

The “Big 5” and beyond: Nurses, paid carers, and adults with developmental disability discuss communication needs in hospital

Bronwyn Hemsley, PhD^{a,*}, Susan Balandin, PhD^b, Linda Worrall, PhD^c

^aCommunication Disability Centre, School of Health and Rehabilitation Sciences, The University of Queensland, QLD 4072, Australia

^bAvdeling for helse- og sosialfag, Høgskolen i Molde Postboks 2110, 6402 Molde, Norway

^cSchool of Health and Rehabilitation Sciences, The University of Queensland QLD 4072, Australia

Received 13 June 2010; revised 2 September 2010; accepted 4 September 2010

Abstract

Adults with developmental disability and little or no speech need to communicate with nurses in hospital to (a) express physical needs, (b) discuss health, (c) convey intelligence and emotions, (d) connect socially, and (e) control the environment. All stakeholders need access to a variety of communication strategies to support communication of these needs.

Crown Copyright © 2011 Published by Elsevier Inc. All rights reserved.

1. Introduction

Communication in hospital is difficult for people with developmental disability (DD) and complex communication needs (CCNs; Balandin, Hemsley, Sigafoos, & Green, 2007) and the nurses who care for them (Hemsley et al., 2001). These patients have little or no spoken communication and may lack an effective means to communicate with nurses and staff (Balandin et al., 2007; Hemsley & Balandin, 2004). When hospitalized, this group has a threefold increased risk of suffering preventable and adverse events (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008). Patients with DD and CCN are likely to benefit from the use of Augmentative and Alternative Communication (AAC; i.e., communication boards, gesture or signing systems, and speech-generating devices [SGDs]) to overcome barriers to communication in hospital (Hemsley, Balandin, & Togher, 2008). When designing AAC systems, the communication needs of the person using the system and the setting in which the system is to be used must be considered (Beukelman & Mirenda, 2005). In addition, the attitudes, knowledge, and awareness

of communication partners (e.g., nursing staff) are important, as these factors can be either barriers or facilitators to successful communication using AAC (Beukelman & Mirenda, 2005; O'Halloran et al., 2008).

In hospital settings, the primary focus of interactions between patients and nurses is the provision of health care, and equally, the primary purpose of communication between nurses and patients is to influence the patient's health (Fleischer, Berg, Zimmermann, Wuste, & Behrens, 2009). In recognition that AAC designed for use in the hospital must support communication between nurses and patients, there is growing interest in the specific vocabulary or topics that patients, relatives, and staff view as important for inclusion in hospital communication boards and SGDs (see Patak et al., 2006; Rodriguez & Blischak, 2010). In a communication inventory for adult hospital inpatients (O'Halloran et al., 2004), 8 of the 15 communicative situations included in the inventory related to the exchange of health information, with the remainder encompassing the need to gain attention, call for a nurse, ask for items, express feelings, follow instructions, and tell about pain and what patients do or do not like. To date, the focus of research into what might be included in AAC systems in hospital has been restricted to patients in the intensive care unit (ICU) and to patients with acquired temporary or permanent communication disability (e.g., Costello, 2000; Patak et al., 2006; Rodriguez & Blischak, 2010). Rodriguez and Blischak (2010) surveyed eight nurses, eight patients, and 11 relatives on what patients had ‘trouble’

This project was funded by a National Health and Medical Research Council of Australia Postdoctoral Fellowship to the first author.

* Corresponding author. Tel.: +61 7 3365 2089.

E-mail addresses: b.hemsley@uq.edu.au (B. Hemsley), susan.balandin@hiMolde.no (S. Balandin), l.worrall@uq.edu.au (L. Worrall).

communicating in the ICU. Common difficulties reported across the groups were in communicating about pain, breathing, suctioning, bathroom needs, and feelings. Patients and relatives identified five additional communication needs (e.g., including information and calling for a nurse), and nurses identified a further five (including positioning, sleep, and medication). This suggests that although there might be a common core set of communication needs that are important to all parties, a diverse range of additional needs might be of importance to different communication partners. Therefore, when considering the use of AAC in hospital, it is important to gather the views of a variety of communication partners to determine the full range of communication needs encountered by people with CCN (Beukelman & Mirenda, 2005).

It is likely that communication situations in the ICU for patients with temporary (e.g., through artificial respiration or tracheostomy) or permanent acquired communication disability (i.e., those patients who previously communicated by speech) are different from those of patients who (a) have DD and have never had functional spoken communication, (b) may have multiple physical support needs, (c) may already be using AAC communication systems, and (d) often rely upon family members or paid carers for support with care, information, advocacy, and communication in hospital. To date, although research has explored the views of older family carers (e.g., Hemsley et al., 2007), there is little information available on the views of patients, paid carers, and hospital nurses regarding the communication needs of patients with DD and CCN in hospital. Thus, the aim of this study was to determine the views of patients, paid carers, and nurses on the communication needs of patients with DD and CCN in hospital. Results will inform the design of ecologically valid AAC interventions in hospital that will support the purposes of communication between all stakeholders in hospital.

2. Method

This qualitative study, a narrative inquiry, was approved by the human research ethics committee of the university and participating hospitals and disability organizations in Queensland, Australia.

2.1. Participants

Fifteen adults with DD and CCN who had been hospitalized for three or more days in the past 2 years, 15 paid carers of adults with DD and CCN who had supported at least three adults with DD and CCN in hospital in the past 2 years, and 15 hospital nurses who had communicated with at least three adults with DD and CCN in the past 2 years were recruited from two metropolitan teaching hospitals and three disability organizations in Brisbane, Australia. For information on participants, including the method of communication, role in nursing, and work setting, see Tables 1–3.

2.2. Interview topic guide

In consultation with an expert reference group (comprising a speech pathologist working with adults with intellectual disability, a speech pathologist working with adults with cerebral palsy, an adult with cerebral palsy who had been hospitalized in the past 2 years, a parent carer, a disability support worker, a disability liaison nurse, and a hospital nurse), a topic guide for each of the three groups of participants was developed to aid consistency across interviews and support comparison and triangulation of results across the groups. Topics included communication experiences in the hospital, the patient's communication needs, the use of AAC in the hospital, and barriers to and facilitators for effective communication in the hospital.

2.3. Conduct of the interviews

The first author conducted conversational-style interviews with all participants in a quiet area at the participant's workplace ($n = 30$), in the community ($n = 11$), or at home ($n = 4$). Following questions to gather demographic information, interviews commenced with the question: "Can you tell me about your experiences communicating [with patients with DD and complex communication needs] in hospital?" According to each participant's response, a variety of follow-up questions were used to explore relevant topics listed in the topic guide and to explore issues raised by participants. All interviews were digitally audio recorded, and immediately after each interview the first author made field notes on the interview, transcribed the digital recording verbatim, and deidentified the interview transcripts. In this way, proceeding interviews contributed to a constant comparative analysis of the data (Taylor & Bogdan, 1998).

2.4. Narrative analysis

The first author conducted a narrative analysis of interview data (Polkinghorne, 1988; Riessman, 1993). This

Table 1
Information on participants: paid carers

Label	Organization ^a	Work role
PC1	1	Paid carer
PC2	1	Paid carer
PC3	1	Manager of paid carers
PC4	1	Paid carer
PC5	1	Manager of paid carers
PC6	1	Manager of paid carers
PC7	1	Paid carer
PC8	2	Paid carer/manager of paid carers
PC9	2	Paid carer
PC10	2	Paid carer
PC11	2	Paid carer
PC12	2	Paid carer
PC13	3	Paid carer
PC14	3	Paid carer
PC15	2	Paid carer/manager of paid carers

^a The participants' employing organizations are differentiated by the numbers 1, 2, and 3.

Table 2
Information on participants: nurses

Code	Experience (years)	Ward type	Title
N1	7	Medical	Registered nurse
N2	10	Gastrointestinal surgery/medical 1	Registered nurse
N3	20	Gastrointestinal surgery/medical 1	Registered nurse
N4	20	Medical imaging	Registered nurse/case manager
N5	10	Gastrointestinal surgery/medical 2	Registered nurse
N6	13	Gastrointestinal surgery/medical 2	Registered nurse/team leader
N7	15	Medical	Registered nurse
N8	5	Emergency	Registered nurse
N9	1	Emergency	Registered nurse
N10	20	Emergency	Registered nurse/nurse educator
N11	30	Day surgery	Registered nurse
N12	20+	Surgical	Registered nurse/team leader
N13	20	Surgical	Registered nurse
N14	17	Medical	Registered nurse/team leader
N15	3	Medical	Registered nurse/team leader

involved identifying stories of communication within the participants' accounts by a structural analysis to locate the stories and a content analysis looking at the story plots and themes. After this, topics were extracted from the interviews that related to the 'communication needs' of the patient with DD and CCN in the hospital. The first author then wrote a 'summary story' of each participant's account representing and encapsulating the plot and themes of his or her experiences. Participants were sent their own summary stories and invited to check the document and verify, change, or add any information or further insights. The first author or a paid carer read the summary to participants with DD and CCN to ensure that they had an opportunity to consider the interpretation and make any changes or corrections. All participants verified that the summary stories reflected their views, two requested minor changes that did not alter the interpretations (clarifying detail in role as registered nurse providing clinical education when students are on the ward; one added further stories to the summary), and none disputed the interpretations contained in the summary. The three authors then read and discussed the narratives across all interviews and identified three main themes relating to the communication needs expressed in the stories, and the results of this analysis are presented here.

3. Results

3.1. Theme 1: Little or no need to communicate

Most of the paid carers ($n = 9$), 4 of the 15 nurses, and 4 of the 15 adults with DD expressed the view that patients with DD and CCN would have little or no need to communicate directly with hospital staff. Related to this view was the common perception among these participants that the

patient's carer would be present at all times to speak on his or her behalf. N11 said: "A lot of the communication is to the parent and the carer." PWD7 narrated: "My sister comes in, to help, to tell them things, and she talks for me." PC10 reported that she had never known a person with disability to take his or her communication board to the hospital from home as "if they've got someone there, they shouldn't need one."

3.2. Theme 2: The "Big 5": Communication of basic needs and wants

Almost two thirds of all participants ($n = 28$), representing all three groups, viewed communication of basic needs and wants relating to physical states of (1) pain, (2) hunger/thirst, (3) comfort (hot/cold, position), (4) hygiene (including toileting/showering/cleanliness), and (5) nausea as being important for adults with DD and CCN in hospital. We have termed these the "Big 5" communication needs, given the convergence of views across all stakeholder groups on the importance of these communication needs. Difficulties in communication about these needs impeded provision of care, as one nurse said: "If they've got a board, they can tell us straight away, you know, 'my foot's sore'—if they can't communicate, they tend to be aggressive or a bit agitated, which makes more of a distance, more difficult to care for them, to actually do the care tasks." Nurses viewed

Table 3
Information on participants: patients with DD and CCN

Label	Age (years)	Method of communication	Method of communication in hospital
PWD1	65	Speech with interpreter	Speech with interpreter
PWD2	54	Communication board SGD	Communication board
PWD3	48	Speech	Speech
PWD4	48	Speech with interpreter	Speech with interpreter
PWD5	51	Speech with interpreter	Speech with interpreter
PWD6	54	Communication board SGD Interpreter	Communication board Speech with interpreter
PWD7	50	SGD Interpreter	Speech with interpreter
PWD8	42	SGD	None
PWD9	42	Speech with interpreter SGD	Speech with interpreter SGD
PWD10	40	Speech with interpreter SGD	Speech with interpreter SGD
PWD11	57	Speech with interpreter SGD	Speech with interpreter SGD
PWD12	35	Communication board SGD (not used in interview)	None
PWD13	70	Speech	Speech
PWD14	32	SGD	SGD
PWD15	42	Speech	Speech

SGD = Speech Generating Device.

communication of basic physical needs as important to provide medical care, ease problems, prevent risks to patient safety (e.g., arising from poor hygiene or deteriorating condition), and predict their workload demands. In their accounts, nurses often fluently listed the needs and related these to workload. An example of such a list is provided by N6:

Food, pain, comfort, obviously lying in bed or not, just all the basic nursing problems and then on top of that, whatever else, their activities of daily living that we need to sort for them.

Indeed, communicating basic needs often featured in participants' accounts as the scope of the communication needs, as N5 outlined:

We'd mainly need to communicate about hygiene—like toileting, showering, just making sure they're kept clean of urine, faeces that sort of thing, so regular toileting, turning as well you don't want them to get pressure area sores...do they need assistance with eating, and making sure that they're safe when they're eating, administering medications, that's probably about it.

Indeed, only two nurses highlighted the patient's need to communicate anything other than basic needs, and none spoke of any need for the patient to communicate for social purposes (e.g., social closeness, emotional needs; Light, 1988).

Participants with DD and CCN also outlined the importance of basic needs communication. PWD2 took his own alphabet and word board to the hospital and found it useful: "When they asked how much pain I was in, and when I could not go to the toilet, I could tell." In stories from all stakeholders, communication about basic needs relied upon nurses determining a reliable way for the patient to respond, asking yes/no questions, and interpreting the patient's nonverbal signals (see Finke, Light, & Kitko, 2008). However, even a combination of these strategies was not always successful. One nurse (N1) highlighted the limitations of interpreting unaided communication as follows:

The only way of showing us is by a gesture, or we could see expression on the patient's face. Trying to read anything, any cues that could help me that the patient is not comfortable.

3.2.1. *Communicating "pain"*

Across all three groups, participants' stories reflected that communication of pain was an important communication need, and often the first mentioned. N2 said: "Basically, the most important thing for us to know is if they've got pain, that's the first thing I'll want to know." Reflecting this importance, nurses narrated having many different ways to detect pain, even in the absence of formal communication, and these accounts were supported by similar stories from paid carers and patients: (a) using scaled response questions (i.e., a scale of 1 to 9 for severity), (b) asking a series of yes/no questions, (c)

interpreting nonverbal facial expressions or body signals in response to a stimulus or an action designed to relieve pain, or (d) relying upon a carer proxy report of the patient's pain. N10, an emergency nurse, described clinical signs:

You rely very much on your clinical assessment skills, the actual physical signs of what's wrong—so you'll take vital signs, and if they've, appear to have pain, you'll give them pain relief, and then reassess to see how that went, you know if it's abdominal pain you'll get a urine specimen, check your blood sugar, and just work with what you've got for the minute.

N3 described attributing meaning to patient behaviors: "In the interactions you have with a patient, if you're turning them and they make a certain cry, that comes to mean pain." Three nurses also outlined the importance of close observation and an awareness of communication being more than words. N9 said: "It's more than just verbal communication, it's seeing how they react as well."

Communication of pain may not be so straightforward or 'objective' for patients themselves, as three adults with DD reported being in pain and being unable to get this across to hospital staff, and two paid carers reported that the patients' communications of pain were not understood or heeded. The paid carers expressed dismay and astonishment that nurses would ask the carer if the patient felt pain rather than look at the patient's own responses directly. In contrast, PC1 praised a nurse as "she kept on asking, 'How was the pain? Do you feel pain? Would you like to rate your pain from 1 to 9?' It was easy for the client to answer."

3.2.2. *Communicating comfort (hot/cold, position) and nausea*

Patients' stories revealed that they needed to communicate positioning requirements, feeling sick, fears about falling, and warnings about potential hazards related to their position (e.g., feeling unsafe, needing a lap strap in the wheelchair, needing side-lying). Nurses reported difficulty interpreting whether patients with DD and CCN were comfortable. N1 said: "We think we have done our level best, but I'm not sure if the patient is satisfied or not—and if we feel it is comfortable for the patient, the patient might think 'I don't want to be like that' but they're unable to relay that." Indeed, some adults reported lying in bed and feeling "unsafe" in their position but having problems communicating this to staff, either through lack of opportunity (e.g., staff walking away or being too busy) or staff not understanding their speech. PWD5 said: "I wanted to say, 'feel unsafe; my position.'" Problems communicating about position or comfort had safety implications for PWD4, who said: "They put me in my wheelchair but they forgot to tie me in, and I had a spasm, and I fell out on the floor, and I hurt my back ... They were there when I fell out, and I couldn't say anything at all." For the most part, problems communicating reflected the person with disability's lack of comfort or control in directing staff to adjust his or her position. PWD13

said: “They put me on my back. I can’t. I’ve got a curvature of the spine. I said I would be better (on my side).”

3.2.3. *Communicating hunger, thirst, mealtime needs, or preferences*

In relation to mealtimes, patients needed to communicate which foods were safe for them to eat, food preferences, and requests for mealtime assistance. However, communication of these needs was problematic for all concerned. PWD4 said: “Every night, they put in an order in for the same food. And every morning, I tried to tell them that I don’t like porridge. But they didn’t listen.” PC3 reported that a patient could not reach her food on the tray, the kitchen staff left it there, and then when they picked it up, they said, “aren’t you hungry today?” PC7 highlighted the safety concerns about mealtime communication for people with DD and dysphagia:

There were some things that she was aware that she couldn’t have, she was trying to convey that to them, but they weren’t really understanding...with having thickened fluids she’s at high aspiration risk and she found that very concerning to try and convey.

Nurses’ stories also reflected difficulty communicating about mealtime assistance or mealtime preferences. N12 said: “We’re probably familiar with the diets but just the feeding itself, often, they’ll just get aggressive because they don’t know us and push us away. It does make it very difficult and frustrating.” N1 also noted ambiguity in nonverbal communication as proving difficult: “While we are feeding the patient, sometimes, the only cue we can have is when they start to turn their faces away—I’m not sure if they’re full or the food is not good.”

3.2.4. *Communicating about hygiene (toileting/showering)*

Stories about providing basic needs care for toileting or showering were linked with safety concerns that the patient be clean and not left in soiled linen because, being unable to mobilize, this put patients at risk for developing skin pressure areas. Paid carers’ stories highlighted the problems with toileting and being unable to ask for assistance before or after soiling the bed. PC3 said: “Communication problems can make it difficult for the person to let the hospital staff know that they need the toilet—I have seen one person not be understood and soil the bed.” Nurses also noted that poor communication about toileting needs increased workload. N3 narrated: “You go in and say ‘do you need to go to the toilet’ and he says ‘ay,’ but then he’s peed the bed later, and you’re like ‘you just wanted a hot shower,’ and he’s like ‘ay’ and smiles, and I’m like ‘damn you’ (laugh).”

3.3. *Theme 3: Beyond the basics: Health care information, intelligence, emotion, and social connection*

Most of the adults with DD and CCN ($n = 11$) highlighted a broad range of communication needs beyond basic needs that included communication for health information exchange (e.g., asking about test results, new diagnoses, treatment plans, and discharge information), the expression

of emotion (e.g., fear and anxiety), social connectedness (e.g., gaining attention, asking to call a carer, and having a chat), and controlling the environment (e.g., requesting the use of an AAC device or the TV or to go for a walk).

Only two nurses spoke about the patient needing to communicate anything more than basic physical needs, and in both cases, this was the need to be told what would happen to them in the hospital. However, people with disability recounted feeling dehumanized when communication did not extend beyond basic needs. PWD14 said: “In their assumptions and judging of me, they didn’t bother to try and know me as a person. I was just a body to treat. They talked at me, like, I was told to roll, not asked ‘can you roll?’” Indeed, paid carers were often the preferred communication partners when it came to health information exchange. PWD5 said: “When I first went to hospital, I didn’t get asked any questions, my carer talked for me.” While nurses noted that communication of basic needs might be achieved by using a range of nonverbal communication strategies, communication of more complex or unpredictable messages such as ‘questions’ or ‘concerns’ of the patient was difficult and resulted in frustration for both the patient and the nurse. N12 said: “It is frustrating, if they can’t communicate, they tend to be aggressive or a bit agitated, which makes it more of a distance I suppose.”

3.3.1. *Communicating health information*

Six adults with disability and six paid carers highlighted the need for the patient to seek information from hospital staff about ‘what is wrong’ and ‘what will be done.’ PWD1 recounted a missed opportunity for seeking information about her own health:

When they all come around, they say to me “what’s wrong” and I say “I’ve got a pain in my chest,” they say, “alright, I’m going to put a needle in your arm.” I wanted to know, how long before I get better?

The paid carers highlighted that because the information related to the patient, the patient had a right to know. Although nurses said that they would give the patient information about ‘what would happen to them’ within care tasks or procedures (as PC4 also said: “They’d be telling him what was going to happen”), this was not considered by other participants to be providing information about the patient’s health. PWD5’s narrative reflected a lack of opportunity for dialogue with hospital staff about his/her condition: “They told me, they have to put a camera down my belly, to find out why I’m sick. They didn’t ask me anything, and I didn’t get to ask anything. I would have liked to ask, ‘why do I get sick?’”

3.3.2. *Discharge planning information*

Six adults with disability and three paid carers noted that the patient needed to communicate about discharge, particularly when the patient would be going home or needed to return to the hospital: “When I am getting better, I ask when I can go home?” (PWD2) and “How will I know when to come back?” (PWD1). As mentioned previously, only two nurses highlighted the patient’s need

to communicate about health information. Indeed, on one surgical ward, discharge information was designed exclusively for carers, who, as N12 explained, might or might not read it: “We would actually write a nursing discharge summary for the carer, assuming the carer reads it, might write the patient’s name, like ‘[Name] will need whatever,’ so it’s not, really to that person, it’s for the carer.”

3.3.3. *The need to convey his or her own intelligence*

A common theme in stories about communication in hospital featured adults with DD and CCN perceiving that they were excluded from interactions because hospital staff presumed that they had intellectual disability. PWD10 described her experiences at admission to the hospital and the role of her sister in directing the nurse to speak directly to the patient with the ‘problem.’ PWD10 said: “Everybody sees the wheelchair. They think you’ve got intellectual disability. They talk to my sister. My sister says, ‘don’t talk to me, don’t tell me, it’s her problem not mine.’” Similarly, PWD13 experienced exclusion from information, and her story reflected both anger and resolve to use direct communication with nurses (through her eyes and talking) to show her intelligence, as long as nurses tried to understand:

I went in for bowels. They did not say anything to me at all (about what that involved), they didn’t tell me anything, that’s why I got so angry. They thought I was dumb..I show them I am intelligent by my face. By just looking, by their eyes. Talking, talking to them, properly. It’s quite easy, when they know how, if they could get the message.

However, direct nurse–patient spoken communication might not always be “quite easy,” and lack of success in communication might lead to nurses “walking away” and the patient “giving up,” as PWD5 recounted:

They thought I don’t have any intelligence. They would walk off when I was talking. I wanted to talk to them about my belly. Lot of fears. My health. When they walked off, I thought, ‘What’s the point?’ I gave up.

3.3.4. *Social aspects of communication*

Stories of communication fulfilling a social purpose also appeared in the stories of people with disability and of paid carers. Being in a hospital was a stressful experience for most adults with DD and CCN, as PC11 noted: “I haven’t had a client who hasn’t found it very frightening and were very disheveled by the experience.” Stories contrasted the isolation associated with the absence of interaction with the social benefits of incidental nurse–patient interaction. Reduced social interaction and the impact of this on the patient were reflected in PWD13’s account:

They didn’t understand me. They wouldn’t try to listen to me. I was looking at the four walls all of the time. It was bloody awful. I was lonely.

PWD5’s story of communication reflected the isolation and negative emotional impact of having interaction during basic care tasks only: “Nobody talked to me in hospital. Not

properly. Mainly when they were doing something to me. At the moment they had to turn me over. I felt unhappy.” The counter-narrative to this appeared in stories about successful interaction and reflected the benefits to patients of having ‘chat’ interaction with staff, as reflected in this excerpt from PWD4’s summary story:

There was one nurse who I really liked, out of all of them. She understood me, and she had a better understanding of what I needed. When she was over in another part of the hospital, when she knocked off from her shift, she always dropped in to see how I was.

4. Discussion

Analysis of the narratives about communication in hospital revealed much about the communication needs of adults with DD and CCN on a range of hospital wards and the impact of difficulties in communicating those needs to hospital staff. Communicating the basic needs of pain, hunger/thirst, comfort (hot/cold, position), hygiene (toileting, showering, cleanliness), and nausea was important. The fluent ‘listing’ of these communication needs by many of the participants might reflect their high saliency and connection to the basic principles of nursing as conceptualized in the 1960s by nursing theorist Virginia Henderson, who expressed the basic components of nursing as being to support patients to good health by enabling them to breathe, eat and drink, eliminate, move, sleep and rest, select clothing, maintain body temperature, keep the body clean, avoid dangers, avoid injuring others, communicate with others, worship as desired, work, play, and learn (see [Thorson & Halloran, 2007](#)). In regard to the need to communicate about pain, hospital staff reported a wide range of adaptive strategies to fulfill this need. However, nurses did not describe using aided AAC in relation to pain, and patients reported that their attempts to communicate pain were not always successful. Hospital nurses might need greater access to communication boards designed to assist communication about pain in patients with CCN.

In this study, adults with DD and CCN reported negative stereotyping by others based on their disability and their need to highlight their intelligence and capacity to understand information in the hospital. Indeed, nurses have reported assuming that the patient with DD and CCN will not understand or has intellectual disability and expect that lack of success in communication wastes their time ([Hemsley, Balandin, & Worrall, in press](#)). Therefore, improving the access of patients with DD and CCN to information about their own health might require the use of AAC strategies to support understanding ([Finke et al., 2008](#)).

The narratives across groups reflect that (a) difficulties communicating basic needs might impede nursing care and increase the nurses’ workload and leave the patient feeling uncomfortable and at risk of patient safety incidents; (b) lack of direct communication with the patient about health information, and reliance upon paid carers as a proxy reporter

for the patient, may leave the patient feeling disenfranchised and disempowered in decisions about care; and (c) lack of direct communication with hospital staff during everyday care tasks can result in negative emotional impacts for the patient. Thus, it is important to consider how a focus upon the communication of basic needs might outweigh but not diminish the need for communication for other purposes. Given that patients on hospital wards face a wide variety of communicative situations (see O'Halloran et al., 2004), a focus on the Big 5 communication needs alone might leave the adult with DD and CCN vulnerable to gaps in health information and perpetuate reliance upon third parties for access to information. Whereas paid carers also highlighted communication for social and emotional purposes, participants with DD and CCN highlighted the broadest range of needs. AAC systems must be "designed to support and foster the abilities, preferences, and priorities of individuals with complex communication needs" (Blackstone, Williams, & Wilkins, 2008, p. 192). As such, it is important that AAC systems designed for use in hospital take into account the patient's need for communication about more than basic needs and the patient's need to participate as much as possible in decisions about their own lives (Blackstone et al., 2008).

The view held by many in this study that the patient with DD and CCN does not need to communicate with hospital staff constitutes an environmental barrier to communicative participation (Beukelman & Mirenda, 2005) and might further explain why many people with DD and CCN do not take and use their AAC systems in hospital (Hemsley & Balandin, 2004). Reliance upon a carer for communication support in hospital has been reported previously by nurses, family carers, and adults with cerebral palsy and CCN alike (e.g., Hemsley et al., 2008). However, the suggestion that this might mean the patient has little or no need to communicate in hospital has not been noted previously (e.g., Patak et al., 2006; Rodriguez, 2010). Such a view fails to recognize the importance of nurse–patient communication in nursing care (McCabe, 2004), the central role of patients in influencing the nurse–patient interaction, and their right to knowledge about themselves and to participate in decisions that affect their health (as conceptualized in Imogene King's influential nursing theory of goal attainment and conceptual framework of nursing that reflects interrelationships of personal and interpersonal communication, relationships, health, and social institutions; see Frey, 2005). It also perpetuates dependency of patients with DD and CCN upon carers who might not always be available to support the patient in the hospital, leaving the patient vulnerable to gaps in care arising through lack of an effective means of communicating their needs to hospital staff.

5. Limitations and directions for future research

Because each participant group comprised only 15 members, it is not possible to generalize the results as being

applicable to all nurses, paid carers, or adults with DD and CCN in hospital. Also, no nurses from the ICU participated in this study, and it is possible that their inclusion would have broadened the range of communication needs identified. Observational studies of adults with DD and CCN communicating with nurses and carers would provide further insight into (a) the opportunities that these patients have to communicate the full range of needs outlined in this article, (b) the communication needs arising in context without relying upon participant recall, and (c) how communication needs are met on the hospital ward or the barriers to these needs being met. It is also important to examine how success or difficulty in communicating these needs relates to patient safety incidents in hospital in this population.

6. Conclusion

Nurses, paid carers, and patients with DD and CCN agree that communication of basic physical needs is vital in hospital. Few nurses identified communication needs beyond basic physical states, paid carers emphasized reliance upon a carer to communicate, and adults with DD highlighted the broadest range of needs and emphasized the importance of communicating about health care information and emotional states. Although many participants discounted the patient's need to communicate, the narratives of adults with DD and CCN revealed the negative emotional impact of being alone and unable to communicate directly with hospital staff. It is important that people with CCN who are preparing for hospital admission, and those providing AAC services to them, consider what AAC options best support communication about the Big 5 and other communication needs for direct nurse–patient communication. Although it is tempting to promote basic needs communication over other needs, the use of AAC for more complex and less predictable messages that relate to health information, social connection, and environmental control must also be considered as important in impacting upon the patient's health care experience in the hospital. The sharing of information with adults with DD and CCN about their own health, including test results, diagnoses, treatment, and discharge plans, is vital, and the use of AAC to support their understanding of this information should also be considered.

Acknowledgments

The authors would like to acknowledge and thank the disability organizations and hospitals assisting with recruitment and the participants for giving so generously of their time and experiences in being interviewed in this study.

References

- Balandin, S., Hemsley, B., Sigafoos, J., & Green, V. (2007). Communicating with nurses: The experiences of 10 adults with cerebral palsy and

- complex communication needs. *Applied Nursing Research*, 20(2), 56–62.
- Bartlett, G., Blais, R., Tamblin, R., Clermont, R. J., & MacGibbon, B. (2008). Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *CMAJ*, 178(12), 155–162.
- Beukelman, D., & Mirenda, P. (2005). *Augmentative and alternative communication: Supporting children and adults with complex communication needs*. 3rd ed. Baltimore: Paul H. Brookes.
- Blackstone, S., Williams, B., & Wilkins, D. (2008). Key principles underlying research and practice in AAC. *Augmentative and Alternative Communication*, 23(3), 191–203. p.192.
- Costello, J. (2000). AC in the intensive care unit: The Children's Hospital Boston model. *Augmentative and Alternative Communication*, 16, 137–153.
- Finke, E. H., Light, J., & Kitko, L. (2008). A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication. *Journal of Clinical Nursing*, 17(16), 2102–2115.
- Fleischer, S., Berg, A., Zimmermann, M., Wuste, K., & Behrens, J. (2009). Nurse–patient interaction and communication: A systematic literature review. *Journal of Public Health*, 17, 339–353.
- Frey, M. A. (2005). King's conceptual system and theory of goal attainment. In J. J. Fitzpatrick & A. L. Whall (Eds.), *Conceptual models of nursing* (pp. 225–246). New Jersey: Pearson Prentice Hall.
- Hemsley, B., Balandin, S., & Worrall, L. (in press). Time: 'Enemy' or 'friend' to nurses communicating with adults with developmental disability and complex communication needs in hospital. *Journal of Advanced Nursing*.
- Hemsley, B., & Balandin, S. (2004). Without AAC: The stories of unpaid carers of adults with cerebral palsy and complex communication needs in hospital. *Augmentative and Alternative Communication*, 20(4), 243–258.
- Hemsley, B., Sigafos, J., Balandin, S., Forbes, R., Taylor, C., Green, B., & Parmenter, T. (2001). Nursing the patient with severe communication impairment. *Journal of Advanced Nursing*, 35(6), 827–835.
- Hemsley, B., Balandin, S., & Togher, L. (2007). Narrative analysis of the hospital experience for older parents of people who cannot speak. *Journal of Aging Studies*, 21, 239–254.
- Hemsley, B., Balandin, S., & Togher, L. (2008). "We need to be the centrepiece": Adults with cerebral palsy and complex communication needs discuss the roles and needs of family carers in hospital. *Disability & Rehabilitation*, 30(23), 1759–1771.
- Light, J. (1988). Interaction involving individuals using augmentative and alternative communication: State of the art and future research directions. *Augmentative and Alternative Communication*, 4, 66–82.
- McCabe, C. (2004). Nurse–patient communication: An exploration of patients' experiences. *Journal of Clinical Nursing*, 13, 41–49.
- O'Halloran, R., Worrall, L., Toffolo, D., Code, C., & Hickson, L. (2004). *The Inpatient Functional Communication Interview (IFCI)*. Oxon: Speechmark.
- O'Halloran, R., Hickson, L., & Worrall, L. (2008). Environmental factors that influence communication between people with communication disability and their healthcare providers in hospital: a review of the literature within the International Classification of Functioning, Disability and Health (ICF) framework. *International Journal of Language & Communication Disorders*, 43(6), 601–632.
- Patak, L., Gawlinski, A., Fung, N. I., Doering, L., Berg, J., & Henneman, E. (2006). Communication boards in critical care: Patients' view. *Applied Nursing Research*, 19, 182–190.
- Polkinghorne, D. E. (1998). *Narrative knowing and the human sciences*. Albany, NY, US: State University of New York Press.
- Rodriguez, C. S., & Blischak, D. M. (2010). Communication needs of nonspeaking hospitalized postoperative patients with head and neck cancer. *Applied Nursing Research*, 23, 110–115.
- Riessman, C. K. (Ed.). (1993). *Narrative Analysis*. Newbury Park, CA: Sage Publications.
- Thorson, M. J., & Halloran, E. J. (2007). Henderson's conceptualization of nursing. In J. J. Fitzpatrick & A. L. Whall (Eds.), *Conceptual models of nursing* (pp. 68–82). New Jersey: Pearson Prentice Hall.
- Taylor, S., & Bogdan, R. (1998). *Introduction to qualitative research: A guidebook and resource* (3rd ed.). New York: Wiley.