

COMMUNICATION INCLUSIVE RESEARCH: MIXING SENSORY AND VISUAL ETHNOGRAPHY WITH AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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ABSTRACT

Advancing the field of disability can be difficult when the insights of many are beyond the science of rudimentary data collection. People with complex communication access needs, including many citizens with intellectual disability, are frequently overlooked as participants in research investigations. This article provides an overview of the methodological adaptations made to a study titled *The meaning of home for people with complex communication (access) needs*. The study combined augmentative and alternative communication with sensory and visual ethnography to create new methods that were tested and eventually implemented and evaluated within a formal study cohort that included people with intellectual disability.

METHODOLOGY

The study used augmentative and alternative communication (AAC) as a starting point from which a methodology, and methods capable of working in concert with diverse forms of AAC, were chosen. From here a methodology was chosen. As an emerging field of research practice, sensory ethnography offers advantages over traditional forms of ethnography such as interviewing and observation (Pink, 2015) and by transcending written and spoken exchange, it complements AAC.

Sensory ethnography entails the embodied experience of the researcher in being with a participant (Pink 2015) that is, it highlights the sensory aspects that commonly go unnoticed (Valtonen, Markuksela and Moisander 2010). In this context, the researcher is invited to acknowledge and learn from their own sensory experience in sharing, as closely as possible, the experiences of the participant.

METHODS

Other alternative research methods, visual ethnography, in particular, was combined with sensory ethnography and AAC to create a set of adapted methods explored in two phases. Phase one focussed on the question - *can AAC and visual research methods be combined to create a set of methods offering practical utility with participants with CCAN?* Phase two sought responses to the question - *can these methods be useful with a diverse range of people with CCAN, including those with intellectual impairment?*

Using a combination of elements drawn from literature (sensory and visual ethnography, and the psychology of graphic images, and AAC) the following methods were created and tested (phase 1).

(1) Theory Generated Photo Elicitation Developing this method began with selecting images (simple scenes, photographs of people, faces and hands); that resulted in the development of photographic-studio created hand images in different postures using simple props. These were trialed, reduced to a final set of images and then used in *The meaning of home for people with complex communication (access) needs* study.

(2) Participant Generated Sensory Selection. Using the participants choice of communication to convey their experience of 'home' through smell, sounds, images.

Underlying this method was the question *If you could show/explain what it feels like to live in your home by imagining or showing/pointing out a picture (or referring to a smell, or a sound/song), what would it be?* Supports provided to participants to assist in answering this question were, for example, using an accessible camera (with a wheelchair attachment) or a word bank of sounds and smells. Participants also had the opportunity to reflect and respond to this question over time.

(3) Adapted Image Selection. Using a Talking Mats® structure to select and organise symbols relating to 'home'. A Talking Mat was adapted to reflect a scaling-range with icons aligning to underlying research theory. These helped participants indicate what features of 'home' mattered most to least to them across themes. The conversation began with participants asked to select five of the most important qualities of a 'good home' for them.

Phase 2 involved implementing the methods in a formal study. With ethics approval granted from the Flinders University Human Research Ethics Committee, ten adults with complex communication access needs (six male including three with intellectual disability, and four female) were recruited for the study. Two of the three men with intellectual disability were living in the same group home, the third living between a group home and with family.

PARTICIPANT FEEDBACK

Participants, as with the test groups, were asked to provide feedback on the methods using a scale of good/okay/not good/do not know. The responses are below (Table 1).

Table 1.

Evaluation of the Study Methods

Study Group	Method	Good (thumb up)	Okay	Not Good (thumb down)	Don't know	NA
CCAN (N=10)	TGSS	2 (20%)	2 (20%)	2 (20%)	2 (20%)	2 (20%)
	TGPE	8 (80%)	0	0	1 (10%)	1 (10%)
	AIS	6 (60%)	3 (30%)	0	0	1 (10%)

Notes: TGSS = Theory Generated Sensory Selection; TGPE = Theory Generated Photo Elicitation; AIS = Adapted Image Selection

The Participant Generated Sensory Selection (TGSS) received an overall poor rating from the study group, with only 40%, in combination, indicating that it was either good or okay. The three participants with intellectual impairment did not answer the question; two appeared confused by the question and chose not to answer it. The other participant was not presented with this question due to the severity of disability.

In contrast, the two participants who rated the method as 'good' were university graduates with positive experiences of home; they appeared to enjoy the opportunity to find a sensory metaphor to describe their home. One participant described 'home' as having all the sensory qualities of a 'warm open fire'; another found a photograph from the internet, which connected a special place overseas to 'home'.

The Adapted Image Selection method received positive results with a 60% ranking of 'good', 30% 'okay' and 10% not applicable. The participants were asked to select five of the most important qualities of a 'good home' for them. The average number of cards selected was 5.5 with the most frequently selected card being 'Support Workers' chosen by six of the nine participants (including the two participants with intellectual disability who answered this question).

The Theory Generated Photo Elicitation (TGPE) founded on hand images, was very well received, it provided the greatest amount of information related to the study question. It received the highest scaling of participant feedback – 80% indicating it was good, the remaining 20% combining as 'Don't know' and 'NA'. All of the participants answered this question, including a participant described (in his group home file) as having severe cerebral palsy and profound cognitive impairment. He focussed on one of the hand images (it showed hands holding a floral mug, one wearing a woollen glove) and uttered the word 'Mum' and then 'go home' (a place that had ceased to exist after his Mother died several years earlier).

Considerable information directly related to answering the key research question was obtained from this method, appearing to enable participants to arrive at a deeper level of meaning relatively quickly and with less effort required. Essentially it provided a 'short-cut' to deeply significant meanings of

home. Some of these reflected overall positive meanings of home, whereas several did not. Figure 1 shows the selections made from one of the participants with intellectual disability living in a group home. The selections going clockwise from left indicate 1. Things being done to me – forced to do things against my will. 2. Standing up for myself. 3. My good support worker (him). 4. Stuck.



Figure 1. Participant selections TGPE

METHOD 4. SENSORY ETHNOGRAPHY

There was a fourth method used in the study; evident in the experiences shared with participants and information gathered through the methods. There were also other, unexpected, data collected. The notes taken after when setting up for an interview in a group home provide an example.

I see myself looking at the video and I remember my thoughts at the time: 'The video will never be able to capture what I'm experiencing right now' – smells, disinfectant cleaning agents, an uncomfortable stool that had to be pulled from somewhere so I could sit because visitors don't appear to come here.

Sensory ethnography, as both methodology and method in this study, validated and welcomed a parallel world of 'knowing' through the senses. Through sensory-aware emplacement, it invited the researcher more deeply into an experience of 'places' and the possible meaning those places might have for participant(s) who live there. The extent to which the sensory experience of people with different intellectual, and indeed, other background differences/capacities can adequately be compared, and reflected is unknown. It was; however, evident through the alignment of the participants' responses, and the researchers embodied experience - this 'group home' was not good.

CONCLUSION

The results of the study (phase 1 and 2) provided affirmative answers to the questions - *can AAC and visual research methods be combined to create a set of methods offering effective utility with participants with CCAN? Furthermore, can these methods be used with a diverse range of people with CCAN, including those with intellectual impairment?* It also provided an answer to the challenge of finding a methodology capable of transcending the confines of traditional communication; one capable of building upon knowledge acquired through means other than speaking and writing. Although there is much to be discovered with problems to be solved, research outcomes offer a positive step forward.

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FURTHER READING

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