease than their neurotypical peers, high levels of unmet treatment need are frequently reported by parents (Nelson *et al.*, 2011; Lai *et al.*, 2012). Communication impairment and challenging behaviour can make even simple dental prevention and treatment procedures difficult to achieve, and familiarity alone may be ineffective in promoting improved cooperation (Marshall *et al.*, 2007). Yet 'children have a right to the enjoyment of the highest attainable standard of health' (United Nations High Commissioner for Human Rights, 1989). Enhancing communication and thereby enabling cooperation in the dental setting has the potential to improve equity of access to improved oral health outcomes for children with communication impairments. An AAC tool with the potential to achieve this is therefore important.

This paper reports a new AAC tool for children with severe and disabling communication impairments which was successfully developed with input from children themselves. A qualitative evaluation, using interpretive methods to capture children's, parents' and operators' perspectives, demonstrated that the tool was effective in improving communication and cooperation in the dental surgery. Operator observations of children's behaviour indicated that the tool appeared to have a beneficial effect on both receptive and expressive language.

The most striking finding was that the AAC tool appeared to 'unlock' verbal communication, sometimes empowering the child to communicate anxieties and preferences to the dental team, previously not expressed. Benefits were observed even when clinicians thought the child could cope without the tool or when other strategies to enhance communication, such as use of a language interpreter, were already in place.

Members of this experienced paediatric dentistry team expressed surprise at the benefits of using the new child-centred AAC tool. They were already in the habit of routinely modifying their own communication skills and the dental environment to meet the individual needs of their child patients, many with autism spectrum disorders, in line with contemporary practice (Charles, 2009; Bellis, 2010; Hernandez and Ikkanda, 2011). Yet dental team members perceived that use of the new AAC tool enhanced communication over and above existing practice, and voiced feelings of increased confidence and job satisfaction.

Increased operator-reported confidence and job satisfaction is an important finding since other researchers have observed an association between dentists liking to treat children with ASD and LD and them providing care for more children with these impairments (Weil *et al.*, 2011). It would be interesting to explore whether use of this AAC tool by dental teams previously inexperienced in providing care to children with ASD and LD might increase their likelihood of offering care to this group of patients, thereby widening patient choice and improving access to services that meet their needs. This could be particularly significant in locations poorly served by specialist services, such as rural areas, and might enable children with ASD and LD to attend the dentist together with other family members for routine care rather than always travel to a distant specialist centre, thus promoting inclusion and reducing the social and economic impacts of healthcare appointments on the family unit (Department of Health, 2004; Department of Health, 2007).

Professionals are expected to encourage and support children to participate in decision-making about their own healthcare (Department of Health, 2004). Disabled children cannot be assumed to be incapable of doing so, yet those with complex needs and communication impairments may be seen as 'hard to reach' (Franklin and Sloper, 2009). Our approach was underpinned by a commitment to develop child-centred information for our patients in a comprehensible format, as is considered contemporary good practice (British Society for Disability & Oral Health and Faculty of Dental Surgery of the Royal College of Surgeons of England, 2012; Gilchrist *et al.*, 2013), and by so doing to empower participation of disabled children in their own dental care at a level appropriate to the individual. Expansion of the tool to include other procedures is under consideration and further amendments will be made as required in response to children's feedback.

Whilst commending this new AAC tool as a useful addition to the communication 'toolbox', we are not advocating a one-size-fits-all approach; flexibility is essential to support individual children appropriately. Nor can we claim from this study that our findings are generalisable beyond the setting described. However we do suggest that further independent evaluation of the tool's effectiveness with respect to patient outcomes, dentist outcomes and health economics in a range of other settings is merited. This could include evaluation of its use with children unfamiliar with this particular symbol system, with other patient groups including adults with learning difficulties, in the hands of other clinicians and in comparison with alternatives such as high-tech AAC aids.

Limitations

This service evaluation was completed without modification of normal clinic schedules or staffing. Useful data were obtained simply by collecting field notes of observations. Use of parental interviews or questionnaires might have provided additional perspectives but we did not consider that the potential additional yield for this service evaluation justified delaying parents, since they usually needed to give their full attention to their child and to leave promptly on completion of the dental treatment. Use of this methodology offers a feasible way of involving disabled children in developing services and could be applicable in a variety of circumstances. It could be modified to reduce potential for bias by introducing an independent observer who had not been involved in development of the tool.

Terminology used to describe communication impairments was that used by the parent or supplied in a referral letter. Our caseload included a large proportion of children with ASD and severe impairment, or core autism. Further medical history details were not sought unless specifically necessary for provision of dental treatment so it is likely that the results underestimate the frequency and extent of learning difficulties and medical comorbidity. Yates and Le Couteur (2013) describe the lay and medical terminology in use with respect to autism at the time of the study.

Conclusions

The input and involvement of children with severe communication impairments was successfully obtained to inform development of a new child-centred AAC tool. The tool was effective in improving communication and children's cooperation in the dental surgery. Further evaluation is needed in other settings.

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