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A Survey of AAC Need in a Children's Hospital

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Introduction

When a child or young person is admitted to hospital ill or badly injured, communication can be severely affected. The child, their family and those who look after them may need effective and timely AAC intervention but little is known about what is appropriate. The provision of Augmentative and Alternative Communication (AAC) is known to be an important aspect of care for adults in hospital who have lost speech as a result of the illness or injury. But the literature shows little that looks at the AAC needs of children and young people in acute hospital settings.

The Birmingham Children's Hospital (BCH) in-patient Speech and Language Therapy (SLT) team sensed that we had a growing caseload of children with AAC needs. We knew we had to find out more about what was appropriate for these children and analyse what we were currently offering. The increased incidence of children needing AAC appeared to be related to growth in:

- Our skill in identifying their needs;
- The severity of the illnesses and injuries survived;
- Colleagues' awareness of what we could offer.

This combination was leading to the referral of children with very significant communication needs at a very critical time in their life.

We had many questions about the AAC service we were providing. Were we:

- Offering the most appropriate approach(es)?
- Meeting the differing needs of children referred from a wide range of specialities?
- Meeting the needs with the resources we had?

The Literature on the AAC needs of people in acute medical settings

Adults who are taken acutely ill and admitted to Intensive Care Unit (ICU) and other hospital wards are acknowledged to be at a critical time when they may need urgently to communicate, but when they might be least able to talk (MacAulay et al 2003 & Costello 2000). The stress placed on them, their families and those who care for them professionally by communication needs, is understood, as is the help provided by AAC.

Work has been done by Costello (2000) in Boston USA with adults and children for whom the admission to ICU is planned, and for whom there is time to get AAC systems ready: systems are personalised and their use has been practised. The act of preparing for the temporary loss of speech enabled patients and families to ready themselves for the actual immediate results of surgery. Professionals found it easier to communicate with their patients as people with lives outside of the immediate medical need, as well as appreciating the improved efficiency of communication.

The Dundee ICU team, while developing and using their ICU-Talk (MacAulay et al 2003), found that nurses can identify breakdowns in communication with intubated patients (receiving help for their breathing and unable to speak) and that having an electronic system of spoken phrases accessed by the patient can help. These patients had not necessarily been able to input to the preparation of their vocabulary and phrases, which led to difficulties with the use of the aid while they learned.

Cockerill and Burgul (2006) have described the AAC journeys of children in their hospital in the UK. This work showed the need for consistency of approach to communication for children and families at such a critical time, as well as the swiftness of the changes in the needs and skills of the children during acute illness.

A team at Bristol Children's Hospital looked at the needs of children admitted to hospital with long standing disability affecting their communication. Their solution to the immediate needs of the children, their families and the hospital staff was to produce `All about me' (Cook et al 2006) booklets that could be personalised to produce personal communication passports (Millar & Aitken 2003). This pragmatic approach to communication difficulties of children outside their usual environments, interacting with staff that are unused to them has resonance with our own findings.

Reviewing practice between authors and institutions (Blackstone 2007) shows that low tech (paper based) approaches might be the most useful in acute settings perhaps because of flexibility and immediacy and that electronic communication aids while used and appreciated may have more of a secondary role to play.

Little work is available that looks specifically at the AAC needs of children and those around them in acute/ICU settings. This applies to children who have become suddenly ill/injured as well as those with long-term neuro-developmental conditions.

The final group of children for whom there is little information about their AAC or pre-AAC needs are those very sick and very young children and babies who are likely to have had all, or most, of their lives so far in hospital and who are likely to have long term communication needs. Our study looked least at this group.

The Hospital and the SLT department

Birmingham Children's Hospital is a large regional teaching hospital with Foundation Trust Status. The hospital serves the West Midlands and beyond with specialist and general services. The hospital has 220 beds: 18 of these are Paediatric Intensive Care.

During the period of our study, November 2004-6, the hospital admitted 37,200 children for stays of more than 1 day.

SLT services to In Patient children during the period of the survey were 2.5 whole time equivalent (WTE) SLTs and 1 WTE SLT Assistant. During the period of the study we received 348 referrals: 0.9% of the hospital's admissions, 26 of these children proved to need AAC. The majority of referrals are actually for extremely unwell infants and children for whom eating and drinking needs are the main focus.

Carrying out the survey

To find answers to our questions about our AAC service we retrospectively surveyed the notes of all the children to whom we had offered AAC over two year period. We chose the start (November 2004) to coincide with the discharge from hospital of a long-standing patient who had taught us a lot about AAC, but whose discharge freed time to look at the needs of other children.

We took our definition of AAC to be very broad covering the use of sign, symbols and a wide range of techniques and technologies. We expanded this definition pragmatically to include the counting of speaking valves for those children with tracheostomies. The option of speech using the valves made the difference in terms of our ultimate ability to meet the needs of the children. 40% of the children had tracheostomies (a surgically created breathing hole in the neck) that can prevent speech.

Trawling of the case list for the two year period yielded the 26 children to whom we had offered AAC. The 26 children were 7.4% of the referrals to SLT over the two years.

A survey sheet was devised that allowed us to examine the SLT notes and extract similar information for each case. Each set of notes was read, the sheet filled in and the data added to an electronic database.

Characteristics of the children who needed AAC

We collected basic information about the children and their admission (Table 1). The age range was 1:11 to 15:06.

Most (18) of the children spent under six months in hospital; the longest stays were two children staying more than 18 months. Twenty-five of the children came from within the West Midlands NHS region.

Referrals came from the medical and surgical teams at the hospital. The primary referring team were Neurosurgery (14). However many of the children were known to two or more teams up to a maximum of five. This pattern led to the children having a range of pathways through the wards and departments of the hospital. These pathways impacted on how effectively consistent AAC approaches can be implemented. In 64% of cases the children had time on Paediatric Intensive Care Unit (PICU). Most of the stays on PICU were 3-6 weeks.

The children had a range of underlying conditions and diagnoses that brought them to the hospital (Table 2). Usually these were the reason for them needing AAC, but not always. These figures are for the conditions that drove the need for AAC.

All the children were referred on to other SLT departments when they left the hospital. Four were also referred to the regional AAC service for further assessment and provision.

When the children left the hospital the majority were using speech as their main means of communication. This included those who were able to speak because they were using a speaking valve. Of those who were using AAC four unfortunately could not take with them when they left the hospital the AAC system they had been using while in-patients.

The `usefulness' of the AAC approaches

For the 26 children, 80 examples of use of AAC techniques and technologies were identified from the notes. The range was 1-9 per child. The most frequent (mode) number of approaches was 1 that accounted for 8 of the children, but for 6 of the children we used 5 AAC techniques and technologies. Overall the average (mean) was just over 3 AAC techniques and technologies per child. This includes the speaking valve, which made such a difference to the number of children who could return to speech (5).

We graded the outcomes for the techniques and technologies as `not useful', `partially useful' and `useful'. We did this subjectively but on the basis of how the case notes described the use and value placed on the approach by the child/family/staff including SLTs and on more than one comment in the notes.

Not useful: not taken up by the child or family or actively rejected by them (e.g. a communication book that was too detailed and not used).

Partially Useful: the approach was taken up and used/valued by the child and family/other communication partners in:

· Some situations;

· For direct SLT activities;

· Led on to ultimate system;

· Full usefulness may be unclear.

Example: An aided language display for games, where the child was able to use the display with the SLT, but family and other staff did not make use of the display.

Useful: Used consistently and over time by the child in more than one situation. Valued by the child, family and other communication partners, and/or supported a significant move to ultimate system/speech.. Example: Communication passport that was lost and family immediately asked for another.

We divided the techniques and technologies we used into the following categories:

· Advice (e.g. what is AAC and what can it offer?)

· High Tech AAC (e.g. LightWriter)

· Low Tech AAC (e.g. ALD)

· Low Tech: Alphabet based spelling charts

· Low Tech: Symbol communication book

· Low Tech: Communication Passport

· Low tech: Symbol timetable

· Medium Tech AAC (e.g. Step by Step or BIGmack VOCAs)

· No Tech AAC (e.g. yes/no eye blink system tried by ward staff)

· Sign (Makaton)

· Speaking Valve (Passy Muir swallowing and speaking valve)

· Speech

Results

There was no clear relationship between the child's duration of stay or condition and the number of approaches that we used:

Medium Tech

We found 13 examples of Medium tech AAC use and 53% of these were coded as `useful'.

High Tech

There were only 7 examples of high tech AAC use but 57% of these were coded as `useful'. These figures are very small but we are working on adding more cases from November 2006 onwards.

Low Tech

Low tech AAC approaches, were coded `useful' on slightly over 50% of the occasions they were used. These were our most frequent type of intervention for example we offered 8 communication passports, and 5 of these were coded as `useful' or `partially useful'.

Signing (Makaton) was only used 3 times but on 2 of these occasions it was coded `useful'. Makaton was used for children with developmental needs, rather than because of the reason for their hospitalisation e.g. a toddler with Down syndrome and leukaemia. Children with brain injuries, etc. may not have the dexterity to sign which is why signing is apparently under-represented.

The speaking valves were used by five children, allowing them to return to speech when otherwise AAC would have been the only option.

No Tech

The least success lay with No tech AAC approaches. We had 15 examples of use but only 26% coded as `useful'. However 60% are coded as `partially useful'. This category includes all the `eye blink' and `mouthing words' systems evolving with the child's medical situation. Whilst not really AAC, these approaches were often used before referral to SLT - frequently when the child was still in PICU and at their most unwell. Clearly at this time any approach might be relatively difficult because stress levels and illness are at their greatest. However, we were able to introduce more useful approaches while children were in PICU.

Conclusions

This is a difficult patient group to study, as there is such diversity of need.

We have shown that we need to continue to offer a range of AAC techniques and technologies that are flexible and responsive overtime, as the child and their circumstances change. These changes are in the child's stage of illness or recovery and in their pathway through the hospital.

We are able to show that overall we are offering AAC perceived as useful or partially useful in the majority of cases. Particularly useful are the Communication Passports produced by our invaluable SLTA, reflecting the intuition of the Bristol team.

`Non-useful' approaches seem to occur more frequently in situations where the child is so ill that any approach will be a challenge and/or where we have not yet had a chance to offer our input. Indicating that AAC and SLT can offer significantly to the care of a child in that situation.

Currently medical colleagues do not always refer all the children with whom we might intervene at a time when we might begin to be useful. This is something we are addressing by raising awareness of AAC and our service. We want to establish a picture of the numbers of children who are not being referred and who we could assist and link this to the ongoing analysis of cases we do see.

As an SLT team we appear, on current information, to be almost meeting needs at the referral rate we have. We are able to offer the range of AAC approaches that are needed: there is no evidence in the notes of a child having to wait to use a piece of equipment e.g. a BIGmack because another child was using it. But some children (16%) cannot take home what they need to continue to communicate as they have been doing in hospital. This relates directly to our very limited resources of high tech AAC equipment (i.e. 2 LightWriters) - devices that we cannot afford to send out of hospital with a child on discharge. These children took low-tech alternatives with them and were supported by their local SLT teams when they returned home. With a struggle, local services were able to provide replacement high tech aids. If we had not had the speaking valve option we would have met this challenge significantly more.

The Future

We continue to gather more data and will analyse this to learn more about what is successful and appropriate and plan to tease out some patterns and guidance. A part of this is the possibility of studying in more detail one diagnostic group and their needs. This should enable us to develop audit standards and then test these.

We should continue work on training and awareness raising with colleagues. If this process increases referrals we need to check that we can still meet the need: standards and audit work should help with this.

We should work with the wider hospital and beyond to explore how we can ensure that children who need to do so can go home with high tech AAC.

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Passy Muir Swallowing and Speaking valves www.passy-muir.com

Lightwriters: www.toby-churchill.com

Makaton: www.makaton.org