



Creating a communicative environment in hospital for adults with developmental disability and complex communication needs

Bronwyn Hemsley, Susan Balandin, and Leanne Togher

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When adults with developmental disability and complex communication needs enter hospital, their family carers often take a central role in providing care and supporting communication. These adult patients often lack access to systems in the hospital setting and thus rely upon their family carers to be present at all times to speak on their behalf. In this paper, we will (a) outline the implications of a recent body of research investigating the experiences, needs, and roles of family carers of adults with developmental disability for speech pathologists supporting these patients in and out of the hospital setting, and (b) discuss barriers to and strategies for increasing the communicative accessibility of the hospital ward for adults with developmental disability and complex communication needs.



Bronwyn Hemsley

People with complex communication needs have reported that difficulties in communicating with nursing staff coupled with few opportunities to communicate in hospital impact negatively upon their comfort, safety, social interaction, and access to information in hospital (Balandin, Hemsley, Sigafoos, & Green, 2007; Balandin et al., 2001). Nurses have also reported that they have difficulty in communicating with adults who have complex communication needs, and must rely upon family carers to avoid compromising nursing care and to facilitate successful communication between the patient and the nurse (Balandin et al., 2007; Buzio, Morgan, & Blount, 2002; Iacono & Davis, 2003).

The main purpose of the research conducted recently at The University of Sydney (see Hemsley & Balandin, 2004; Hemsley, Balandin, & Togher, 2007a, b) was to explore the experiences of family carers of adults with cerebral palsy and complex communication needs in hospital to (a) arrive at an in-depth understanding of their roles and support needs, (b) gain the participants' expert insights into the communicative environment for the patient with cerebral palsy, including barriers to communication, and strategies for increasing the communicative accessibility of the hospital ward for these

patients, and (c) discover how best to support people with complex communication needs, their family carers, and the hospital staff in communicating effectively in hospital.

An overview of our research design

Phase 1 of our study, a narrative inquiry, involved in-depth interviews with 12 family carers who had provided support in hospital to an adult son or daughter with cerebral palsy for three or more days in the previous two years. Phase 2 of the study involved three focus groups of key stakeholders discussing the experience of family carers of adults with cerebral palsy and complex communication needs in hospital. The focus group transcripts were analysed according to content themes (Morgan, 1988). All participants were sent a summary of the researchers' interpretations for their verification. All participants verified that the written interpretations of the discussions represented their views. (For a full account of both study phases contact the first author and see Hemsley & Balandin, 2004; Hemsley et al., 2007a, b; 2008a, b, c, d.)

Results from this research can be used to inform speech pathologists and others working with these patients about ways to improve both communication and healthcare outcomes for people who have complex communication needs in hospital. In addition, it can inform the development of hospital policies to ensure that those with complex communication needs are not disadvantaged or discriminated against during a hospital stay. Furthermore, such information could be used in developing policies to alleviate difficulties commonly encountered by others who interact with people with complex communication needs in hospital. The information derived from the study has been summarised in this paper to inform speech pathologists supporting adults with developmental disability and complex communication needs and their families both in and out of the hospital.

Summary of results and implications for speech pathologists

As the results of the studies are reported elsewhere (see citations above), here we will discuss the major themes and the implications of our findings for community and hospital speech pathologists. Speech pathologists are called upon to adopt a collaborative approach in implementing a range of service delivery models and strive to improve communication for all people with a communication disability (Speech

Pathology Australia, 2003). Thus, speech pathologists in hospitals are well placed, in their training as communication specialists and in their roles within the hospital environment, to influence the communicative environment for adult patients with pre-existing communication disability and those who care for them. Effective direct nurse–patient communication might ease difficulties in the care of this group of patients and reduce their risk of adverse events in hospital (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008). Family carers, in having knowledge and experience in the patient’s communication methods, are an important resource to for speech pathologists supporting communication in hospital.

Roles of family carers supporting adults with developmental disability

In hospital, family carers often provide support for extended periods of time to adults with cerebral palsy and complex communication needs. Our research indicated the carers ‘dropped everything’ including other work (often foregoing an income), family, or social responsibilities to stay at the hospital and enact a comprehensive set of roles. These included: supporting communication in hospital, advocacy, protecting the patient from adverse events (e.g., pressure ulcers, medication errors, choking, falls), supporting the exchange of information, providing emotional support, and assisting in positioning and direct care (e.g., toileting, showering, dressing, mealtime assistance) (Hemsley, et al., 2008a).

Furthermore, our findings revealed the enduring nature of responsibilities in providing care in hospital for older parent carers and their emerging concerns for the future when they will no longer be able to provide care in hospital (Hemsley, et al., 2007b). Indeed, hospitals cannot rely upon family carers providing this support forever and may need to consider ways to avoid a crisis in care for these adults in the future. At present, there are no hospital policies guiding the involvement of family carers in providing care on the ward, negotiating their roles with hospital staff, or passing on their expertise and care or communication roles to hospital staff (Hemsley et al., 2007a). While they are still able to provide support, these family carers are a valuable resource in their knowledge and experience in using multiple modes of communication and strategies for improving communication.

Speech pathologists promoting accessible communication can also support family carers to go beyond the role of ‘speaking on behalf of the patient’ and enhance their roles in ‘promoting direct nurse–patient communication’ and the successful use of augmentative and alternative communication (AAC) in hospital. Improving direct nurse–patient communication would relieve the family carer not only of the burden of being present at all times to provide support in communication, but also of the anxiety associated with being away from the ward when they know the patient cannot communicate directly with hospital staff.

Lessons from family carers on barriers to communication

Patients lack a readily available communication system

A common theme across both phases of the study was that the patient with complex communication needs lacked access to AAC in hospital. Supporting the results of a growing number of studies on communication using AAC in hospital (see Finke, Light, & Kitko, 2008), participants in our study described the following barriers to communication: 1) the patient not taking the AAC system to hospital; 2) the patient being unable to use the system when lying in bed; 3) fears that the system would be damaged, lost, or stolen; and 4) staff not knowing how to communicate using AAC or not having time to communicate using AAC. In addition, some carers and hospital staff perceived that people with complex



Student nurse Vicki Clausen is taking a patient’s blood pressure reading whilst being supervised by an RN (Photo by Chris Stacey)

communication needs do not need to take existing AAC systems to hospital because they do not need to communicate as the carer was there to speak on their behalf.

Older carers in our study described encountering negative attitudes in hospital staff that further reduced the patient’s opportunities to communicate (e.g., staff avoiding the patient, the patient being ‘talked over’ or ignored in discussions, or staff assuming that the patient had intellectual disability). This combination of barriers meant that (a) when carers were present, nurses did not gain opportunities to communicate with the patient, and (b) when carers were absent, the patient had no way to communicate directly with hospital staff. This in turn led to patients feeling isolated, and carers feeling under pressure to be present at all times to support communication.

Nurses lack time to communicate

Our results support previous research that hospital staff are very busy and that the workload pressures on the ward mean that there is limited time available for communication (Hagerty & Patusky, 2003; Iacono & Davis, 2003; Iezzoni, O'Day, Killeen, & Harker, 2004; Magnus & Turkington, 2006; Mendes, Trevizan, Nogueira, & Sawada, 1999). Lack of time is a major barrier because it is (a) a "universal barrier" that could apply to *any* activity where there are competing demands within any period of time, (b) fixed, but perceptual, context bound, and affected by many other environmental and personal factors (e.g., how long a person wishes to engage in an interaction), and (c) unclear who is in the best position to influence the time available to communicate (i.e., policy, administrators, individuals).

The communication barrier 'lack of time' provides a challenge to speech pathologists working in community and acute care settings who aim to improve communication in hospital for patients with pre-existing communication disability. First, 'lack of time' to communicate is a nebulous concept, is not unique to the hospital setting, and occurs whenever communication partners face time restrictions (e.g., at schools, home, shops, travelling). Second, 'time' as a barrier to communication commonly exists for all people who have complex communication needs who attempt to communicate with natural speakers in any context (Beukelman & Mirenda, 2005). Time is also a barrier common to all patients in hospital, as nurses report lack of time as a barrier to forming relationships with patients consistently (Anoosheh, Zarkhah, Faghihzadeh, & Vaismoradi, 2009).

Implications for speech pathologists

Raise the profile of communication at pre-admission

Patients with developmental disability may have pre-existing communication disability and are likely to enter hospital frequently as they get older (Young et al., 2007; Young et al., 2005). Therefore it is important that they prepare well for communication during both planned and unplanned hospital admission (Hemsley et al., 2004; 2008a, b). Speech pathologists from all services may consider they have a responsibility to advocate that during pre-admission interviews with patients, hospital staff seek information on the patient's method of communication. Speech pathologists may also prompt *patients* to bring and use their own low-cost communication boards to hospital for rapid basic needs communication with nurses and *carers* to support nurses in using these systems for direct communication.

Prepare for brief interactions focused on basic needs

Given the common difficulty related to "lack of time" to communicate, speech pathologists supporting adults to prepare for hospitalisation and supporting universal patient communication accessibility on hospital wards should aim for increased success in brief interactions around daily care tasks (see Hemsley, Balandin, & Worrall, *in press b*). Non-electronic communication aids (e.g., message cards, communication boards) might be helpful in the hospital setting if designed to convey messages that relate to everyday basic care tasks. Speech generating devices or other electronic communication aids (e.g., adapted switches for a call system) might be of help in this situation if they provide the patient with a way to gain the nurse's attention

from a distance and communicate with the nurse who is otherwise engaged in a care task.

Establish an effective communication method

Hospital speech pathologists have a crucial role in assisting nursing staff to establish a successful mode of communication for yes/no messages and other messages (see Finke et al., 2008). This is an important first step in supporting nurses and patients to communicate successfully and directly about basic care needs, particularly in the absence of a carer. Given that all stakeholders are currently reporting problems and barriers to successful communication, hospital speech pathologists can influence better nurse-patient-carer interaction through:

- encouraging the family to bring in any easy to use communication system for hospital staff to access in daily basic care tasks;
- enlisting the support of family carers or paid carers in the set up or use of the person's communication aid in hospital;
- providing information to (a) nursing staff about different forms of aided communication strategies (including the appropriate use of speech interpreters, sign or gesture systems, communication boards, word or picture boards, spelling boards, and speech generating devices) and (b) family carers about providing care in the hospital setting (e.g., Hemsley, 2008);
- collaborating with nursing staff, family carers, and patients in the design of suitable communication aids (e.g., boards or message cards) for use on hospital wards and accessible to hospital staff at all times;
- training hospital staff in 'communication disability awareness' and communication rights for patients who have developmental disability and complex communication needs.

Conclusion

Speech pathologists have an important role in improving direct nurse-patient communication between patients with developmental disability and complex communication needs and hospital staff. Their actions might involve collaborating with all concerned to design a functional, easy-to-clean and use low-technology communication board that is readily available for use in planned and unplanned admissions to hospital. The results of our study indicate that patients with complex communication needs, their family carers, and the nurses who care for them, are ill equipped to overcome the communication barriers that they encounter in hospital. Hospital speech pathologists who are aware of the barriers to and facilitators for effective communication in hospital may be best placed to influence hospital policy to improve communication access for adults with developmental disability and complex communication needs in hospital.

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Dr Bronwyn Hemsley is an NHMRC Postdoctoral Fellow at the Communication Disability Centre, University of Queensland, and a speech pathologist with a special interest in communication for people with lifelong disability and complex communication needs and people who use AAC. Bronwyn is currently the Australian Representative to the Executive Board of the International Society for Augmentative and Alternative Communication (ISAAC), and is engaged in a 4-year research project on communication in hospital for people with developmental disability, at the Communication Disability Centre, University of Queensland. This paper is based on findings of her doctorate (awarded in 2008) on the experiences and needs of family carers of adults with cerebral palsy and complex communication needs in hospital.

Correspondence to:

Bronwyn Hemsley, PhD

NHMRC Postdoctoral Fellow, Communication in Hospital Project
Communication Disability Centre

Level 7, Therapies Building, The University of Queensland

phone: +617 3365 2089

email: b.hemsley@uq.edu.au

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