Final Report

The Acute Hospital Experience for Adults with Complex Communication Needs[1]

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[1] Complex Communication Needs:
"Some people have complex communication needs associated with a wide range of physical, sensory and environmental causes which restrict/limit their ability to participate independently in society. They and their communication partners may benefit from using Alternative or Augmentative Communication (AAC) methods either temporarily or permanently." (Balandin 2002)

1. SUMMARY

When a person with complex communication needs is admitted to hospital the experience can be traumatic for the patient, family members, and nursing staff alike (Balandin et al., 2001; Hemsley & Balandin 2004; Hemsley, Balandin et al., 2001). CCN can have profound effects on patient health and well being in hospital (Costello, 2000; Robillard, 1994). This is a cause for concern as patients with CCN are at risk of injury or neglect if they cannot communicate with nurses effectively. An estimated 85% of errors in the health industry result from communication failures (Pronovost P et al. 2003). More effective communication between nurses and patients with CCN would prevent some of these failures and improve patients' health outcomes, both during the period of hospitalisation and after discharge. Patients with CCN are at risk of poor discharge planning that may result in readmission and increased health care costs (Brown & Piper, 1997). Previous studies have looked at this topic from either the perceptions of carers (Fox D and Wilson D, 1999), (Hemsley B et al. 2001) or staff (McConkey and Truesdale, 2000). This study examines experiences from the three viewpoints, people with CCN, carers and staff and compares the results with those of previous studies.

2. ORIGINAL AIMS

1. To obtain the views of people with CCN of their stay in an acute hospital.
2. To obtain the views of acute staff about their support for people with CCN when they are admitted to hospital
3. To obtain the views of carers about the person with CCN's stay in hospital.
4. For all participants, what are the barriers and solutions to successful communication in hospital?

3. METHODOLOGY

Two qualitative methodologies were used - individual interviews and focus groups.

a) Individual Interviews

Individual interviews were conducted with eight people with CCN.
using Talking Mats, a low tech communication framework (Murphy, 1998). This method was chosen to allow people with communication disability to express their views on a particular topic. All interviews were video recorded and photos taken of the completed mats. Detailed field notes were taken.

Developing the Talking Mats interview

A literature review was conducted to determine the topics and the interview was piloted with 4 volunteers with CCN. Three main topics (Personal care, Communication and Information and knowledge) were developed for use with

Talking Mats to explore the participants' views during their stay in hospital (appendix 1):

Recruitment

Recruitment of participants to the project was done through the Speech and Language Therapy departments in Forth Valley and Ayrshire and Arran. Speech and Language Therapists were invited to ask clients who had had a recent experience of being admitted to hospital, whether they wished to participate. Participants were excluded if they had significant visual impairment, if they had severe or profound learning disability or dementia. All therapists referring to the study were asked to confirm that the participants had a comprehension level of 3 or more key words in one sentence and were likely to be able to understand the nature and the purpose of the study.

Analysis

In order to limit researcher bias the video tapes were watched by three raters to examine the participant's effectiveness on Talking Mats using the framework established by the AAC Research Unit Stirling (Murphy et al. 2004). The views expressed through the Talking Mats were analysed using cognitive mapping (Jones S, 1985) to identify common themes.
Any other issues were documented and field notes were reviewed.

b) Focus groups

The study was conducted in two health boards and two sets of focus groups were conducted in each; one focus group for acute staff and one for carers. The numbers in each of the focus group were small partly because of the difficulty releasing staff in the acute sector and arranging time for the carers to meet.
The format of each focus group was the same. Participants were asked to consider the acute hospital experience under the following headings:
your feelings, communication supports, specific issues, others on ward, patient's feelings, discharge , ways to improve. Each participant was given a mind map with the broad headings (appendix 2). The facilitator's mind map (appendix3) was extended so they could give discussion prompts if required.

Carers

One carer of each participant with CCN was invited to be involved in the focus groups. There were two exceptions – for one person two family members wished to be involved and there was one participant whose carer did not wish to participate.

Acute hospital staff

Two hospital wards were approached and six members of staff volunteered to be involved in the focus groups.

Analysis

The tape recordings were transcribed verbatim, then read and listened to several times for familiarisation with the data. The data from each focus group were analysed using progressive thematic analysis (Orfali B and Markova I , 2003) to take into consideration not only what the participants said but also how they developed their arguments and negotiated issues in question.

4. RESULTS

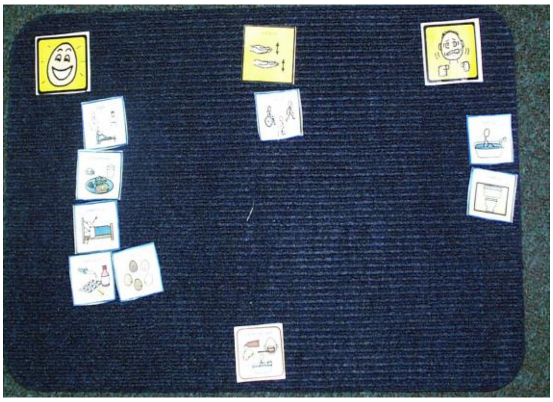
a) Individual Interviews

Demographics of participants with CCN	
Mean age	27
Age range	25 - 58
Male	5
Female	3
Type of Accommodation	
Family home	2
Supported accommodation	6
Method of communication	
Predominantly Verbal with additional support though low tech AAC and key word signing	5
Predominantly Low-tech AAC	2
Predominantly High-tech AAC	1
Diagnosis	
Cerebral Palsy	3
Recognized syndrome which causes Learning Disability	3
No known aetiology	2
Type of hospital admission	
Emergency	5
Planned	3

Out of the eight people interviewed six people were judged to be effective users of Talking Mats; one was judged to be on the ‘threshold of effectiveness’ due to repeated absences (petite mal seizures) which influenced her ability to express her views; one was judged not to be effective at using Talking Mats on the day the interview was carried out and his opinions about being in hospital could not be obtained.

Completed Talking Mats from three participants are shown below to illustrate views on Communication, Care and Knowledge & Information:

Communication (P7)



Care (P5)

Knowledge and information (P2)

The following table, illustrated with quotes, summarises the key points analysed thematically from the Talking Mats interviews.

Views of people with CCN
Communication: • Generally positive about their interaction with health staff • Some individual exceptions including negative comments about doctors, nurses, cleaners, therapists • All relied on carers to assist with communication with ward staff • Difficulty expressing what they wanted if carer not present • Difficulty attracting attention – particularly for those with additional physical disability • Difficulty indicating pain • No specific communication resources available on wards • Own communication books not used by staff • High tech user had device throughout stay and used it • Staff unable to sign • Would have liked access to phone to receive reassurance from family/carers *“Some doctors did spoke to my Mum without communicating with me eye to eye” participant 6* *“Pain is hard to tell” Participant 3*
Personal Care: • Family members were important in providing help with personal care such as bathing, mealtimes • Most personal care issues were viewed positively • Mobility within hospital was problematic for two people – wheelchair not available • Lack of hoist caused problems with bathing and toileting for one person • Discharge problems due to lack of appropriate equipment *“The nurses did help my Mum” Participant 6* *“Had to wait another night for bed to come” Participant 5*
Knowledge and Information: • Most said they knew why they were admitted • Most did not understand procedures once in hospital • No accessible information e.g. symbolised explanations except in one case • *“Signed “**good**” for picture information and looked puzzled and said “**don’t know**” in response to written information”. Participant 7*

b) Focus Groups

The carers in the focus groups included five parents, one sibling and two paid carers. Three carers took responsibility for personal care, one staying for 24 hours a day. The six members of staff were all nurses, four with more than ten years nursing experience and two less then ten years. None of the staff had received any nursing training in caring for people with CCN.

Results are presented to compare the views of the carers and the hospital staff on the main themes extrapolated from the data.

Feelings and attitudes	
Carers	**Staff**
• The majority were apprehensive • Fear of no one speaking up for person with CCN • Fear of what would happen if they were not there • Four felt the person with CCN enjoyed the attention in hospital • Four felt the person was distressed due to communication difficulties. • No resentment or stress expressed at providing care or visiting • Some staff enjoyed having younger patients on ward	• All felt frustrated and inadequate because of their lack of knowledge • They recognised it must be a terrifying ordeal for person with CCN • Enjoyed being able to banter with patient
“It is very difficult to understand her. You need to be brought up with her. If I wasn’t there she wouldn’t go for her operation”. Carer 5 *“There was no way I was leaving” Carer 6* *“ They said it was great fun having a youngster in” Carer 6*	*“Sometimes I feel quite inadequate – can feel embarrassed - I think that comes from a lack of insight into the real problem be it cerebral palsy or whatever – don’t have the knowledge base”. Staff 4* *“we kid on a lot with our patients and have a laugh – that’s part of our job” Staff 2*

Communication support on ward	
Carers	Staff
• Staff reliance on family members • Staff reluctance to recognise the support of paid carers even when they knew person’s communication system well. • No resources provided on ward except where a Speech and Language Therapist had provided low tech symbols • Person’s own communication aids were daunting for staff without training. • Difficulty of person with CCN in attracting attention *“They did kind of ignore you rather than giving you your place of being carer”. Carer 8*	• Main resource was carers • Would use anything that was brought in • Acknowledgement of the importance of context and non verbal communication • Awareness of Speech and Language Therapy and Sensory Impairment Services • Only 1 resource mentioned - pain chart for observing non-verbal responses • Position of bed within ward – some given single room – one positioned near nurses’ station *“The family are able to tell you the do’s and don’ts – you’re taking on board their advice”. Staff 5*

Care	
Carers	Staff
• Three took responsibility for the majority of personal care – one stayed 24 hours/day • Staff unaware of high pain threshold • Lack of staff knowledge about specific disability e.g. cerebral palsy • Concern that decision making was given to people with CCN and that carers involvement was reducing *“People don’t realise the syndromes they are working with –they don’t have the knowledge.” Carer 3*	• Acknowledgement that personal care was difficult • Concern around over protectiveness of carers and the impact on care • Families need a break from care and some of them view hospital as respite *“They respond to their relatives and carers better – they might pull away from us”. Staff 1*

Sharing information	
Carers	Staff
• Paid carers not given information • Conflicting information at times • Having to repeat information to staff • Pre-admission preparation in an accessible format was helpful – only happened in one case • Poor explanation of procedures e.g. reason for catheter • Unwillingness of staff to listen to carers e.g. medication and eating and drinking requirements *“The doctors just didn’t listen to you. They made you feel you didn’t know what you were talking about” Carer 1*	• Explanation of procedures viewed as problem • Patients do not understand terminology • Problems resulting from using a medical rather than social model of care *“ It’s a huge issue – sometimes we do it on a wing and a prayer” Staff 3*

Discharge	
Carers	Staff
• Several major problems reported • Lack of equipment for home • Poor liaison with GP • Early discharge with lack of preparation “*Sheer terror cos they sent him on Friday instead of Monday. I wasn’t ready”. Carer 2*	• All felt there were systems in place to support discharge e.g specialist teams, liaison with GPs • Discharge support available from local authorities varied significantly “*If you look at X or Y, X is a nightmare. Y – we can get carers the next day” Staff 3*

Ways to improve	
Carers	Staff
• Staff need to understand the reason behind the CCN • Identified staff to know about communication and learning disability • Increased information prior to admission e.g. care plans, communication systems • Nurses need more time “*We have a condensed information sheet for emergencies that says how people communicate and their routines. We had that with us but I don’t think they even looked at it as all the questions they asked – the information was on the sheet”. Carer 1*	• Better training about disability and communication • Link nurses to take responsibility for CCN • More information before admission • More communication resources – communication boards, booklets, symbols “*Even an information leaflet coming in with the patient describing his routines, likes and dislikes would be really helpful to us”. Staff 2*

Individual Issues

Some carers raised individual care issues which all caused distress and some which were considered by carers to be life threatening. These included:

- removal of essential medication
- drinks being left out for person who was nil by mouth
- person left lying in own urine
- no drinks being offered to person
- insertion of catheter without explanation
- removal to different ward without explanation
- not checking medical notes e.g. video fluoroscopy report not read

These were all exacerbated because the person with CCN was either unable to understand or communicate the problem.

5. DISCUSSION

Previous research has not sought to obtain views directly from this group of patients as the difficulties interviewing people with significant communication difficulties is often considered insurmountable and has instead relied on interviewing carers or staff. It is a significant achievement that in this study seven out of eight people were able to express and document their views on going into hospital.

Obviously each person's experience was different and they were all in different wards but some themes were expressed in several of the interviews. Some views expressed by only one person are included as they are pertinent and impact on patient care.

In this study half of the people with CCN had an overall positive experience and half had a distressing experience. This was confirmed by the carers' views.

Communication

All three groups of participants viewed the carers as the most important communication resource and would have found it a significantly more distressing experience without the support of their carers. Some people in this situation may even refuse hospital treatment unless they know their carer will be present. For example, one person indicated that her main fear was not having to undergo major surgery but was about being unable to communicate her feelings. Her carer said:

> "*If I hadn't been there I'm 100% sure she wouldn't have had the operation – all because of the communication, not because of the physical side of things." carer 5*

There was agreement about lack of resources on the wards and frustration from the people with CCN that their own low-tech communication systems were not used, even though staff said they would use anything that was brought in. The one high tech device was used successfully. This imbalance may be because low tech systems initially require skill and effort on the part of the communication partner.

Increased pain threshold was stressed by people with CCN and carers and highlighted as a key anxiety due to the difficulty people with CNN have at conveying this to staff. However staff did not acknowledge this or the impact of patients' inability to attract attention. Control of pain must be a key factor in hospital care yet it appears that people with CCN are at significant risk of their pain going unnoticed.

Despite some individual negative communication experiences, all three groups made positive comments about the overall interaction between people with CCN and staff.

Care

Some carers, but not all, had a significant role in providing personal care which was generally valued both by people with CCN and staff. Although the hospital experience disrupted carers' lives there was no indication from the people in this study that they found this an undue burden. On the contrary those who provided significant amounts of care "*wouldn't have had it any other way".* All carers appreciated the lack of restrictions on visiting times. Staff valued the help from carers but a concern was raised that occasionally over-protectiveness got in the way of patient care. One parent acknowledged this and even hinted that her son might have liked some time without family present, but she felt strongly that she needed to be there. Some carers were disconcerted that health staff encouraged the person with CCN to make decisions about their medical care as they felt cut out of the decision making process. This has implications for the Adults with Incapacity (Scotland) Act (Scottish Executive, 2002) which aims to increase the ability of people with disabilities to make decisions and have more control of their own lives. Some staff commented that some carers needed the respite provided by a hospital stay but this was not raised by any carers.

Knowledge and Information

Both staff and carers felt that a central problem was lack of staff knowledge and experience of working with people with CCN and limited understanding of the conditions/syndromes causing communication disability. No staff had received any training in disability and communication. One staff group discussed the disadvantage of focusing on a medical rather than a social model of care which leads to seeing the person's current medical problem rather than viewing the person holistically e.g. taking into account the person's cerebral palsy as well as the reason for medical intervention . In addition having carers present throughout someone's hospital stay may prevent staff from learning how to communicate with a people with CCN.

The appeared to be a discrepancy between the way family members were treated compared to paid carers. Paid carers expressed most anguish, as they felt ignored and had difficulty getting information from staff, as due to patient confidentiality procedures staff would only communicate with next-of-kin. In these cases next-of-kin had no knowledge of the person's daily routine and care needs. This led to life threatening situations for two people and significant distress for the carers.

There were problems in explaining hospital procedure to people with CCN which also had serious health consequences for some. This was due to lack of staff knowledge about communication, lack of accessible information and lack of time. The people in this study are a group who need clearer explanations of what is happening to them because, by the nature of their disability, they cannot easily ask questions, clarify or express their views and some have additional difficulties understanding. This lack of knowledge caused real fear for the people in this study.

Discharge

Discharge was seen a major problem for some people with CCN and their carers which contrasted with staff's view who felt that health systems were in place, whilst recognising that there was variable community support from different local authorities. This discrepancy suggests that acute and community services need to address the transition from hospital more thoroughly and take account of the person and the carer's future needs in discharge planning. Several people with CCN and carers were distressed by the discharge experience with ongoing implications.

Complaints

None of the participants, carers or people with CCN, considered making a complaint. The expectations of the people with CCN appeared so low that even when there were clearly strong feelings about things that had happened they accepted them and did not view making a complaint as a possibility. Although some carers voiced serious concerns they also did not make any complaint to the hospital.

Ways to improve

Carers and staff agreed that training is a crucial requirement. There is a need for improved, accessible and easy-to-use resources available on wards such as symbolised information sheets, picture charts and communication books/devices. However, these resources will be useless unless staff are trained and competent not only in how to use them but have an awareness of the importance of these tools in delivering care to the person with CCN. This was illustrated by the example in this study where the carers provided a summary information sheet with details of the patient's communication and daily routines but staff did not make use of it and the patient's care was compromised.

There is also a need for carers and people with CCN to make their existing communication systems visible and functional. Speech and Language Therapists are the key professionals in providing communication support and should have a role in this, as well as preparing appropriate materials for hospital stays.

Having an identified staff member with specific skills in disability and communication, who could be called on to provide support and materials, would raise the profile of the risks of ignoring problems of people with CCN.

There needs to be recognition that it can be difficult for parents who have always taken decisions for their children to let the locus of control shift to their adult sons and daughters.

There requires to be a change in the way paid carers are treated as their knowledge and input should be seen as valuable as that of a family member. Strict adherence to patient confidentiality and dependence on next of kin, even when they do not have detailed knowledge, are significant barrier to care.

Finally, people with CCN who do not have a carer present should be flagged as being at risk requiring increased support and nursing time.

Comparison with other studies

Our findings are similar to those of a larger study of the hospital experiences of 68 parents of adults with learning disability which indicated that more than half the participants were satisfied with their experiences (Fox D and Wilson D, 1999). This contrasts with the overall dissatisfaction experienced by six unpaid carers of adults with cerebral palsy and CCN (Hemsley B and Balandin S, 2004). Both of these other studies noted that family members advocate for and support the communication of people with CCN in hospital and a common feeling of carers was one on fear of what would happen if they were not there. Our findings concur with this. The other studies identified that parents may not wish to be involved in the nursing care of a son or daughter but may feel forced to take on nursing responsibilities. This was not reflected in our study.

(Hemsley B and Balandin S, 2004) report that patients refuse to take their AAC system to hospital for fear of loss, damage or an inability to access the system when in bed. This was not the case for the one high tech user in our study who used his machine effectively.

Our findings corroborate previous studies which identify that nurses need skills and understanding of how best to communicate with these patients (Beukelman and Mirenda 1998; Helmsley, Sigafoos et al 2001).

In our study carers appreciated the facilities available to them. This was not the case in other studies who described poor amenities resulting in additional stress for carers (Hemsley B and Balandin S, 2004).

Limitations of the study

Recruitment for this study was more difficult than had been anticipated. At the time the study was planned there were several admissions to hospital that involved potential participants who were subsequently unable to be included. In some cases there was a longer time period between discharge from hospital and the patient interview which may have had an impact on perceptions and recall. Fewer staff were involved than expected due to busy wards and staff shortages.

The numbers in this pilot study were small and the findings should therefore be treated with care.

6. CONCLUSION

Admission to hospital can be stressful for people with CCN, carers and nursing staff. This study, unlike others, has obtained the views of all three groups and has identified some of the communication barriers to health care and suggested ways for health improvement.

Poor communication was acknowledged by all as a serious problem when someone is admitted to hospital but there are very limited, and in some cases no, resources available on wards to help staff and patients. All those interviewed agreed that carers are the most important communication resource for people with CCN in hospital but problems were identified where the main carer was a paid carer, not a family member, and was excluded from the partnership of care. Lack of staff knowledge and limited experience of working with people with CCN were also identified as barriers to good health care and the study identified possible grave consequences if people with CCN cannot communicate with hospital staff effectively.

On the positive side there was a clear commitment from staff and carers to work together to find ways to improve the situation and a number of positive suggestions were made, principally pre-admission preparation, improved training for staff, accessible resources, and better discharge planning. Improved communication will have benefits for all patients, not just those with CNN, as many people in hospital are anxious and have difficulty expressing themselves.

7. IMPORTANCE TO NHS AND POSSIBLE IMPLEMENTATION

This study has also provided a model of research that should ensure that, in future, people with CCN are not excluded from studies. By using creative interview frameworks such as Talking Mats the views of people with CCN can be included in research.

It is crucial that people with CCN, who are at risk of stress and poor quality health care because of communication difficulties, are provided with additional support when they are admitted to hospital. This pilot study has produced evidence of the specific difficulties experienced by the three key groups of people involved. This has identified a number of positive suggestions, which if implemented, would improve the situation such as:

- Better preparation before planned admissions
- Provision of resources such as simple, easy to use communication aids
- Provision of accessible information to patients
- Genuine cooperation between family and carers, paid and unpaid
- Communication training for ward staff
- Specialist nurses trained in communication – link role
- Closer working with Speech and Language Therapy departments
- Improved discharge procedures

8. FUTURE RESEARCH

This study has identified the need for:

- Further studies using the methodology established in this study to corroborate the findings of this pilot.
- Piloting of resources to identify the most effective way to support people with CCN, their families and hospital staff.
- Research into how people with CCN can be given information in accessible formats to improve the quality of decisions making.

9. DISSEMINATION

The researchers have already been invited to present some of their findings at conferences and study days:

Peer review conferences:
27th May 2005: Invitation to give key note presentation and seminar at Communication Conference in Gothenburg, Sweden
26th Sept 2005: Presentation to Communication Matters Symposium, Leicester.
August 2006: Joan and Lois have been invited to run a pre-conference instructional course at the ISAAC Conference in Düsseldorf, Germany
November 2006: Joan has been invited to speak at a communication conference in Helsinki, Sweden

Other presentations:
March 15th 2005: Presentation to Argyle and Clyde NHS Study Day
May 11th: Presentation to Falkirk Social Services Learning Disability Strategy Group
May 16th - 20th 2005: Invitation to The Centre for Augmentative and Alternative Communication at the University of Pretoria, South Africa to run 2 full day workshops including presentation on this project
June 17th 2005: Presentation to the Scottish Learning Disability Special Interest Group
September 15th 2005- Presentation to Learning Disabilities Forum, Viewforth, Stirling

Training including information on this project
Feb 8th and March 8th 2005: Training course in Borders
March 31st and April 28th 2005: Training course in Dumfries
May 5th and June 2nd:2005: Training course at University of Stirling
June 23rd 2005: Training course at Beaumont College in Lancaster with a follow up day in September
August / September 2005: Rolling programme of Talking Mats training at University of Stirling
September/October 2005: Rolling programme of Talking Mats training at University of Stirling

Workshops are planned for speech and language therapy staff.
Presentations will be made at other relevant conferences.
Papers based on the findings will be submitted for publication in peer reviewed and professional journals

10. RESEARCH WORKERS

The study was carried out by Joan Murphy and Lois Cameron who obtained the relevant ethical permissions, collected the data, analysed it and wrote the report. Dr Susan Balandin contributed to the early stages of the study when she was on sabbatical from the University of Sydney. She also carried out a literature review which will be incorporated into papers for publication. A student transcribed the interviews and helped with the analysis.

11. FINANCIAL STATEMENT

To be provided by Finance Department, University of Stirling University

12. EXECUTIVE SUMMARY (see attached)

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