A Collaborative Approach to Communication Support in a Hospital Environment

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The aim of this paper is to share the experience of supporting a functionally nonspeaking young man with severe learning difficulties through a major surgical procedure. The paper shares ideas and resources used, discusses the value of a collaborative approach with the various services involved and the potential for developing additional resources with these service providers.

BACKGROUND

In this case study, a young man with severe learning difficulties, attending Selworthy School in Taunton, Somerset, was supported through a planned spinal operation at Musgrove Hospital, Taunton. The family and the young man involved in this case study have given their full consent for the presentation and publication of this paper.

The young man concerned, Ed, is 16 years old with severe global developmental delay and an undiagnosed medical condition. Ed presents with a sensory integration disorder, a verbal and developmental co-ordination disorder (*dyspraxia*) and considerable difficulties with his independence and social skills. Ed has significantly delayed speech and language skills but despite this he is keen to communicate, is sociable and generally happy. He has a short concentration and attention span, is easily distracted and needs support using visual cues to encourage him to remain on task. Ed has particular difficulties with concepts of time and change, and needs clear warnings when changes in activities and events are likely to happen.

Ed uses a small, hand-held communication device (Tellus Smart) to help him with his communication and learning. He generally uses single symbols to communicate his needs but can put two or three symbols together when prompted. In terms of communication in the home environment, Ed signs everyday words and sometimes uses his communication device to communicate more complex thoughts and ideas.

UNDERSTANDING THE ISSUES

In 2011 Ed's consultant recommended spinal surgery. The surgery, for a scoliosis correction, involved screwing two titanium rods either side of his spinal column to provide the necessary correction to his curvature, allowing Ed to walk and to continue managing daily activities independently. Ed's family were concerned about his understanding of what was going to happen to him and approached the school regarding this. They were particularly concerned about his understanding of the time scale of his operation and his communication needs in the hospital environment.

A COLLABORATIVE APPROACH

Following discussions with the family and the school nurse, it was decided that there were several strands to the support required and it was therefore agreed that the strategies in Table 1 would be put in place:

1. Understanding the concept of time

One of the first difficulties to overcome was that of 'time'. Ed struggles with the concept of time and past experience has shown that this could become a cause of great concern and frustration in the family environment. We had some success in the past with the use of a calendar to show how many days there were before an event and this was replicated for the hospital visits (Fig 1). Ed's family had communicated that they did not want any of this work to start until after Christmas. We therefore started work with Ed in January, a full three weeks before his operation.

2. Expressing needs and visual support

Selworthy School's community nurse was involved in preparatory discussions with Ed's family and together we were able to come up with words and concepts that Ed would need to understand. Photographs and images of some medical procedures were included in a small communication book. Parts of the body,

	What	Who
1	A resource to help with the concept of time - leading up to the operation and his stay in hospital	- School communication specialist - Family
2	A resource to help express his needs in the hospital environment and to help with the understanding of what was going to happen to him	- Ed - Family - School communication specialist - School nurse and hospital nurses
3	A resource for expressing pain	- Ed - School communication specialist - Family - School nurse & play therapist
4	Familiarisation visit for Ed and his family	- Ed - Family - School nurse & play therapist
5	Familiarisation visit for Ed and school friends	- Ed & classmates - Teaching staff - School communication specialist - School nurse & play therapist

Table 1 Schedule of resources

feelings and people made up the majority of the pages with some additional 'hospital specific' vocabulary. These included 'cannula' and 'catheter' as well as 'surgical tights'.

The value of working collaboratively here is obvious, as these were not words which would typically be generated by a speech and language therapist or a parent. The play specialist provided additional photographic material showing a young lady who had undergone the same surgery and some of the equipment and physical changes (scars) he would experience. The play specialist also provided a gas mask for 'practising' with at home, as Ed was going to be anaesthetised in this way.

3. Expressing pain

A very important consideration for both the family and Ed was how he was going to express his pain. Ed's level of understanding did not allow him to use the traditional 'Wong-Baker' (2012) pain chart (Fig 2). Ed does not have sufficient understanding of emotions to enable him to express his pain using these faces, neither is his understanding of numbers sufficiently embedded to relate to pain in this way.

Enabling non-verbal children and young people to express pain has been an ongoing concern of mine and over the years I have developed a couple of resources which have helped meet the need in my practice. The symbols used change as my thoughts around the topic change, but the basic concept has remained the same for a number of years now (Fig 3). At the time, it was a laminated paper resource, with Velcro tags. It not only allowed Ed to express his level of pain ('hurt' was the terminology used by the family) but also to independently express other concerns.

Ed had used this tool before his operation and he was therefore able to show the staff at the hospital how to use it. He had considerable anxiety over the use of needles and medication, so this pain chart was specifically developed to enable Ed to talk about this with the nursing staff.

4. Familiarisation visit for Ed and his family

Ed and his family went for a pre-op visit on the Monday before his operation. At this visit Ed was able to handle some of the equipment. He was shown the bed and the ward he would be in and was able to meet the staff who would be looking after him.

5. Familiarisation visit for Ed and his school friends

What worked surprisingly well was a repeat visit the next day, where Ed took his class friends into the hospital and showed them round. As Ed had been the day before, he was able to show everyone the equipment, the ward and introduce the nursing team to his friends. Ed took great pride in showing everyone around and it was a very empowering process for him. Support from Musgrove Hospital play therapists made these visits possible and Ed was definitely more relaxed about his surgery as a result of these visits.

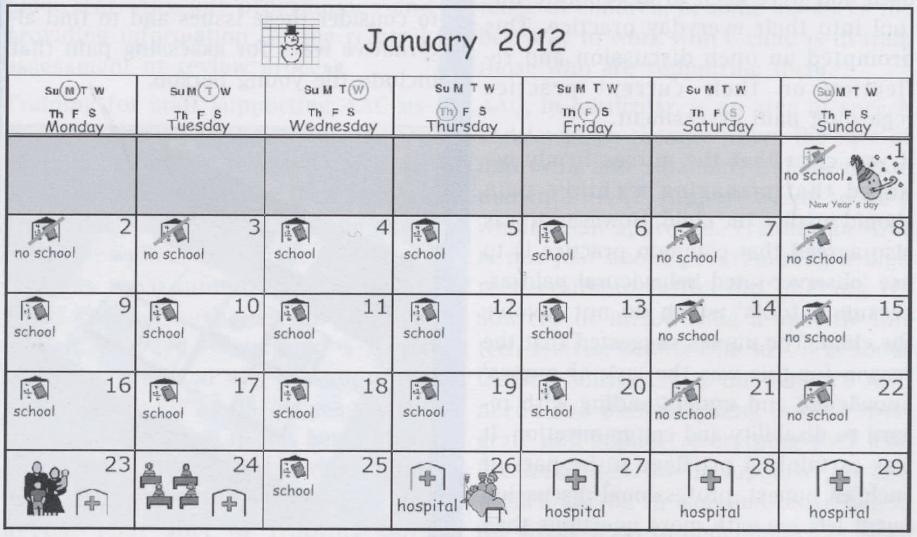

Figure 1 Calendar to show how many days there were before an event

RESULTS

The operation went ahead as planned and Ed's recovery was remarkably quick. The family were very grateful for the support they were given and felt the resources had played an important role in contributing to his speedy recovery.

Comments from family

"The lead-up to surgery was far less stressful than we had imagined. The calendar proved to be an invaluable resource. It allowed us to discuss with him when it was happening, and allayed some of the anxieties previously demonstrated prior to any major events in Ed's life. Ed's use of the pain chart not only eased our concerns, as his parents, but also put the control of his pain management in his hands. We had no doubts that he was able to clearly and definitively communicate the level of pain he was experiencing. Ed was extremely relaxed on the day of the surgery and when the time came to be anaesthetised, even the anaesthetist was surprised by how calm he was and easy to deal with."

Comments from school nurse

"In my experience the benefits of preparing children for hospitalisation have long been recognised, however communication still does not get the

recognition it deserves. I have cared for children undergoing spinal surgery for fourteen years and it is my opinion that this multi-disciplinary project played a large part in enabling Ed to make an uncomplicated recovery and, as a result, have the shortest hospital stay of any spinal patient.

"As well as enabling Ed to communicate his pain, the pain chart enabled the nurses to assess the effectiveness of the analgesics given. In turn, if a child is not in pain and is less anxious, they are more likely to mobilise thus preventing post-operative complications such as chest infections and thromboses. I am looking forward to continuing this valuable working relationship and developing further resources for children in the hospital environment."

Musgrove Hospital

The lead play therapist involved communicated that the resources had been of significant benefit and that the whole nursing team had used them extensively. As a result of this, she expressed an interest in looking at developing additional resources for people with communication difficulties for use at Musgrove Hospital and I was invited to speak at the Play Therapists' annual conference in May 2012.

The conference was a great opportunity for an insight into the nursing perspective. After a short introduction into basic speech, language and communication needs, we discussed the use of symbols and alternative methods of communicating and came up with some possible low-tech solutions for the hospital environment.

The issue of expressing levels of pain was of course a major concern. The nurses were all very positive in their comments regarding the pain scale used and were keen to incorporate this tool into their everyday practice. This prompted an open discussion and reflection on their current practice regarding pain assessment.

It was clear that the nurses firmly believed that managing a child's pain should involve the child. However, it was also agreed that common practice is to use 'observer-rated behavioural pain assessment tools' which do not involve the child. The nurses suggested that the reason for this was the lack of nurses' knowledge and understanding with regard to disability and communication. It was certainly a privilege to be part of such an honest, professional discussion but it left me with more questions than answers.

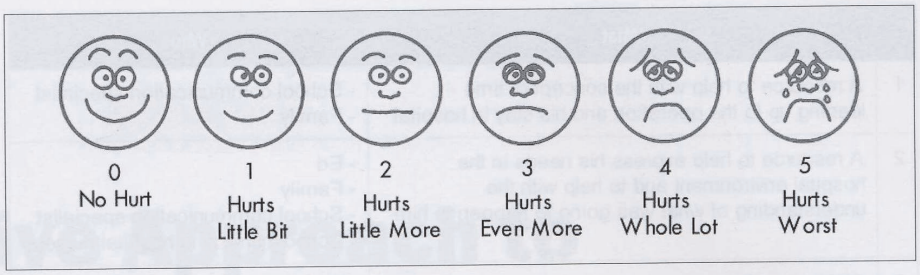

Figure 2 Wong-Baker pain chart

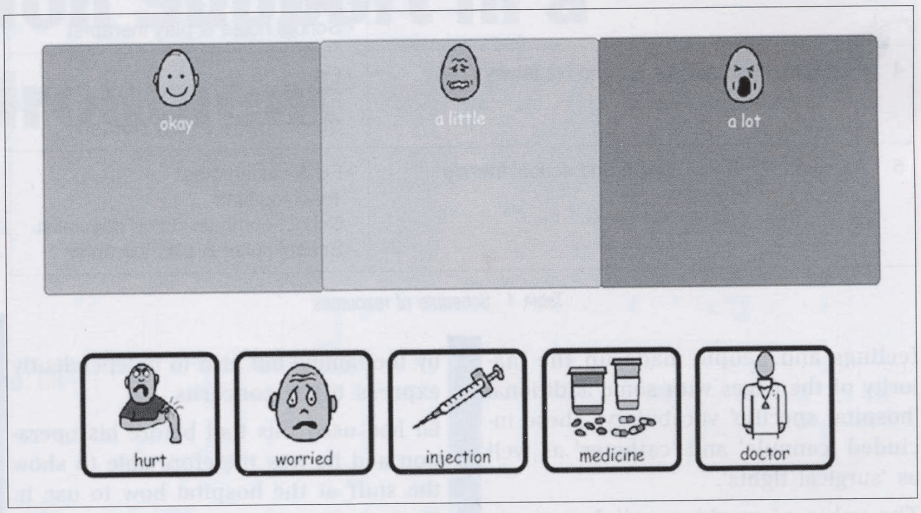

Figure 3 Symbol chart for expressing pain

CONCLUSION

Subsequent research in the area of pain assessment led me to an article which fully supported the nurses' practice. McKay and Clarke (2012) state that not only is observer-rated behavioural pain assessment common practice but it is recommended as 'good practice'. The suggestion is that children with severe learning difficulties are not able to communicate their pain; therefore observer-rated assessment tools are more appropriate. The article goes on to critically review three pain assessment tools, none of which include the child.

There is obviously much work to be done in bringing professions together to consider these issues and to find alternative ways for assessing pain that include the young person.

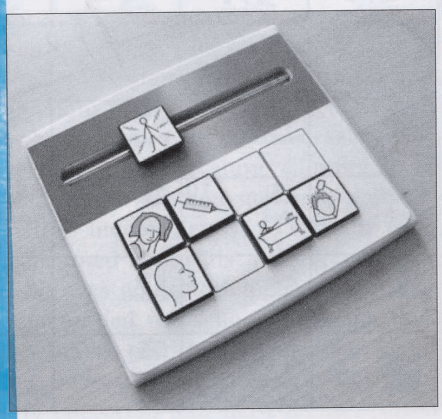

Figure 4 Pain scale device

I would suggest that not all children with severe learning difficulties are unable to express their pain and that a combination of observer-rated and self-reported assessment methods could be jointly used.

Unrelieved pain is due to ineffective pain assessment and management; children with severe learning disabilities have the same rights as any other child with regard to this.

As practitioners, we need to find ways of making expressing pain accessible for this group of people.

FOLLOW UP

The pain scale was of particular interest to the nurses at Musgrove Hospital and has always received such a positive response that it prompted further developments for a device suitable for the hospital environment.

It has now been made into a low-tech device with magnetic symbol tags and anti-microbial surfaces suitable for a range of clinical environments (Fig 4). ✱

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