

*Communication during hospitalisation:
Adults with developmental disability
navigate the path to better healthcare*

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*“Communication is
everything, I think.”*

(Parent of child who uses AAC, Marshall & Goldbart, 2007)

*“The essential aspect of nursing is
communication, because all else*

*“Nurses spend less time on
that will allow them to communicate
with all of their patients whether or
not they can speak.”*

(Finke, Light, & Kitko, 2008)

Communication in hospital

People with developmental disability enter hospital more frequently and with significantly longer stays than people without disability.

Murphy et al., 2006, Young et al., 2007

Many people with lifelong disability have complex communication needs

~CP, 30%; Access Economics report, 2008



Issues

**Adverse events,
problems with discharge
planning in pts with
communication
disability**

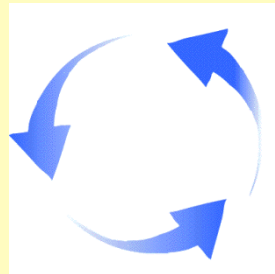
(Bartlett et al., 2008; Efraimsson
et al., 2004,2006)

**Reliance on family
carers for care in
hospital**

(Hemsley & Balandin, 2004; Hemsley,
Balandin, & Togher, 2007,
2008a,b,c,d)

**Health inequalities,
discrimination, access
difficulties, communication
problems, lack of
knowledge**

Beange et al., 1995; Lennox et al.,; Mencap n.d.;
Iacono & Davis, 2003; Cooper, Melville, &
Morrison, 2004; □Gibbs, Brown & Muri, 2008;
etc etc - many studies)



**Need for unaided and aided
AAC skills for health care
communication in hospital**
Finke et al., 2008 (lit review, 12 studies)

ID and hospital care

Backer, Chapman, & Mitchell, 2009

Journal of Applied Research in Intellectual Disabilities 2009, 22, 514–525

- Reviewed 13 studies between 1990-2008 and concluded that:
- “It would be useful to have more research to explore the experiences of people with intellectual disabilities, carers, and hospital staff.”

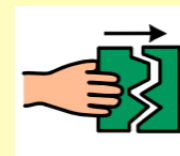
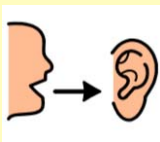
This study



- Is part of a larger NHMRC study
- 4 year NHMRC Postdoctoral fellowship at the University of QLD “Communication during hospitalisation: the path to better health care.”
- Phase One: Interviews with 15 people with disability, 15 paid carers, 15 hospital nurses
- Phase Two: Observations in hospital, of 30 adults over 2 year period.

Aims

- Identify barriers and strategies to effective communication in hospital
- Understand the experience of people with developmental disability and communication disability in hospital
- Identify policy and practice areas to improve hospital health care
- Identify aspects of communication that will be important for observations in the next phase of the larger study



Method


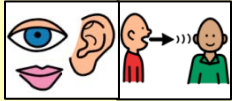
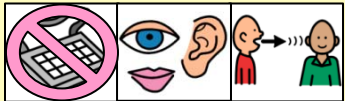



- **Narrative Inquiry**
- **Qualitative analysis of 15 in-depth interviews**
- **Verifying analysis with participants**
- **Discussion of findings among the research team**

Participants

- 15 adults - 6 males, 9 females
- aged from 32-64
- 1 with ID; 14 with Cerebral Palsy
- All with complex communication needs
- Independent living in the community: 3
- Supported accommodation (1): 4
- Supported accommodation (2-4): 8

Interview protocol

- Topic guide: based on literature review and expert reference group
- Eliciting stories of experiences (tell me about a situation when ...)
- Roles, experiences, strategies, barriers, perceptions, about the communication between the patient, nurse, and paid carer/family carer

Method	<i>n</i>
Speech only 	3
Speech + Paid Carer 	4 8
SGD + Speech + Paid Carer 	2
SGD + Board 	4 3
SGD 	1
Mini-laptop 	1 PWD14

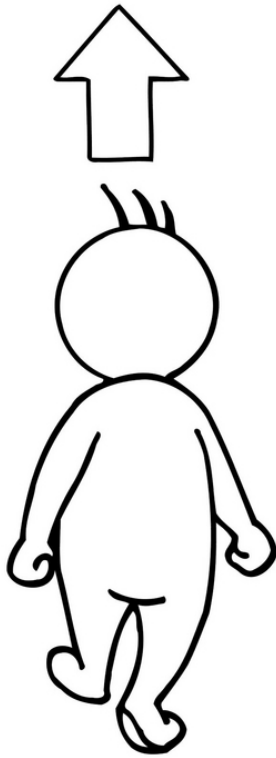
*PWD14: “One nurse took the computer off me, I was sick throwing up and I knew I needed a glass of milk and I tried to ask for it and **she took the computer n said I don’t have time for you right now.** She put it on the side table but way out of reach and I was incapacitated. I’m yet to make a formal complaint.”*

Common Issues arising

- Being alone, ignored, left out
- Sense of isolation and loneliness
- Lack of opportunity and success in communication
- Emotional reliance upon the carer / carer returning to ward
- Carer taking strong advocacy (almost parental) role

QuickTime™ and a
decompressor
are needed to see this picture.

Interactions?



- Report staff walking away / negative attitudes of staff
- Negative perception that they are viewed as having ID because they cannot speak
- Sense of disempowerment (talking over the patient, not included in decisions)

Need to highlight own intelligence / ability to communicate in order to have better care



Emotional response

PWD11: The staff didn't really talk to me at all ... they looked at my carer. It felt awful. I wondered what they were saying. I would have asked how my operation went. In the end my carer found out for me. My carer gets frustrated, and angry, that they won't even look at me. But I get very depressed. I give up trying. I go quiet."

Like other patients in hospital:

*“I didn’t get a chance to ask them anything,
I wanted to, but **they didn’t ask me**, I
didn’t really feel that I could just talk to
them, you know, it’s not embarrassing -
‘til I got to know them,
I felt a bit shy.”*

PWD3

*“If they don’t talk to you,
how else can you show
that you’re a human?”*

PWD11



They need to know I'm here, and *can* understand,
So I take my alphabet board,
I can spell, takes a while, a few letters,
It's another way to say 'yes' and 'no',
It the nurse comes over, looks at me, talks,
I point, and look over, and she'll get it.
Once they see it, they know I can think.



(PWD6, verified poetic re-storying)

- High tech AAC meets barriers (individual and environment - attitudes)
- Lack of successful use led to frustration, withdrawal, depression, anger
- High tech AAC [if used successfully] replaced need for written information
- Written information not used well or easily

Communication needs

- **Basic needs communication (needs, wants, instructions, directives, requests)**
- **Social closeness (reassurance, support, connecting)**
- **Information about disability support needs**
- **Recognising/thanking staff**

*My carer wasn't there all the time,
Sometimes the nurses got my board for me.*

*I think it saved them some time.
Like, when they asked how much pain I was in.
Or when I could not go to the toilet, I can tell
them.*

*When I am getting better, I ask 'when I can go
home?'*

Sometimes you get a good nurse, but you can get a rotten one. A good one will stop and make an effort.

But everybody sees the wheelchair, and they think you've got intellectual disability. So they talk to the carer or my sister. My sister says 'don't talk to me, don't tell me, it's her problem not mine.'

*The nurses don't have any idea about cerebral palsy. Because **they think you've got nothing upstairs.***

Not all horror stories ...

- 1 participant was 'matter of fact' about his experiences:

When I am sick and uncomfortable,

I go to hospital to get better.

I leave my talker at home,

I can say no, and I blink my eyes for yes,

that's the main thing, it goes quite well for me.

My sister comes in, to help, to tell them things.

and she talks for me.

Problems relating to positioning



- Lying in bed (on back)
- Not able to tell staff how to position
- Staff not gleaning this from written information
- Feeling ‘unsafe’ with position
- Lack of suitable equipment (e.g., shower chairs with lap straps)

“feel unsafe”

PWD5



“couldn’t turn me”

PWD1

“head got stuck in the rails”

PWD4

*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.*

PWD4

Encapsulating the positive ...

- Common story: ‘one good nurse’ who encapsulated the ‘good’ strategies for communication (15 pts)
 - Coming in close
 - Figuring out a yes/no
 - Perseverance
 - Taking the time
 - Trying, making an effort
 - Using AAC or whatever mode Pt uses



Evidence based 'good nurse' practices

Finke, Light, & Kitco, 2008

- Determine mode of communication (7)
- Pause, allow time for Pt to initiate (8)
- Confirm (4)
- Use AAC (5)

The 'one good nurse' good communication practices

- Policy to make 'good practice' 'common practice'
- Policy to influence communication *styles*
- Policy on communication and social closeness and not only basic needs
- Train communication strategies to 'get over barrier' of no speech
- Provide generic AAC systems on hospital wards in the event of no speech + no AAC system
- Involve speech pathologist in & out of hospital

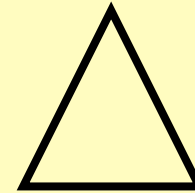
Implications: AAC

- Essential to take own AAC to hospital
- Barrier in hospital higher for high tech AAC
- All could potentially benefit from a communication board
- Staff need to promote the person's use of AAC and ability to communicate
- Staff need to promote the inclusion of people with disability in conversation and decisions in hospital
- Need to condense info to 'fit' that needed by hospital

Implications: Policy on interactions

Support use of AAC
in hospital for
communication and
interaction

Valuing people



Advocacy

Self-advocacy

Information
exchange: form of
information to fit
needs of hospital

Training & Disability
Awareness /
Attitudes

Other Implications

- Differences in report according to functional abilities: how to address diverse needs
 - Possibility of lower function, lower expectations - more satisfied? More passive, learned helplessness, or expect less?
 - Higher function, want to know more, expect more, problem with the 'status quo' of being left out of discussions or talked over

Future research

- Does successful use of low-tech AAC boost positive nurse perceptions?
- How does this relate to the interactions of nurses with patients?
- Need to observe interactions of people with ID who are unable to report on their experiences

Conclusion

- Supports findings of previous research
- Provides further imperative for people to take their communication systems with them to hospital
- Raises issue of perception of stigma of ID associated with being unable to speak / also that perceptions of intellect might influence care received
- Results will contribute to development of an observation protocol in hospital, for the next phase of the study (2010-2011).

Growing awareness ...

Communication Access Within Healthcare Environments

- www.patientprovidercommunication.org
- Information on clinical and research outcomes
- Free low-tech AAC systems for use in healthcare interactions
- US Justice Commission's position paper on health care communication

Next steps in the NHMRC project:

- Dyadic and triadic interactions with a person with communication disability and lifelong disability on the ward
- Comparing and contrasting the views of these participants with those of the nurses, paid carers, and family carers.
- Identifying features to observe within interactions on the ward
- Observing 30 adults entering hospital over the next 2 years using the observational protocol and qualitative field notes and audio-recordings of interactions.

Next steps in new projects

- 2 honours projects: focus groups investigating the same issues for parents of children with cerebral palsy in hospital and AAC professionals supporting children with CP
- 1 UQ New Staff Grant investigating hospital communication for children who use AAC
- 1 UQ early career research grant for additional study of allied health staff and nursing staff on these issues for children