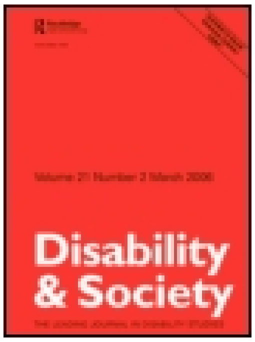

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Every voice counts: exploring communication accessible research methods

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ABSTRACT

Despite a proliferation of qualitative research methods and the advancement of augmentative and alternative communication (AAC), people with Complex Communication (Access) Needs (CCAN) are often absent from sociological study cohorts. Proxy interviewing is common but it leaves viewpoints to be shaped by others. Herein the purpose of the study was to develop and test new methods of data collection that would improve access to research participation for people with CCAN. This article reports on the development, implementation and evaluation findings of four data collection techniques. These methods, 'theory generated photo elicitation' 'adapted image selection' 'participant sensory selection' and 'sensory ethnography' were tested and implemented in a study of people with CCAN. The study contributes to the knowledge of communication accessible research participation with applicable to disability-based qualitative research across multiple fields.

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KEYWORDS
complex communication needs; communication access; augmentative and alternative communication; qualitatitve research methods; ethnography

Points of interest

- Due to a range of barriers, such as gaps in awareness and research guidelines, people with communication disability are grossly underrepresented in qualitative study cohorts.
- In this investigation, normative notions of communication competence were challenged. This included the term *complex communication needs* often used to describe someone who is without the use of speech. However, based on the evidence of communication access as being just as significant as other forms such as ramps and curb cuts, the phrase complex communication 'access' needs (CCAN) was used to propel the study in a social model direction.

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- Drawing upon experimental research, the study explored, adapted and tested a range of methods. These were combined with various tools and devices used to support communication and were aligned with investigative themes.
- Photographs of hands in various postures, reflective of quality of life themes were particularly useful in discovering meaning from participants, as was the adaptation of Talking Mats© for research purposes.
- All participants, including a person with profound intellectual disability, participated in this study, offering rich insights into 'what works' when conducting interviews with people with CCAN.

Introduction: Leaving voices out

The term Complex Communication Needs is the dominant term used by the field of augmentative and alternative communication (AAC) with the focus being on therapeutic intervention as viewed from the perspective of 'client needs'. Clinical in nature, this definition is deficit-oriented and situates the problem of communication with the individual with impairment, denying the broader appreciation of communication from a non-therapeutic position. Encompassing a range of communication tools and devices such as Picture Communication Symbols (PCS) and computer eye-gaze tracking, the field of AAC has grown extensively in recent decades (Kent-Walsh and Binger 2018; Light and McNaughton 2015; Williams, Krezman, and McNaughton 2008) yet the status and participation of people with severe communication disability has not (Dee-Price 2019). In light of this, the current study (imbedded within a broader investigation of the meaning of home for people with complex communication needs, utilises the social model of disability in locating needed changes in the research environment rather than a focus on building the communicative competence of the individual. With respect for this theoretical position, the concept of 'access' is highlighted with the term (CCAN) Complex Communication 'Access' Needs hereafter used in this paper.

The first-person insights of people with complex communication needs (CCAN) are often not collected within research studies and therefore not captured in research findings (Stafford 2017; Ison 2009; Hodge 2007; Lloyd, Gatherer and Kalsy 2006). Multiple reasons for this exclusion exist. Stafford (2017) suggests that societal assumptions about body movement, speech and social interaction as fitting to an accepted 'norm' leads to perceptions of the legitimacy of research participants. Those who are outside these norms, such as people with CCANs, risk being viewed as unreliable research participants. Further barriers are often erected by human research ethics committees that can adopt a protective stance towards 'vulnerable' participants based upon generalised perceptions of the capacity of people with significant communication barriers to participate (Iacono 2009). Researchers wanting to study the views of people with CCANs are further hindered by a lack of ethical standards and methodological guidance (Cascella and Aliotta 2014) The extraordinary exertion and fatigue on the part of the person, and its relation to the amount time required to interviews is indicated. (Boggis 2011; Castrodale and Crooks 2010; Teachman and Gibson 2018) as manifested in resource restrictions, particularly in relation to the time it might take to interview someone with CCAN. Castrodale and Crooks (2010), in reporting on a study of researchers in the field of disability, highlight institutional pressures as a deterrent to engaging in certain kinds of disability research. "When one is working with deadlines and tight budgets, it is not always possible to use emancipatory or even participatory approaches. One must generally be pragmatic" (p. 96) with pragmatism often resulting in access limitations. Where people with CCAN are involved in research it is common for researchers to attempt to capture their views via proxy interviews (Ison 2009). Such an approach is problematic, as information from the proxy may not necessarily concur with the view of the individual with disability (Ison 2009; Lloyd, Gatherer and Kalsy 2006).

The voices of people with CCAN are not only excluded from empirical research but are relatively silent within the context of political activism. Where inroads to rights have emerged from the political activism of disabled people generally (Shakespeare 2006), people with CCAN appear to have been left behind. (Dee-Price 2019). Thill (2009) makes the point that 'voice' in its traditional form is an important tool in the struggle for the recognition of disability. Suggested here is the diminished opportunity for protest that may come with the experience of CCAN. Moreover, Duchan (2006) notes that arguments about access are prominent in the disability field, yet communication access is afforded little attention. As highlighted by Johnson, West, Solarsh and Bloomberg (2010) there are ongoing challenges to placing communication access within political agendas, a sentiment echoed by Levin (2013) who notes that people with communication impairments are largely excluded from disability politics, wherein like other politics, arguments are dominated by people who communicate typically through written or spoken language.

Considering the absence of the 'voices' of people with CCAN from research and political contexts, it is not surprising that little is known about the day-to-day lives and experiences of those with communication impairments (Hodge 2007; Duchan 2006). This lack of knowledge contributes to the serious challenges people with CCAN face in educational, vocational, healthcare and community environments (Light 2015). Such challenges have been found to heighten the risk of people with CCAN risk of becoming victims of crime, suffering abuse, and neglect (Bornman 2007) and experiencing significant barriers to the criminal justice system (Bornman 2017; Bornman et al. 2016).

Existing research approaches

In order for the study to achieve its purpose of developing and testing new methods of data collection that would improve access to research participation for people with CCAN, a search of the literature was conducted across several databases. This search revealed pockets of alternative research methods used with participants with CCAN. Several approaches were identified from the fields of observational and visual ethnography, visual netnography and hypothetigraphy. These approaches offered possible inroads into research in this area.

Observational ethnography with people with CCAN has been explored in the literature by Johnson, Douglas, Bigby and Iacono (2011) and by Cocks (2008). However, these studies were not deemed to provide an example of a satisfactory solution to participation as they were limited to the observation of behaviour which relied upon the interpretation of researchers, rather than an account of the thoughts and ideas of participants.

Visual ethnography can be described as the use of a diverse range of visual media within ethnographic research (Pink 2007). It includes a range of visual approaches such as Photovoice and video ethnography. Video ethnography is a naturalistic method for recording daily activities as they occur in real time and in a person's usual environments. Watson, Wilson and Hagiliassis (2017) made use of video in their study focused on supported decision making for people with CCANs, to assist communication partners to collaboratively acknowledge, interpret and act on a person's expression of preference (Watson, Wilson, and Hagiliassis 2017). Photovoice is described by Lapenta (2011) as the creation of photographs of aspects of community life resulting in the discussion of their meaning with other group members and the researcher is exemplified in Seed's research with people facing significant communication barriers (Seed 2016). As an alternative form of interviewing, *photo elicitation* was influential in the study presented in this paper. As an ethnographic technique, photo elicitation enables the researcher to analyse participant responses, usually provided verbally, to images shown to them during the research process. There are variant forms of photo elicitation not necessarily limited to images that are selected by the researcher. Lapenta (2011) refers to other approaches such as participant-generated image production wherein images are produced or provided by the participant such as Photovoice. This method appears to be flexible and had the capacity to evoke deeper meaning in participants and forms a valuable contribution to co-design, an approach noted by Carroll et al., (2018) as needed in research with people with communication. “I believe photo elicitation mines deeper shafts into a different part of human consciousness than do words-alone interviews” (Harper 2002, p. 22–23). The potential to arrive at a more profound level of meaning, particularly in light of the restriction of conventional speech, captured the interest of this researcher. However, the process of gathering these responses from a diversity of participants with CCAN may not be feasible by this method, alone.

During the investigation of visual-based research methods, the concept of *hypothetigraphy* was described. Massironi (2003) in his book *The Psychology of Graphic Images: Seeing, Drawing, Communicating,* constructs the term *hypothetigraphy* to define the type of pictographic images used in scientific practice, including research. The purpose of these images is to communicate concepts usually described in words. This differs from the use of more abstract symbols utilised to replace a word in AAC or pictures used in photo elicitation. Rather it includes, but is not bounded by, the concept of photo elicitation through its visual description of potentially complex constructs and in a variety of visual formats. Massironi refers to examples that include the function of a vortex (Massironi 2003, fig. 6.20, p. 171) and the concept of time (Massironi 2003, fig. 7.1, p. 179). Hypothetigraphy offers the possibility of helping to guide the viewer to meaning(s) that are specifically linked to choices, such as “home” being connected to “identity” (Hauge 2007, Butler and Robson 2001).

Talking Mats©, an evidence-based tool for helping people with communication difficulties to participate in conversations and communicate effectively, was used in the study. It has been successfully adapted for, and evaluated in qualitative studies of participants with intellectual impairment (Mackay and Murphy 2017; Murphy and Cameron 2008), Huntington’s disease (Hallberg, Mellgren, Hartelius, and Ferm 2011) and dementia (Alm et al. 2007). Presented as a physical mat and an electronic application, Talking Mats© comes with several subject-based sets of image-based vocabulary that can be extended and modified. Despite the effectiveness of Talking Mats© as a research tool, its reliance on pre-set vocabulary symbols impedes generative communication. The problem of reliance on pre-set vocabulary displays was raised by Bornman and Bryen (2013). In discussing this problem, they cite Carlson (1981) noting that people who use AAC “are unable to spontaneously create their own lexicon and must operate with a vocabulary selected by someone else or preselected, not spontaneously chosen by themselves” (p. 140). Hereto lies the problem for research; ensuring the research participant with CCAN has adequate access to personal lexicon adequate for describing information of personal significance.

Netnography is described as “a specific approach to conducting ethnographic research that uses the archival and communications functions of contemporary Internet-based technologies such as mobile phones, tablets, and laptop computers" (Kozinets 2018). Ison (2009) in noting the value of using this method with people facing communication barriers outlines the benefits of email interviews as convenient, time and cost saving, and providing opportunities to gain a longitudinal perspective and to clarify points over time. However, Ison (2009) also notes significant limitations such as barriers for people without access to a computer or an email account.

Anthropologist, Sarah Pink, describes sensory ethnography as a re-thinking of ethnographic methods based on sensory perception guided by understandings of the senses (Pink 2013, 2015). Sensory ethnography offers advantages over traditional forms of ethnography (interviewing and observation) commonly used in sociology. Pink (2013, 2015) refers to anthropologist Regina Bendix who argues 'sensory perception and reception' require methods capable of grasping "the most profound type of knowledge, [which] is not spoken at all and thus inaccessible to ethnographic observation or interview" (Bendix 2000, p. 41).

Sensory ethnography acknowledges the embodiment of experience and the meaning we make of places, others and ourselves through the medium of the body (Sunderland et al. 2012). The role of the sensory ethnographer is to observe and register all sense-related aspects, including the scents, savours, temperatures, and textures involved in a context (Valtonen, Markuksela and Moisander 2010) with perceptions emerging from shared experiences with participants (Pink 2015).

In validating multi-sensory communication and in engaging the ethnographer's sensual awareness into these experiences, this methodology evokes possibilities for the creative involvement of AAC. Whether it be through pointing (using eye gaze or hand pointing) or from controlled use of a communication device or the informal grasp of a hand, sounds and body movements, AAC is also sensory. The sensory ethnographer in this context is propelled to heighten awareness, acknowledge and learn from their own sensory experience in sharing, as closely as possible, the experiences, including the communication experiences of using an AAC device.

Sensory ethnography does not claim to be an objective account of reality. Rather it relies upon the ethnographer's version of their experiences that remain loyal to the reality of the source of the knowledge production (Pink 2015). Because sensory ethnography entails the embodied experience of the researcher in being with a participant (Pink 2015), it requires a new kind of analytic orientation that would bring to the fore the sensory aspects that commonly go unnoticed (Valtonen, Markuksela and Moisander 2010). "The senses not only provide people with a means to experience the world but also link people to place, most notably through emotions" (Hemer and Dundon 2016, p. 10). This approach also supports multiple methods of recording information including video, digital media, art works, photography as well as traditional written recording (Pink 2013).

Research questions and method

The research reported in this paper consisted of two phases. In the first phase, the researchers used an action research approach to develop data collection methods designed to maximise “first person” (as opposed to proxy) research participation for people with CCAN. In this phase data collection tools were developed based on what was learned from the literature and then piloted with people with ($n = 1$) and without $n = 22$) CCAN. Consistent with an action research approach, as a result of this pilot, these tools were refined. These refined tools were used to support the investigation of the meaning of “home” for people with CCAN in phase 2. Within this context, the efficacy of the data collection tools was qualitatively evaluated.

The research was founded on three key questions:

1. *What are the barriers impeding research with people with CCAN? This was answered in the review of literature as outlined earlier).*
2. *Can AAC and visual research methods be combined to create a set of methods offering effective utility with participants with CCAN?*
3. *Can these methods demonstrate utility with a diverse range of people with CCAN including those with intellectual impairment?*

Both phases of the study were approved by the Flinders University Human Research Ethics Committee in 2014.

Phase one: Adapting, testing and refining methods

Phase one was founded on answering question two. *Can AAC and visual research methods be combined to create a set of methods offering effective utility with participants with CCAN?* Using a combination of four elements derived from the existing literature – sensory ethnography, photo elicitation, hypthetigraphy and AAC in a mixed methods approach, three unique methods were developed: (1) Theory Generated Photo Elicitation, (2) Participant Generated Sensory Selection and (3) Adapted Image Selection. Each of the methods were designed to overlap so as to ensure consistency and accountability through the process of triangulation wherein several types of methods are used in a study in order to check the results of one and the same subject (Rothbauer 2008; Patton 2015).

These methods were aligned to core theoretical qualities of ‘home’, as embodied and emplaced (Pink 2009, Sunderland et al. 2012):

- "Home" social, forming the centre of a complex web of social networks of relationships and connection (Hulse, Jacobs, Arthurson and Spinney 2011; Reinders and Van der Land 2008; Shakespeare 2006).
- "Home" as safety, security and protection (Fox 2005)
- "Home" as closely connected to identity (Hauge (2007) and to how individuals define their position in society (Butler and Robson 2001) and experience a sense of control (Annison 2000).

In addition to some core themes of home as embodied, and as a place where social connection, identity, safety/comfort, power in environment can flourish, the list of 10 capabilities articulated by Nussbaum (2006, p. 76–78) as essential to the experience of a "good life" were

1. *Life*. Living a full-length quality life.
2. *Bodily Health*. Having good health.
3. *Bodily Integrity*. Safety from violence, including sexual assault and domestic violence; opportunities for sexual satisfaction and reproduction.
4. *Senses, Imagination, and Thought*. To have adequate education and able to use the senses, to imagine, think, reason, create and to exercise choice and decision making.
5. *Emotions*. Being able to form attachments and express emotions.
6. *Practical Reason*. Being able to reflect on notions of good and to engage in critical reflection about the planning of one's life.
7. *Affiliation*. Being able to enjoy relationships with others that help foster positive self- regard.
8. *Other Species*. Being able to live with concern for and in relation to animals, plants, and the world of nature.
9. *Play*. To enjoy recreational activities.
10. *Control over one's Environment*. Both political (to participate in political choices, freedom of speech) and material (the right to meaningful employment, being able to own property and goods),

Nussbaum's capabilities (2006) provided an opportunity to loosely compare the content of participant responses with the list of qualities required to live a good life. The comparison provided a general guide rather than a tool of measurement because of the subjective nature of the capabilities, and indeed, quality of life. For instance, if participants were consistently reflecting a sense of freedom and control within their home environment but their demographic background did not reveal broader areas of control such as access to employment or study or the ownership of larger items such as furniture, art works etc. then this alignment with the particular capability was considered only partial.

Theory generated photo elicitation (TGPE)

Using a name adapted from Lapenta's (2011) description of a form of photo elicitation (*Theory Generated Image Selection*) combined with the concept of hypothetigraphy, photographs designed to reflect underlying theory were created. In this instance, images would be used to compare participants' selections of photographs, icons and sensory experiences of home aligned with housing theory such as the close relationship between the meaning of home and the shaping of identity, freedom and control, safety, and so forth.

This involved the creation of hypthetigraphical photographs to represent loose variations of these capabilities; symbolically representative of underlying theory and capable of being introduced to the participant for selection in a photo-elicitation format. To do this required images capable of evoking an emotional connection to theoretical themes across a continuum of possible responses.

To identify what images might reflect such theoretical meanings, a Google Image Search was conducted. Seventy-nine (79) Internet themed-search images were found and shown to more than 30 people including a person with a CCAN. Those viewing the images tended to analyse rather than respond to them personally with many of these images not aligning, in any way, with the theories. There were some images (largely simple images of hands in different poses) that received consistent responses relating to the theory. It became evident that images needed to be:

1. Simple, and
2. have the ability to 'talk' to the viewer at a personal level, and
3. be linked to the theory used in the study
4. *but* allow for some diversity of interpretation, and
5. be limited to a few images.

This led to the creation of simple photographs of the researchers' hands in various positions as illustrated in Figure 1.

There is neuro-scientific evidence, however, suggesting that the semantic representations of concepts expressed by meaningful hand postures have similar properties to those of abstract words (Gunter and Bach 2004). These photographs "fisted in power," "nested in companionship," "isolated and stifled," "comforted or imprisoned"; these hands aimed to unlock deeper meaning(s) for participants. Indicating 'yes' or using a point were possible selection methods (indicating up to 5 images) for a word chosen by the participant that best confirmed the meaning they attributed to their selected image. Pilot test participants ($n = 22$ without CCAN) and the pilot participant viewed the display of the 16 study photographs with their feedback leading

Figure 1. Photographs of hands representing concepts. Top left hand holding a business card with the text 'me' (representing identity). Top right hand tied with thin rope (representing entrapment and struggle). Bottom image of stacked hands (representing affiliation with others).

to 13 images selected as sufficient to cover the theoretical meanings being sought for the study.

Participant generated sensory selection (PGSS)

Participant Generated Sensory Selection was developed through a combined influence of photo elicitation, traditional ethnographic questioning and sensory ethnography. It diverges considerably from the described notions of sensory ethnography in that it directly asks sensory questions, essentially turning sensorial experience into a cognitive representation.

Not limited to a visual orientation, the participant is invited to express meaning based upon any one of their senses. The underlying question behind this method being – *If you could sum up what it 'feels like' 'smells like' 'tastes like' 'sounds like' or 'looks like' to live in your home what would that smell(s) sound(s) etc. be?* The purpose of this method was to identify the potential for research participants, particularly those with CCAN, to use sensory expressions in a way that expands 'personal lexicon' to communicate deep levels of meaning in the research setting. To increase the opportunity for participants to find and reveal their answers some additional tools were included in the development and testing of this method. Providing a GoPro camera with readily available wheelchair attachment, head and body operated attachments were made available to participants along with an iPad with music applications and word lists of sound and smell sourced from the Internet.

The group of 22 test participants without CCAN were asked *If you could explain what it feels like to live in your home by imagining or showing/pointing out a picture (or a smell, or a sound/song), what would it be?* There was no time limit placed on the provision of a response and the test participants were invited to answer the question however they wished, such as referring to a picture on the Internet, describing smells, taking a photograph, etc. Several pilot test participants responded by providing visual imagery, such as a shed full of memorabilia or a garden. Four people chose nonvisual responses to answer this question. For example, one participant stated '*baking biscuits, and detergent'* in response to what smells are best associated with your "home.". Seven of the 22 chose not to respond to the question with comments such as *"Too abstract for me"* and *"It'll take me a long while to think of something"*.

Adapted image selection (AIS)

The field of AAC provided potential research formats that did not rely solely on spoken or written language. Talking Mats©, in particular, could readily be adapted as a research tool. Lois Cameron, one of the developers of the Talking Mats© technique, assisted in the informal testing of the Talking Mats© for this study. This process identified the need to extend vocabulary as well as to build more detail into the existing scale used in Talking Mats©. This was achieved by extending the yellow 'thumbs up/down and don't know' options, which currently exist with Talking Mats© so as to provide the options of 'Good', 'Ok', 'Don't know' 'not good' and 'not applicable' (NA).

Several specific vocabulary cards were developed,19 initially and 21 after feedback was provided by the pilot test participants. These reflect the core theoretical themes such as 'identity', and 'social connection/affiliation' as well as more detailed language specific to aspects of home, such as 'house mates'. This involved adjusting or creating new cards for the Talking Mats©, using the templates in the Talking Mats© kit. This method required an adequate selection of options from which the participant could choose.

In responding to the Adapted Image Selection, participants were asked to select approximately five of the most important qualities of 'home' for them. The method was tested by a smaller group of test participants ($n = 10$ without CCAN) and with responses indicating a strong association with the underlying theory. The feedback about the use of this method was positive with 9 out of 10 participants giving it the highest rating 'good.'

Phase 2: Evaluating the efficacy of data collection tools to ascertain the meaning of "home"

Phase two was founded on answering question three. *Can these methods demonstrate utility with a diverse range of people with CCAN including those with intellectual impairment?*

Study participants

Ten adults with CCAN (six male and four female) were recruited with the support of AGOSCI who shared information about the study online. posted information about the study on the AGOSCI website and listserv. The study required participants to be adults with CCAN and able to provide consent.

Ascertaining consent

The consent process was developed specifically for the study and required two forms of demonstrated capacity. The first being directed at the researcher's own capacity to identify the participant's expressions of 'yes' 'no' and 'undecided' (as would need to be confirmed by the participant themselves, and in the presence of a trusted support, if required). The second required an indication from the potential participant that they knew where they lived and could express a basic indication of value; whether home felt basically 'good' 'ok' 'bad' 'don't know'. This was only used with individuals that were known to have significant intellectual impairment or their capacity was otherwise unclear.

Interviews

Four of the study participants primarily used Voice Output Communication Aids (VOCA) devices for communication. Two only used PCS symbols and word vocabulary built into wheelchair lap trays but also in book and key-ring form to display the symbols. One participant used a combination of picture communication symbols and words accessible from a wheelchair tray. Another accessed a computer application on a mini-iPad.

Interviews were conducted in the home of participants. The ‘yes’ ‘no’ and ‘don’t know/not sure’ expression of each participant was established as part of the criteria for obtaining consent. Seven of the 10 participants were accompanied at the interview by a support person of their choosing. All questions were directed to the participant and each support person was requested to maintain a passive role.

Evaluation procedures

There were two forms of evaluation applied to the study. A set of criteria was established for the study with responses recorded by the researcher at the end of each interview session and these recordings were compared across the cohort.

- Participant answers the question (as designed) and the researcher understands the responses provided.
- Selections made by each participant are consistent across each of the methods including the sensory ethnography data gathered by the researcher.
- Participant responses are able to be interpreted by theory (either providing evidence that the qualities described in home theory exist in the home of the participant or evidence that they do not) and, where appropriate, are able to be compared loosely with Nussbaum’s (2006) list of capabilities.

Participant evaluation was presented using the Talking Mats© and a scale of ‘good’ ‘ok’ ‘not good’ ‘don’t know’ and ‘na’ (not applicable) immediately after the interview(s). Both the study and test groups received the evaluation in the same way, with participants informed, prior to commencing the study, of the novel nature of the methods, and that they would be invited (if they wished) to ‘rate the questions’ at the end of the interview. At the conclusion of the study (and pilot test) participants were asked to score the methods used from a selection of – good, okay, not good, don’t know (this was represented along a continuum at the top of the Talking Mats©). Both participants and test participants were asked the same question *Do you feel you were able to adequately express what home means to you by using this method/approach*?’ At the beginning of the interviews and again at the end of the interview, participants were also invited to make suggestions about helpful ways to conduct interviews with people with CCAN.

The Participant Generated Sensory Selection (TGSS) received a poor overall rating from the study group, with only a total of 40%, indicating that it was either good or okay. In contrast, this method received a more favourable response from the pilot test group, with a combined good/okay score of 76%. This method consisted of one question: “Is there an image, sound or smell that comes to mind that could show what it is like to live in your home?" To provide support with answering this question, participants were provided with options, for example, using the Internet, an accessible camera (Go-Pro with the wheelchair attachment) or a word bank of sounds and smells was offered.

The method did not adequately meet the evaluation criteria. Only five of the ten participants appeared comfortable enough to attempt this question with only four providing an actual response. Four chose a visual metaphor to describe the feeling of their home and one chose two songs, however, he did not wish for these to be considered in the study because they were not quite right and he needed more time to think about it. The pilot participant also indicted interest in this question, but indicated that it would take considerably more time (days) to think about his response to it.

There were positive exceptions to this method as was successful only for two of the participants, both with high levels of education and access to technology. One participant suggested 'warm open fire'. Another turned to his computer (an organic use of netnographic method) and found a photograph of a town square sourced from the Internet.

> *Operating the computer with eye-gaze technology, he began a search of the Internet. The image of a town square emerged. He waved his arm about the room and used speech that I did not understand and nodded his head back to the computer. I was confused. After a few moments I realised he was gesturing from the walls to the image and back to the walls…. and a sudden wave of understanding emerged. … He had shown me an image of what home means – a beautiful photograph of a town square – I followed his hand gestures indicating the walls all around, each wall coloured as in the picture, and realised the town square surrounded us.*

Through the use of the selected image and the movement of his hand, the participant spoke of his sense of home as being connected to a place on the other side of the world; as integrated in the décor of the home in which he lives. Coupled with his selection from the TGPE method of a hand holding, a business card with the word 'me' in large font, concepts of identity and freedom were evident, as well as indications for Nussbaum capabilities (2006) such as *senses, imagination and thought* and *power and control in ones' environment*. This method offered a deep insight into the meaning of home for this participant. It also broadened the perception of the researcher by introducing the possibility of home not necessarily meaning 'where one lives, and that home can also be 'more than one place'.

The Theory Generated Photo Elicitation (TGPE) founded on hand images resulted in a deep understanding of the meaning of home (the broader study into which the method study was imbedded) for each of the participants, was very well received. It provided the greatest amount of information related to the study questions, and received the highest scaling of participant feedback – 80% indicating it was good, the remaining 20% ‘Don’t know’ and ‘NA’. Considerable information was obtained from this method, appearing to enable participants to arrive at a deeper level of meaning relatively quickly and with little need for narration. This was revealed in a photograph of the selections a participant made to describe her experience of group homes. The participant was asked to find a word that would best indicate what this image means to her. She chose the word ‘difficult’ from the many words on a tray attached to her wheelchair. The other words ‘oppression’ and ‘imprisonment’ were selected from a comprehensive list of adjectives (provided by, and read aloud by the researcher) to clarify each image with a word. These words were –

- Puzzle image - *difficult*
- Blankets image – *oppression* (from the adjective list)
- Syringe image – (unfortunately was not understood by the researcher)
- Cage - *imprisonment*
- Hand over face – *loss self*

The Adapted Image Selection (AIS) provided a clear understanding of what participants consider most important in relation to home. The participants were asked to select five of the most important qualities of a ‘good home’ for them. Nine of the10 participants answered this question with all 21 vocabulary (icons with text) options selected at least once. 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 who answered the question). ‘Comfort’ and ‘Being Myself’ followed, with five participants selecting ‘Comfort’ and four choosing ‘Being Myself’. Without being requested, two participants placed their selections in priority order both having the ‘Support Workers’ card at the top of a self-created pyramid. The selections made, as well as the assessment of the overall method contrasted between the test and final study group. None of the pilot test group selected ‘Support Workers’ or ‘Access’ or ‘Body safety’. For the pilot test group (without CCAN) this method received the highest score (90% good) with comments including ‘so interesting,’ ‘great to have it all mapped out for me so I can think it’ (sic answers). In comparison, the study group (with CCAN) scores were less - 60% ranking of ‘good’, 30% ‘ok’ and 10% not applicable.

The sensory ethnography of the embodied researcher contributed to the study. There was a symbiosis between the experiences shared with the participant and the information provided through the use of the methods. For example, when setting up for the interview in the home of the participant whose selections are illustrated in Figure 2, the face of the researcher is filmed which later prompted the following research note.

Figure 2. Example of participant selection – Theory Generated Photo Elicitation.
Note: Top row from left to right: Tricky/problem solving, care/loss of control/oppression. Bottom row from left to right: treated/being done to, imprisonment; Middle row: hidden/voiceless

> *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-based information that transcended the confines of traditional communication was recorded by the researcher and related back to housing theory and Nussbaum's list of capabilities. The above indented note from research recordings provides one of repeated examples of social isolation experienced by one participant. This information was consistent across all responses, which highlighted the absence of both social connection (as described in housing theory) and the capability of social affiliation outlined by Nussbaum (2006). For this particular participant, her residence, through the meaning she ascribed to it, clearly was not a home.

Summary of the findings

The purpose of the study was to support the investigation into the meaning of "home" for people with CCAN by developing, testing and evaluating new methods of data collection that would optimise access to research participation. When combining the criteria used to measure success with participant rating of the individual methods, the results reveal the following:

1. The methods as a collective (mixed methods) group showed consistency (the intent and meaning of participants) matched throughout. The

questions asked of participants did feel somewhat repetitive, however this was important to ensure accountability. For example, 'warm open fire' was the Participant Generated Sensory Selection (PGSS) choice of a participant, which was supported by her icon selection of 'comfort' in the Adapted Image Selection (Talking Mats©) and the selection of an image of knitted gloves holding a warm drink in the Theory Generated Photo Elicitation method.

2. Not all methods were well received. The Participant Generated Sensory Selection was not answered by most of the cohort. It appeared to be confusing and challenging for most participants and received a low overall score. It was included in the study, however, due to the positive response it received from the pilot participants, all of whom had university qualifications).
3. Theory Generated Photo Elicitation (TGPE) was answered by all the participants and received a high participant score in response to this question *Do you feel you were able to adequately express what home means to you by using this method/approach*?' The images selected by participants each told various stories about home – some very positive, several mixed and three clearly indicating that their experience of home is like prison, very little freedom, trapped, 'being done to' and that their identity is not nurtured. These selections were reinforced by their word selections, in some cases with assistance from their support/companion. They were also reinforced by the information gathered from the fourth method - sensory ethnography.
4. The experience of the researcher closely matched the data gathered from the participants. For example, the three participants who selected negative images (to reveal their experience of home) lived in two group homes. The sensory ethnographic experience highlighted the strong smell of disinfectant in these group homes and the shaved or near-shaved heads of participants. A support worker in one of the homes mentioned that short hair is much easier to care for. Unlike some of the other participants, no one from these homes selected the hand images representing freedom, identity or power, moreover they selected images which represented the opposite.

Discussion

This study developed and tested new methods aimed at optimizing the research participation of people with CCAN. This involved identifying an appropriate methodology and combining these with visual methods and recognized AAC approaches in order to develop effective participatory research methods. It also involved discovering, in advance, the unique 'yes' 'no' and 'don't know/undecided' expressions of potential participants, which was essential to the success of each of the methods. AAC is sensory by nature; it can be seen, heard, touched and even smelt just as other electronic devices and books can emit a smell. The shared use of AAC, where appropriate, contributed to the sensory ethnographical knowledge gathered in the study. For example, the volume capacity on various devices shaped experience. During the pilot interview, the VOCA was too quiet to hear and so the physical positioning (and indeed experience) of the interview changed. The opposite of this experience emerged during an interview with a participant wherein -

> *The sudden robotic 'man' that boomed out from the device made us both jump. Neither of us were expecting the computer volume to be up so high.*

An immersion into sensory ethnography offered the researcher an opportunity to explore the corridors of inquiry possibilities that exist beyond doors of spoken and written language. It also invited the researcher to pay attention to other forms of 'knowledge gathering' by personally experiencing what it feels, looks, sounds, smells and tastes like in sharing time with participants. This invitation extended to the sensory experiences of using the AAC already prepared by the researcher but also, where appropriate, sharing the use of the participant's AAC. From this, not only could the sensual experience of what it might feel like to live in the participant's home be evoked, but also insights into the use of AAC. The use of an AAC device can be extremely time consuming and result in extraordinary fatigue on behalf of the user, making the acquisition of first-person insights of people with complex communication needs (CCAN) further challenging.

However, study design, more specifically the 'best known practice of or 'the how to' recruit, partner-with and/or interview people with CCAN, appears to be a neglected science within the field of AAC. The researcher, seeking good practice methodology for involving people with CCAN in research, is often left to extrapolate what they can from research where study design is often written for the AAC peer expert. The use of focus groups for research and evaluation purposes is common in the field of sociology, and a relatively common method used in AAC research (Iacono, Balandin, and Cupples 2001; Hemsley, Balandin, and Togher 2008). Yet this research is conducted by AAC experts, often speech pathologists, with the '*how to conduct focus group research with people with CCAN*' presented as assumed knowledge. The transfer of research knowledge from the field of AAC to other disciplines appears to present a significant gap, contributing to the further silencing of the voices of people with CCANs in research relating to all aspects of the human condition.

The theory and practice of using photo elicitation and hypothetigraphy (theory represented in image – in this instance the use of photographs of hands) enabled the development of methods which, in combination with sensory ethnography, could evoke responses not founded on written and verbal expression. The hand images were well received by participants with CCAN, and offered the richest source of knowledge about the meaning of the concept of home.

The adaptation of the Talking Mats© as both a research tool and communication device, contributed greatly to the study. It was used to present research questions, in particular, forming the basis of 'Adapted Image Selection.' It was also used as a communication device, helping to capture more detailed information, to scale responses, and sometimes just to chat with a participant to discover their interests or thoughts about being interviewed. It was easy to use, versatile and supported a variety of communications with participants (clarifying points, assisting with understanding scale, and with the process of gaining consent, as well as general thoughts, feelings and conversation with people with CCAN). Furthermore, as a research tool, it was well received by the test cohort (participants without CCAN). From here it is possible to imagine the benefits of including AAC as normalised practice within general research, therein breaking down communication barriers while raising the normative status of AAC. Talking Mats© (available in physical or digital form) offers both face-to-face workshops and on-line training in support of its use. Overall the development of new ways of adapting the mats to serve qualitative research purposes offers the field of sociology an exciting opportunity for discovery.

The Participant Generated Sensory Selection method (aligning meaning to senses) was a deviation from sensory ethnography and was, overall the least successful method developed for the study. Both the study and test groups reported confusion as well as time constraints (specifically that it would take too long to think of a response). Despite this, one of the richest insights into the meaning of "home" was obtained through this method, with the participant later emailing to reveal how by responding to this question increased his own self-awareness, which in and by itself, was valuable to him.

The study was not without notable shortfalls. The methods required participants to be visual; it was only by chance the cohort did not include persons with sensory impairments. This study did not have methodological answers for people with CCAN with significant visual impairment. It is the opinion of the researcher, however, that this is an oversight of the study and does not reflect the possibilities of overcoming this problem by developing other forms of sensory-based research. Greater thought and investigation are needed here.

The time and effort it took to develop the hand images is also an important consideration. It involved the creation of new images with four phases of testing them before the final 13 photographs were identified. When considering the earlier point of pragmatism as a barrier to research. Yet this method was successful; every participant was able to answer the questions without difficulty, it provided the greatest amount of information, and received only positive feedback from participants. Furthermore, it captured a clear insight about the meaning of “home” and required very little use of spoken or written language. Herein lies the question of the extent to which the hand images might have utility for other research questions, particularly focussed on quality of life issues. If the use of these hand images proves to be transferable to other research questions, and able to be utilised in other types of study, then the time required in developing the methods may not be an issue.

The future development of co-design in relation to these methods may lead to richer shaping of methods suitable for people with diverse impairments. Providing greater opportunities for input and control, *Participatory action research (PAR)*, a sociological methodology that recognizes people with disabilities as key partners in the research process (Whyte 1991, McIntyre 2008). “At its heart is collective, self-reflective inquiry that researchers and participants undertake, so they can understand and improve upon the practices in which they participate and the situations in which they find themselves” (Baum, MacDougall and Smith 2006).

Prior to the commencement of the interviews, participants were invited to offer ideas or suggestions for helpful ways to conduct interviews with people with CCAN. Five participants provided responses to this question, including two people who emailed feedback after the completion of the interview. Their recommendations included using photographs (hands), email, Skype, social media, Talking Mat and other AAC, on-line forums, no detailed writing, researchers trained in AAC and spending time getting to know the AAC used by participants and also the person (and their families/attendants).

Although obtained from a small research group, these suggestions cover a broad range of ideas that might be reduced down to three key themes:

- ‘Involvement of digital tools e.g. social media and technology’
- ‘Researcher qualities (background knowledge, communication partnering skills, ability to be comfortable, connecting effectively with participant support network’)
- ‘Use of pictures, images, symbols’ not solely spoken or written language

Drawn from this feedback is the knowledge that many different elements contribute to accessible and user-friendly research participation. It was encouraging to note that two participants recommended the continued use of the hand photographs. However, this method was only one aspect of what this group considered good research practice with people with CCAN. The inclusion of digital tools and social media were highlighted as were communication partnering skills and researcher qualities. These have particular implications for sociologists with little or no knowledge of AAC. Sunderland et al. (2015) notes "As researchers, we must continuously ask: who gets to speak and how? To what extent are we limiting this interaction to match our own abilities as researchers" (p. 54)? With this comes the invitation for sociologists to extend their knowledge and use of communication to include such things as AAC, the use of AAC tools and devices, good communication partnering, and a willingness to expand into alternative areas of research.

Conclusion

Omitting the voices of people with communication barriers from research cohorts is problematic on multiple levels. In addition to the moral and ethical considerations outlined, exclusion of any cohort from a body of research is likely to result in poor scientific outcomes. It is imperative that every effort is made to ensure all voices are included in research with the responsibility being placed with researchers and research bodies to ensure this happens.

The study provides an illustration of how sociology (and potentially other fields of inquiry) might shape research methods to collect and understand the insights of participants with CCAN. In this instance, it was achieved through the combining of ideas, experimental adaptation and testing of alternative research methods to AAC, coupled with the guidance and advice from people with CCAN. The study also reinforces the view that not only is it possible to accommodate the research contribution of people with CCAN but that it is ethically and fundamentally appropriate to pursue access to research participation for every human being. The study findings challenge several gaps in methods, ethical guidelines, research or policy standards which prevent the 'voices' of people with CCAN.

Alongside the rest of the community, people with CCAN have valuable knowledge to contribute through the corridor of research. If given the opportunity to be shared, these insights have the potential to inform and shape societal thinking and experience. Yet until they are shared (and in a myriad of ways), the insights of many people with CCAN will remain unknown.

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