Chapter 4

Describing participants in research on augmentative and alternative communication

Julie Marshall, Lindsay Pennington and Juliet Goldbart

Background

Although the number of people who use augmentative and alternative communication is relatively small and research in this area attracts limited funding, the volume of augmentative and alternative communication research has grown considerably over the last two decades. Current research is now testing the efficacy of augmentative and alternative communication interventions that focus on many diverse aspects of language and communication. This research involves people who use augmentative and alternative communication and they may vary widely, for example in age, (dis)ability, education, family and home circumstances and communication needs.

It is hoped that as the body of evidence on augmentative and alternative communication interventions grows, it may be possible to examine if interventions have worked for individuals who share characteristics, then to test these interventions further with groups of people, and eventually to map interventions to those who share similar features (Pennington, Goldbart and Marshall, 2004; Sevcik, Romski and Adamson, 1999). However, recent narrative and systematic reviews of augmentative and alternative communication research have highlighted the lack of detailed description of study participants (e.g., Bedrosian 2003; Granlund and Olsson, 1999; Pennington et al., 2004; Sevcik et al., 1999). Lack of detail in the description of participants in research prevents researchers and practitioners alike from replicating research, considering the effect of confounding variables on the outcomes described, and making decisions about the appropriateness of the intervention for other clients.

Development of a descriptive framework of research participants and environments would standardise the participant data reported in augmentative and alternative communication studies and hence:

- Increase generalisability and transferability of research findings
- Help identify whether clinical subgroups exist
- Help in determining if unconsidered, and potentially confounding, variables may be affecting outcomes
- Assist practitioners in comparing research participants to their clients, thus facilitating the implementation of evidence based practice

Aims of the seminar

The seminar was a collaborative enterprise and owes a great deal to the Chair, Katie Price, and to the participants: Erna Alant, Shushi Dreyfuss, Orit Hetzroni, Toby Hewson, Hilary Johnson, Jennifer Kent-Walsh, Gunilla Thunberg and Ollie Wendt. Its aim was to begin to develop a framework to guide descriptions of participants and environments in published augmentative and alternative communication research. The framework was to address three main components:

- The people who use augmentative and alternative communication
- The communication partners of people who use augmentative and alternative communication
- The environments in which the augmentative and alternative communication research is being conducted

The seminar was intended to be the first phase in an informal consensus approach which would draw on both *Delphi* and *Nominal Group Techniques* (Jones and Hunter, 1999), whereby a framework would be presented for discussion to the self-selected panel of reserachers who were attending the present seminar. The framework was added to and amended over the course of the two day seminar and presented briefly to a wider group of researchers attending the other seminars in the Research Symposium.

The next phase of the consensus procedure will involve the development of the framework in accordance with recommendations from the initial panel. This refined version will be circulated to the original panel and to additional identified experts for feedback, during 2005. The final version will be submitted to a key journal within the field of augmentative and alternative communication for peer review and hence, if accepted, disseminated to the full journal readership.

Considerable work was carried out during the seminar, and this paper reports the initial development of the framework that took place prior to and during the seminar. There was an agreement from participants that they would continue to be involved in the framework's development.

The initial framework

In the seminar the need for thorough but concise descriptions of research participants and their communication environments was discussed. A rationale for the framework was presented (see background above), together with some of the ethical, practical and financial implications of researchers adopting such an approach. For example, although the collection of more detailed research data may be welcomed, the costs needed to be balanced against the benefits. For example, costs could be measured in time for researchers, time and effort for research participants and their partners and the use of assessment materials. These additional costs may affect recruitment to research projects and increase the funding required, thus potentially adversely affecting the volume and quality of successful research on augmentative and alternative communication. Consideration should be given to whether participants' privacy may be infringed by the collection of

additional data and, if frontline practitioners were involved, whether the time required for additional data collection could impact on the amount of time available for intervention. It is also important to consider that the collection of extra data may require the services of other professionals, again adversely impacting on scarce resources.

It was decided that the detailed data required by the framework would only be collected on those people who were included in any study, not those who are excluded during the recruitment process. Similarly, data would only be collected on the participants' main environments, or those in which the intervention took place. Cultural and linguistic variables and their effects on the definition and measurement of a number of participant factors such as cognition, attention, language, communication contexts, usual environments, partners and modes of communication were raised. Similarly culture may affect partner and environmental factors (e.g., partner behaviour, location of research and uptake). Conclusions were not drawn about the impact of these factors but participants' and presenters' awareness of potential impact of such factors was increased.

The intention of the presenters is that the framework would be as objective as possible. This implies that categorical descriptors frequently found in published research, such as "mild, moderate or severe hearing loss" or "learning difficulties" would be based on explicit criteria and that the raw data would be available, for example in appendices or on research websites.

Development of the framework

The first step in developing the framework was the collation of data on participant, partner and environment information provided in recently published research. To this end the presenters searched electronic databases and hand-searched the journal *Augmentative and Alternative Communica-tion* for research reports on studies which met the following criteria:

- Papers reporting on augmentative and alternative communication intervention
- Published between January 1st 1990 and December 31st 2004
- Included people of all ages, with any type of disability, using any type of augmentative and alternative communication
- Qualitative and/or quantitative studies
- Published in journals and books, but not theses
- Full report available in English language

Studies were excluded if they were concerned with: signing by deaf individuals; literacy-only interventions; drawing in people with aphasia; longitudinal, observational studies that did not include intervention, positioning; attitudes towards augmentative and alternative communication use(rs); or voice recognition.

The above search criteria identified 300 papers which were checked for suitability by reading the abstracts. A sample of 75 was selected randomly for the initial development of the framework. The Method section of

Table 4-1: Variables to include when describing people who use augmentative and alternative communication

Variable/ characteristic	Comments	Rating	Percent of studies published 1980-2004 that include data on variable (n= 52)
Selection criteria for participants	Q: What about in single case design and case studies? D: Keep for all studies to demonstrate why participants are included. Demonstrates researcher reflexivity.	1	42.3
Biographical and demographic information			
Age of participants	No comments	1	94.2
Gender of participants	No comments	1	94.2
Participants' ethnic background	Q: How is it defined, for example country of origin or languages spoken? D: Languages spoken at home is easiest and is a non-politically contentious term in some settings. Needs contextualising information. Researcher dependent data that are relevant to the country.	2	13.5
Socio-economic status (SES) of participants/families	Usually defined in terms of occupation, income or qualification. Important to structure data on SES to context of study and to make it explicit.	2	9.6
Educational experience of participants *(for adults highest level achieved; for children current level)* and educational *history*	Use highest level achieved. Descriptive and explicit data may be most manageable. Grade level may be more useful rather than 'educational experience'. Add literacy level as sub-category.	1	44.2
us intervention	Still needs to decide how to define and describe.	1	@
Languages used			
Health and physical status			
Overall health			9.6
Medical diagnosis	Add subcategory of mental health.		86.1
Time post onset (acquired and progressive communication disorders only)			@
Epilepsy	Add subcategory of mental health.		3.8
Vision	Type of visual impairment should be included where relevant, for example hemianopia and use of peripheral and central vision.		38.5
Hearing	Unclear how useful some data are, for example hearing loss versus functional hearing. State if measurement is not possible.		32.7
Gross motor function	#		59.6
Upper limb function	#		42.3
Medication	#		3.8
Pain	#		0
Cognition			
Intellectual functioning	#		59.6
Cause and effect	#		23.1
Classification skills	#		@

Attention	#		7.7
Working memory	#		3.8
Semantic memory	#		1.9
Play	#		@
Symbolic functioning	#		@
Behaviour			9.6
Communication	Note that an alternative model was suggested that comprises three planes: expressive, lexico-grammatic and semantics		
Key words related to communication diagnosis and *status*	*Key words like 'primary progressive aphasia', 'global aphasia', 'specific language impairment' or a descriptive statement.*	1	39.2
Language comprehension	Receptive versus expressive differences. Is it better to separate syntax and morphology? *Recommend some standardised tests to be used. If informal measures used, must be described. Recommend providing a language age-level as well as standard score. Specify any adaptations to formal assessments used.*	1	61.5
Expressive language	Expressive difficulties. Is it better to separate syntax and morphology?	1	61.5
Preverbal skills (where applicable)	No comments	3	
Motor speech skills	No comments	3	36.5
Phonology	No comments	3	11.5
Intelligibility or comprehensibility	Listener dependent, need to comment on partner. For example familiarity with speaker, experience of impaired communication, intelligibility of mode in question, comprehensibility of total communication attempt, whether taking contextual cues into account.	1	@
Receptive vocabulary and semantics	No comments	1	42.0
Expressive vocabulary and semantics	No comments	1	42.0
Pragmatics	No comments	1	46.2
Voice	No comments	3	0
Fluency	No comments	3	0
Use of augmentative and alternative communication system			
Modes of communication (Include their availability)	No comments	1	90.4
Communication aids and equipment	No comments	1	82.7
Input or access methods	No comments	1	59.6
Positioning and seating	Include mounting (where applicable). Need to be able to inter-relate the sections within this factor.	1	@
* Instruction or *history of using augmentative and alternative communication*	No comments	1	@

Key: Q: question raised in discussion regarding the variable
D: decision reached by the seminar participants on data to be collected
to be agreed later following consultation of International Classification of Functions
@ no data, as variable suggested during seminar

Table 4-2: Variables to include when describing conversation partners of people who use augmentative and alternative communication

Variable/ characteristic	Comments	Rating	Percent of studies published 1980-2004 that include data on variable (n=16)
Communication partners	These data are only needed if the study is on partner intervention.		
Number of partners or participants		1	100
Age		1	60.0
Gender		1	60.0
Ethnic background and languages used by partners		1	6.7
Relationship to users		1	93.3
Educational level (relevant experience of participants	Add sub- category of literacy		40.0
Prior exposure to or experience with augmentative and alternative communication		1	40.0
Prior training about augmentative and alternative communication		1	@

Key: @ no data, variable suggested during seminar

Table 4-3: Variables to include when describing communication environments

Variable/ characteristic	Comments	Rating	Percent of studies published 1980-2004 that include data on variable (N=??)
Environment factors	Dependent on the nature of the study. Cross reference to ICF, particularly ICF level This section provoked much discussion, with little consensus on what was needed.		
Location of study (country)		1	25.0
Environment of study, for example home, school or clinic		1	86.5
Setting where the person spends the majority of his or her days, for example, educational, work or home		1	82.4
Physical environment		1	@
Residence, *social* and communicative context of participants. Exposure to bilingual co-workers. *Personal assistance*		1	36.5
Exposure to languages and other communication modes		1	??

Key: @ no data, variable suggested during seminar

General issues

In the course of the seminar, a number of more general issues were raised. There are summarised below.

1. The *International Classification of Functioning, Disability and Health* (ICF, World Health Organization, 2001) could be used to structure data on a number of variables about people who use augmentative and alternative communication, particularly in the areas of health and physical status, cognition and behaviour. There was also a need to consider activity, participation and environmental factors.

2. The variables given in the tables should be considered to be a minimum set and are not intended to restrict other data that authors may wish to provide.

3. There should be an encouragement for authors to use a standard format for key variables, such as speech, language or communication diagnosis, and augmentative and alternative communication intervention. However, the specific requirements of different journals in relation to terminology would have to be taken into account.

4. Further discussion is needed to reach consensus on how much and what information is needed about users of augmentative and alternative communication if the participants of the intervention study are communication partners, that is, if the intervention is indirect rather than direct.

5. The possibility of a centrally available, web-based, database of research information was discussed. This would reduce the need to include so much detailed data in published papers, whilst still making the data available, especially to those wishing to carry out meta-analyses.

6. Issues of privacy and restricted access by researchers to participants' medical or educational history etc., in some countries, needs to taken into account.

7. Researchers need to monitor their use of descriptors which provide implicit information to some readers but which are not meaningful to others. This is particularly important in the context of an international readership of research reports. Examples include school grading measures and data on socio-economic status.

Summary, conclusions and the way forward

The participants in the seminar unanimously supported the principle of the development of such a framework. The involvement of a geographically, politically and experientially diverse group of participants ensured that a number of perspectives were represented. At the end of the seminar a con-

sensus was reached on the inclusion of a number of variables. The subsequent phase of the consensus procedure is in progress.

To facilitate this, it was agreed that the presenters would develop the framework further, particularly making reference to the ICF (World Health Organization, 2001). The presenters also agreed to continue to review the remaining 225 of the 300 published papers identified, to provide more comprehensive information on what data researchers have previously provided. It was agreed that the findings of this review could also provide useful information for researchers and funding bodies, on who is currently being researched.

At the plenary presentation at the end of the Research Symposium there was agreement to suggest incorporating a final version of the framework into the *Augmentative and Alternative Communication* journal's "Guidelines for Authors". However it was also agreed that the framework should be dynamic and would be likely to need periodic updating.

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