

HEADLINES

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Letter from the Editor

This year I have been fortunate to attend a conference and two study days related to my area of practice. I am in the minority! Many of you find it difficult to attend study days because of time restraints and a lack of funding.

It was particularly disappointing that the BANN conference this year needed to be cancelled in October. The RCN Neuroscience Nursing Forum Conference which was to be held in June this year was also cancelled.

This seems to be a sign of the times. However with increasing pressures on our time and resources it is important that we work together and keep ourselves updated and communicate effectively.

HEADLINES is a way of achieving an improvement in communication. Please contribute to your newsletter. Nothing you have to say is insignificant. Lets share our ideas. Send letters, article, topics for comment to the editor.

EDITOR:

Shanne McNamara
Edinburgh Centre for Neuro-Oncology
Western General Hospital
Crewe Road
Edinburgh
EH4 2XU
shanne.mcnamara@luht.scot.nhs.uk

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British Journal of Neuroscience Nursing now monthly: subscription offer for BANN members

This edition comes with 2 poster supplements:

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Conference 2007 Birmingham

Enabling people with aphasia to access information on a stroke ward

Sophie Cottrell and Alex Davies from North Bristol NHS Trust, describe how a project looking at how people with aphasia are informed has led to an exciting new resource to help healthcare professionals provide accessible information and reassurance for all of their stroke patients.

Introduction

An estimated 20%-30% of those people who have strokes experience aphasia, a language disorder in which the ability to speak, understand, read or write may be affected, and the ability to communicate can be severely compromised. People with aphasia are no different from the rest of the population in their need for information and for involvement in their own health care. However, the medium through which information is sought out, conveyed and received, namely written and spoken language, is precisely the area in which people with aphasia are impaired. Consequently, people with aphasia experience a lack of information, as reported in studies such as 'Talking about Aphasia' (Parr et al., 1997), which presents findings from interviews with fifty people with aphasia. The project outlined below describes how we have tried to make information about stroke and related hospital interventions accessible for people with language difficulties.

Background

Issues of Consent

Healthcare professionals are legally required to obtain informed consent from patients prior to any treatment. Consent issues may arise in many situations whilst a patient is in hospital – in particular, consent to medical interventions, nursing procedures, treatments and therapy, legal, financial and discharge/life planning decisions (Anderson & Forshaw, 2001). Patients on a dedicated stroke ward will need to give their consent and make many shared decisions during their hospital stay.

The Lord Chancellor's Department (April 2002) produced guidance leaflets which acknowledge that some people will require support to understand and communicate choices in order to '*exercise the right to make informed decisions about their care*' (General Medical Council, February, 1999). Green (1999) emphasises the importance of nurses adopting an advocacy role in assisting patients with consent issues and insists that '*ward regimes should enable nurses to perform this role*'. The NHS Plan on consent procedures highlights that consent may not be valid if information is not presented in a form that people can understand (Dept. of Health, 2001).

Observations from Clinical Experience

As speech and language therapists working on a stroke rehabilitation ward, we observed a number of situations where there was the potential to improve communication between healthcare professionals and people with aphasia, and thus increase 'patient partnership' and participation.

The presence of aphasia may affect the decision about whether patients are felt to be capable of giving consent. For example, decisions may need to be made concerning the appropriateness of alternative feeding in patients with dysphagia. If information is presented in a way which the patient can understand, it may be that they are 'competent' to give or refuse consent to procedures such as the insertion of a PEG feeding tube. Other examples of opportunities for increasing patient partnership are at ward rounds

and case conferences, which tend to be directed by healthcare professionals, with little evidence of visual materials to support patients' communication and participation.

'You got no information at all, I just coming back into the ward, taking you off somewhere, bringing you back and that's all'

A person with aphasia remembers her stay in hospital

Project

Our project aimed to explore two main areas: experiences of receiving information by patients with communication difficulties on a stroke ward, and how information might be made more accessible to them. We approached several groups of users in different ways. We consulted seven people with aphasia to find out their experiences of being in hospital and the information given to them, as well as to gain their ideas on resources that may be helpful. We asked the multi-disciplinary stroke team to give their views on what they saw as gaps in information-giving within the ward environment and for suggestions of resources they felt would be helpful for them to use with people with aphasia. We met with a focus group of inpatients without speech and language difficulties on a stroke rehabilitation ward to find out their experiences of being in hospital and information given to them. We also met up with a focus group of carers of relatives with aphasia.

Consulting people with aphasia

In-depth interviews were carried out which were audio and videotaped in most cases to ensure that any nonverbal communication was captured. In order to support participants' communication during the interviews a number of "communication ramps" were used including a collection of pictures and photos, rating scales and diagrams. The 'Talking Mats' method of supporting conversation was used (Murphy, 2000), whereby pictures were selected by the person with aphasia and placed on mats as appropriate, to represent their views.

Findings

Participants reported on the variable communication styles and skills used by healthcare professionals. People valued being given designated time by staff to explain treatments to them. Some staff would show more patience than others.

"I can remember a nurse sat down with me and explained it all and er, she was doing it for my sake"

"you could very quickly work out the ones that would wait for you and the ones that wouldn't wait"

Patients without aphasia commented on how information was given readily only if it was requested.

"If I asked I got told"

"I was (given information) because I complained about it"

However, for people with aphasia asking for information was clearly difficult.

Researcher: *'It was obviously difficult for you to ask...'*

Participant with aphasia: *'it was, yes, dudududududu'*

The lack of participation in treatments and decisions was an overriding theme which emerged. People felt excluded from the doctor's ward round. One participant covered up the patient on a picture of doctors standing at a patient's bedside.

Procedures were often carried out in silence highlighting a general 'awkwardness' when with people with aphasia. People felt they lacked information about stroke and routine procedures such as blood tests.

"I didn't even know, you know a bloke came into the ward, looked at my charts and started to take blood." 'Researcher: Did he explain it to you?' "No, no if he thinks because I'm, um, I can't speak, I can't understand either..."

In discussion about the best ways of presenting information, the main theme that was raised was the importance of having any visual information backed up with discussion.

"as long as it is used in discussion and not just given to you"

Carers reported examples of information that was just too detailed to be understood by people with aphasia.

"some of the written information was so involved that he just couldn't cope with it"

Families appeared to have an important role in deciding what information should be passed on to their relative, and would often 'filter' information according to what they felt their relative could cope with.

I used to pick the leaflets up...take them home and read them without him... and then...I knew that there wasn't anything in there really that was going to frighten him"

As well as information about treatments, more explanation about professionals' roles was felt to be necessary.

'Stroke Talk'

The net result of this project was the development of a collection of information props that explain a number of commonly encountered issues and interventions in hospital care following a stroke, all selected after close consultation. The information is presented in an aphasia-friendly manner, using straightforward language, keywords, images and symbols including handy accessible appointment cards.

In total, 17 topics are covered (see box).

The authors point out

it is really important that this information should not be merely 'handed out', but always used as an adjunct to discussion with patients.' Photocopies of the information can be left with patients to serve as reminders, or to aid conversations with visitors'. To facilitate this, full photocopying rights are granted with the published version of *Stroke Talk*.

Almost all people who have aphasia will benefit from using *Stroke Talk*. Those with more severe aphasia may depend more on the images than on text, but the clear layout and accessible style of writing will be helpful. Furthermore, when stroke patients without aphasia evaluated the information, they also found the style more accessible than other

stroke information they had received, and perhaps contrary to expectations, did not find the use of images patronising or childish. The resource could therefore be used potentially with any stroke patient or indeed with other client groups such as those with visual impairment, hearing loss, pre-existing literacy problems, people with dementia, limited English or people with learning disabilities.

While traditionally, explaining things to people with aphasia has been seen as the role of the speech and language therapist, the ability to communicate effectively is important for all service providers. *Stroke Talk* has been designed especially for use by anyone providing stroke services, including nurses, healthcare assistants, doctors, occupational therapists, ward clerks, social workers, etc.

The feedback about *Stroke Talk* since its initial concept has been very positive from both people with aphasia and stroke service staff. As one participant in the project said, 'This is really different because it's telling me in simple language what's happened... it's marvellous'.

Stroke Talk: a communication resource for hospital care is published by Connect Press as part of its commitment to providing accessible and timely resources for people working in stroke services. ISBN 0 953 60425 X Cost: £60 plus £5.00 postage and packing.

APPOINTMENT CARDS: *photocopiable and designed to be given to clients following discussion with their healthcare professional as a reminder of their appointment*

- CT scan
- PEG feeding tube
- Chest x-ray
- Carotid ultrasound (dopplers)
- Home visit

PROPS: *designed to be used in discussion facilitated by the healthcare professional*
Interventions & procedures

- PEG feeding tubes
- NG feeding tubes
- Videofluoroscopy assessment
- CT scan
- Carotid ultrasound (dopplers)
- ECG (24 hours)

Explanation of Roles

- Role of the Occupational Therapist
- Role of the Physiotherapist
- Role of the Psychologist
- Role of the Speech & Language Therapist
 - Role of the Social Worker

Other

- Medication
- MRSA infection
- Eating & drinking difficulties

- Discharge Planning
- The Stroke Journey in Hospital

References:

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For more information please contact Maria McDonnell, 020 7367 0866,
mariamcdonnell@ukconnect.org.

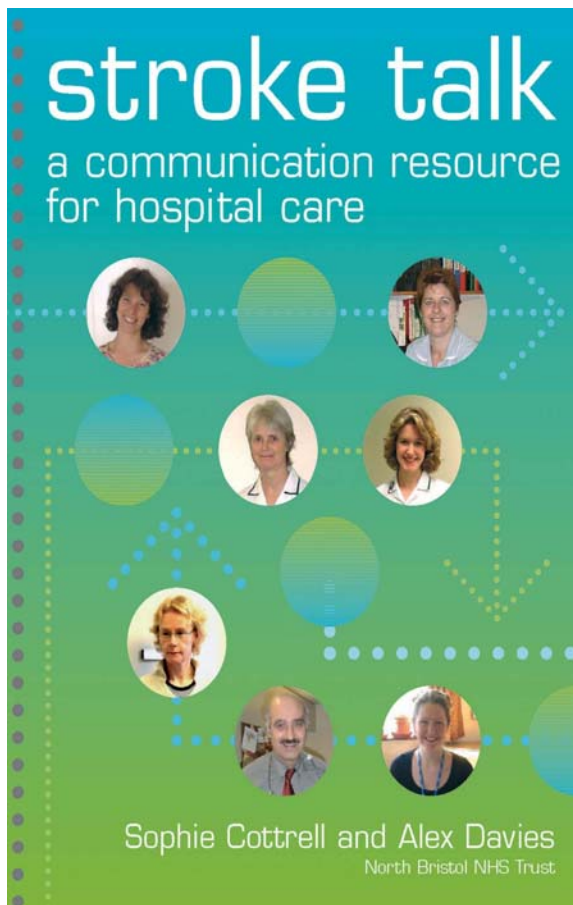
For more details and downloadable sample pages visit www.ukconnect.org

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British Journal of Neuroscience Nursing now monthly: subscription offer for BANN members

Since its launch in April 2005, BJNN has gone from strength to strength. The journal became a monthly publication in April of this year and we have recently been able to add an additional four pages of clinical content to each issue, making it an even more useful resource for nurses working in this dynamic and exciting field of practice. Subscribers are now able to pay through quarterly direct debit at only £32 per quarter, in addition to the usual annual rate. BJNN remains the only neuroscience nursing journal published in the UK and as the editor-in-chief I am proud to maintain close links with BANN. We are all concerned about the current trends affecting neuroscience nurse specialists and I

have written previously in BJNN, expressing these concerns. Through BJNN we aim to champion the cause of neuroscience nursing and to provide a monthly forum for neuroscience nurses to debate current issues, as well as to support and develop the knowledge and experience of nurses who are caring for patients with neurological problems.

The journal informs neuroscience-nursing practice, through the reporting of current and ongoing research, and developments in practice, policy and education, and I am keen to ensure that the journal is meeting the needs of neuroscience nurses throughout the UK. I would therefore like to hear your views on the journal and would like to hear if there are any particular topics that you would like to see featured over the coming issues. The journal is only as good as its contributors, so I would also be keen to hear from any forum members who would be interested in writing for the journal. We are keen to support new authors and there is a lot of help available, even if you have never published anything before.

Details of the author guidelines for the journal as well as subscription rates are available through the journal's website at www.bjnn.co.uk and you can e-mail me your views to sue.woodward@kcl.ac.uk

In recognition of the links the journal has with BANN, I would like to offer a **15% DISCOUNT ON THE ANNUAL SUBSCRIPTION PRICE TO ALL BANN MEMBERS**. All neuroscience course students may also subscribe at the student rate for the academic year in which their course runs. If you have not seen a copy of the journal or would like to receive a FREE sample issue, simply send your name, address, job title and phone number to me via the e-mail address above, including the words "BANN BJNN Offer" in the subject line of the e-mail. I look forward to hearing from you!