

An ethnographic approach to researching the communication of people with severe learning disabilities

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An Ethnographic Approach to researching the Communication of People with Severe Learning Disabilities

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Introduction

“Communication is at the heart of who we are as human beings.” (Jago, no date) and the right to express opinions and communicate information is enshrined in Article 19 of the Universal Declaration of Human Rights. Communication is also the medium through which we exercise a wide range of other human rights such as participating in community, education and leisure. Most people with learning disabilities experience communication difficulties - some have little or no speech - and are therefore at risk of being unheard, excluded and marginalised. Without effective communication, these individuals cannot control their lives, build relationships, and express their feelings, thoughts and needs.

This chapter discusses doctoral research conducted in small group homes for adults with severe learning disabilities. Such settings are part of a wider societal and political context in which people with disabilities are oppressed and devalued. Those with limited communication are further disadvantaged, and this research aimed to investigate how this is evident in the everyday interaction between residents and their care staff.

Recognising the ethical ideal that research about disability is conducted by disabled people themselves, there are nevertheless distinct methodological challenges and ethical issues entailed in people with cognitive and communication impairments being involved in the research process. While striving to demonstrate an emancipatory ethos, the research encountered issues of capacity to consent to participate, and a lack of tried and tested analytical tools that could accommodate the highly asymmetrical interaction between individuals with very limited communication skills and their much more articulate care staff. The research took an ethnographic approach, in which rich qualitative data in the form of field notes, interviews with care staff and video recordings of ‘real life’ interaction were gathered over a long period spent in the ‘field’ (the natural social setting). This chapter makes a case for prolonged periods of engagement with individuals who may communicate in unconventional ways, and the centrality of issues of power.

Background and Outline of the research

This research stemmed from a personal wish to discover the reasons why so many adults with learning disabilities and limited or no verbal communication who were provided with communication aids (such as symbol boards and electronic devices) did not use them. This issue had long been recognised as widespread, and as a Speech and Language Therapist, the researcher had encountered many such situations. From this initial, vague motivation, the research questions emerged and became refined as the project progressed; the aim became to analyse the interaction between residents and staff in terms of power relations, and to consider the differences in both power and communication skills between people with learning disabilities and their care staff (their main communication partners).

The aims of the research:

1. To critically analyse the interaction between residents and staff in terms of power relations.
2. To explore the hypothesis that power relations contribute to a lack of communication aid use.

There is a variety of terminologies used to label research in which people with disabilities have been involved to various extents. Riddell et al. (2001) refer to this collectively as the 'democratic disability research paradigm'. Such research is collaborative, self-aware and critical. It values the contribution of those who need help to express their views, values difference and avoids recreating the traditional hierarchy within societies as a whole, as well as within the research context. This research project did not aim for objectivity and neutrality, but rather adopted an openly ideological stance regarding the position of people with severe learning disabilities in society. It has been argued that ethnographic research should not only aim to understand the world but also to change it; in other words, it should be 'emancipatory', the goal being to contribute to the freedom and empowerment of marginalised or disadvantaged people (in this case those with learning disabilities) in an equal and just society.

Ethnography is an approach to qualitative research which involves participating in people's lives over a long period of time (Hammersley and Atkinson 2007, p3), gathering a variety of data through, for example, observing what happens and asking questions. In other words, everyday contexts are studied in depth in a naturalistic or unstructured way. A small number of settings are usually selected. Analysis of these predominantly verbal data entails "interpretation of the meanings, functions, and consequences of human actions and institutional practices" (Hammersley and Atkinson 2007, p3). It takes an exploratory orientation, in which initially broad areas of interest become gradually more refined, and specific research questions emerge.

This emergent quality, characteristic of ethnography, is evident in the project being discussed here.

Although much has been written about the ethical issue of securing consent to participate in research, it could be argued that the systematic exclusion of people such as those with severe learning disabilities who are not readily able to demonstrate capacity to consent is of equal or even greater concern. As Dee-Price et al (2021) also point out, research findings rarely capture the first-person insights of people with complex communication access needs.

Nevertheless, we need to be honest about the feasibility of people with severe learning disabilities participating in, or controlling their own research. Considerable challenges arise when attempting to conduct emancipatory research with people with severe learning disabilities. The very nature of learning disability means that those experiencing it are unlikely to have the intellectual skills necessary for participation in research in conventional ways, and many will have internalised the power relationships which emancipatory research seeks to challenge. The researcher agrees with Clegg, who says "I struggle to understand why anyone imagines they could obtain informed consent to, say, research participation from a multiply disabled adult with a developmental age of 3 months" (Clegg 2003, p4). However, some methodological progress is being made; Dee-Price et al (2021) for example discuss their development and testing of new methods of data collection that could improve access to research for people with complex communication access needs. The research being discussed in this chapter also concerns people who are, at least to an extent, unable to "articulate and reflect upon their experiences" (Klotz 2004, p101). Klotz (2004) makes a case for approaches which do not rely on eliciting data from people with learning disabilities, but which place interaction and relationships centrally, in naturalistic contextual observations. Ethnography is therefore a valuable approach, since people's behaviour is considered within its natural context; it allows the time needed to get to know them well, to maximise their communication and participation in the research. And although the researcher cannot claim to have undertaken emancipatory research, this ethos influenced all stages of the research.

[Accessing settings, sampling and recruiting participants](#)

'Fieldwork' refers to research in which data is gathered in naturally occurring social settings. The process of negotiating access to fieldwork sites (residential homes, in this case) was implicit in every visit to the sites, but was most explicit early in the programme of fieldwork. As soon as ethical approval from the NHS was received, the directorate manager of social care homes was approached and provided contact details of the managers of several care homes. Each home manager handled the researcher's approach differently, and included invitations to staff meetings, informal visits and an interview; on each occasion, information sheets about the research were supplied. Their appreciation of the topic as an important area in need of

investigation may have been influential in the positive and enthusiastic response all managers gave to the proposed research.

Five small residential homes for adults with learning disabilities were selected, being judged as fairly typical of their type. Within each setting, further sampling occurred, in terms of decisions about 'where to observe and when, who to talk to and what to ask, as well as about what to record and show' (Hammersley and Atkinson, 2007 p35). Four individual residents who could communicate intentionally, verbally and/or non-verbally, and a small number of staff were selected for in-depth study.

Methods of data collection

Data was collected over the course of a year, through weekly visits to the homes; initially the methods used were observations and interviews with staff, which were later supplemented with videos of resident-staff interactions.

1 Participant observation

Handwritten notes were taken while in the field, then typed in more detail immediately afterwards, and meticulously organised and archived. Field notes were initially very broad but gradually narrowed in focus, and became more selective over time; the behaviour and interaction of people were the main research interest. Adopting the role of 'observer-as-participant' (Cohen, Manion and Morrison 2011 p457) enabled the researcher to be unobtrusive at times, joining in with activities at others. Field notes served two functions: to support the development of a clear focus for the research, and as background information to enhance the interpretation of video data.

2 Interviewing staff

Interviews tended to be informal spontaneous conversations, which blurred into participant observation (Hammersley and Atkinson 2007); this was beneficial, as rapport had already been established between the researcher and the staff member, prior to interviews arising. Also, conducting interviews within their familiar environment, helped participating staff relax, and fitted into their work schedule. Interviews were unstructured, as is usual in ethnographic research; they were an important source of data, providing staff members' perspectives on their interaction with residents.

3 Video recording of resident-staff interactions

After a period of field work, when trust and rapport had been established, naturally occurring interactions between staff and residents were video recorded; these can be described as unsolicited data (Hammersley and Atkinson 2007), in contrast to the (solicited) interviews with staff. Re-watching the video clips enabled careful analysis of interactions, including both verbal and non-verbal (multi-modal) aspects of interaction.

Transcription of audio recordings of staff interviews and videos of interactions with residents, combined with contextual information from field notes, constituted the data set.

It is important to point out that such qualitative data is open to a range of interpretations; therefore, the validity of naturalistic qualitative research findings can be called into question. Rigour and confidence rather than certainty or objectivity (Cohen, Manion and Morrison 2011 p181) are the aims. The prolonged engagement in the field, coupled with the triangulation of multiple methods of data collection, contributes to the credibility of the research (Cohen, Manion and Morrison 2011). A certain amount of member checking or respondent validation (Hammersley and Atkinson, 2007) also supported the authenticity of the data; this occurred through the sharing of emerging findings and conclusions with (staff) participants - these would then be discussed further and elaborated or modified.

The processes of analysis and interpretation of data necessarily merged together, as it commonly does in qualitative research. The rich data set combined fine grained detail with the broad social context in which interactions occurred. Discourse analysis was used: "discourse analysis examines how meaning is constructed through texts....It focuses on issues of power, domination and reproduction of power in texts and conversations, language in social contexts and interactions." (Cohen, Manion and Morrison 2011 p574-575). In this project, field notes, interview transcripts and transcripts of multi-modal interactions were all forms of 'text'. Given the subjective nature of this process, it was important for the researcher's possible biases to be made transparent; hence at the outset, the disempowerment of people with learning disabilities in society in general and within research was discussed. A number of key themes arose from the data, and these were presented in the research report and illustrated with small passages of transcription to illuminate the discussion.

Key Findings

Themes that emerged from the data in response to the aims of the research included turn-taking and topic control in interaction, politeness and the use of 'test questions' by staff (questions staff ask residents to which they know the answer e.g. 'What happened yesterday?'). In many respects, much of the staff-resident interaction resembled that between adults and children; but it was also evident that the residents were not entirely powerless in interaction. Nevertheless, staff were adept at controlling aspects of day-to-day interaction, at least partly in order to facilitate residents' participation in it. In the long term though, this significantly constrained the interaction, and residents did not have opportunities to develop more sophisticated communication skills or to express themselves more freely.

Ethical issues

Ethical issues are of central concern in any research, but nowhere is this more the case than among people with limited communication skills and intellectual ability. The British Psychological Society (BPS 2018) code of ethics and conduct identifies four ethical principles, the first of which, 'Respect for the dignity of persons and peoples' was paramount throughout. The following discussion concentrates on the pragmatic issue of informed consent.

Decisions about an individual's capacity to make a decision on whether to participate in research depends on them being deemed able to do so free from coercion, and it being based on an understanding of the research, its risks and benefits. A label of learning disabilities (or any other label) cannot be used to assume they lack capacity. However, for most people with severe learning disabilities their ability to understand information, reach a decision and communicate it will be impaired, and so they will not be regarded as having capacity. This needs to be balanced with the need to ensure they are not excluded (Cameron and Murphy, 2006 p118), and researchers are required to take all practicable steps to support a person to make a decision (BPS 2020). For this research, the NHS ethics committee required information for residents to be provided in alternative 'easy read' formats (even though none of the residents were considered by their care staff to be able to understand either text or symbols, revealing the committee's lack of insight into the group of people being potentially included). Nevertheless, the information leaflets created followed Mencap's (2002) Guidelines for Accessible Writing, and proved useful for other participants, such as care staff. Cameron and Murphy (2006) remind us of the importance of providing accessible and understandable information, using supports such as symbols, simple language, bullet points and repetition of information.

It remained the case though, that "When it comes to ideas which are more complex there is unlikely to be a substitute for working alongside people who know the individual well and can draw on the experience of what works with him or her" (Cameron and Murphy 2006 p116). Indeed, for this research, none of the residents was able to give explicit voluntary informed consent. In line with the BPS guidance (2020), wider consultation was important: the care home managers, key workers, and family members were the 'consultees' involved in deciding whether the residents could be considered happy to participate. The decision was always taken after several visits, and it had become clear to carers that the resident was comfortable with the researcher's presence. Those who knew the resident well were asked to identify what signals might indicate that the resident was not happy with the researcher's presence. It was important to give assurances about the confidentiality of data, especially video footage, about which there was most sensitivity.

Although the risks of being involved in the research were very low, with no invasive procedures, the use of video in particular made it potentially 'intrusive' (BPS 2020). All staff agreed to be interviewed informally and to be observed, but the majority refused consent for video recordings to be made of them, commenting on their embarrassment and self-consciousness. The selective granting of consent from staff resulted in significant curtailment of the amount and nature of data collected. Researchers also need to be sensitive to the possibility of opening up unanticipated areas of discussion (Cameron and Murphy 2006), a risk in this research that was greater for staff than for residents. It is widely recognised that consent should be regarded as an ongoing process, not just a one-off event at the outset of research. Relationships between participants and myself were of greater value than merely following procedures, when it came to ensuring ethical conduct.

Activity

Ethical guidance and standards are constantly changing. Identify the professional body and current guidelines relevant to your research. How will you apply these ethical guidelines to all the stages of your project: your overall research design, your methodology, data collection and analysis, and the dissemination of your findings?

Practical issues in undertaking this research approach

Limitations in the extent to which the learning disabled participants were involved in shaping the project have already been discussed; inevitably there were other practical concerns such as those arising from the compromise between breadth and depth. Data collection was conducted at five homes in all; while this may strengthen the case for some generalisation of conclusions, it resulted in field relationships of insufficient depth for participation in the project to have any transformatory effect. The initial hope had been for participation to facilitate the personal development of staff in terms of their interaction with residents. But this underestimated how difficult this might be to achieve: challenging beliefs and assumptions, and changing habits can be an uncomfortable and long process.

Another major area of practical concern was the video recording and transcription of data. The use of video is a powerful way to capture the idiosyncratic and often fleeting modes of communication used by people with severe learning disabilities, although it is in no way objective: it too is open to interpretation. The same point may be made about transcription of video footage; when meanings may be highly ambiguous, care needs to be taken to be open about the nature of the interpretative process carried out by the researcher and (more powerful) others such as family members and carers.

Transcription is time consuming (Hammersley and Atkinson, 2007), taking at least five times as long as the duration of the recording to transcribe into written text, (although voice recognition software is improving all the time and can make the process much less arduous). Interviews with staff were transcribed in full usually from audiotape using widely used orthographic transcription conventions, to capture only the words that were said.

However, much more fine-grained transcription was conducted on the video footage of interaction involving residents, which aimed to represent the non-verbal nature of much of this interaction. It took well over an hour to transcribe a minute of interaction in this way, so careful selection was necessary: the aim was to achieve a sample of transcribed data that was broadly representative of all of the data, in terms of participants and activities or settings. No transcription provides a complete record of interaction so strategic decisions had to be made about what to transcribe and what detail to include, based on the aims of the research (Atkinson and Hammersley, 2007).

There were two main challenges in transcribing this multi-modal interaction. Firstly, how to convey meaning: a good knowledge of the context and the individual are required for intended meaning to be interpreted correctly, and use of field notes helped in interpreting the interactions. Secondly, how to present the transcription in such a way as to avoid inadvertently privileging spoken utterances over non-verbal communication, and giving prominence to the speaking partner over the less verbal individual. Therefore the residents' interaction was placed to the left of the page and non-verbal behaviours to the left of verbal or vocal information. Presenting one line of transcription per second enabled the reader to get a sense of pace of the interaction, and gave information about relative times that each participant held the floor - an aspect which could be relevant to the analysis of power relations (see figure 1).

Venue: Number 32

Date: 27.04.04

Setting: kitchen, following cookery session

Participants: resident Sarah; staff Sue; researcher behind camera.

Duration: 33 seconds

Selection criteria: coded as 'requesting'

Key:

→ looks towards...

← looks away

▶ points towards

(n) unintelligible speech,
(number of syllables)

Time (Secs)	Resident: non-verbal	Resident: verbal/vocal	Staff : non-verbal	Staff : verbal
1.	→ Sue	I'm wet	Back to camera, wiping crumbs off S's tray and footstool	
2.				You're wet?
3.		umm		
4.				You sure you're wet

Figure 1 An example of multimodal transcription involving a resident with some speech.

Once transcriptions were complete, they and field notes underwent several processes of analysis. First they were split into segments, each consisting of several lines of text; these were identified by date and location. Each segment was then given one or more codes, that related to the aims of the research e.g. 'choice', 'fun/banter', 'care needs' 'control'. A long list of codes were generated, and these were gradually refined, and grouped into themes or categories. With the help of a database, segments of data could be retrieved by code; then by placing them alongside each other it was possible to explore patterns in the data such as which codes tended to occur together, and how frequently. This enabled analysis to work upwards from the data, but also to work in a downward direction from theory and from the research questions. Cohen, Manion and Morrison (2007) provide a useful overview of the many ways in which qualitative data can be analysed, and discuss the inevitable risk of researcher subjectivity that arises.

Evaluation, Dissemination, Impact and final reflections

A common criticism of ethnographic research is the lack of real world impact. Research impact is discussed extensively nowadays, with many research projects explicitly setting out how their research will bring about real-world benefits. In fully emancipatory research, feedback of research outcomes to participants and wider dissemination is a requirement, but more than this is required to bring about change. In hindsight, the researcher recognised that the focus was too narrowly on the dissemination of findings to the participants and other stakeholders. But even this was, unfortunately, very challenging. The nature of the findings entailed abstract theorising of concepts which were out of the reach of many of those with learning

disabilities. To an extent the same could be said for the staff, whose generally practical orientation to their work allowed little space for reflection of a more theoretical or abstract nature. At a pragmatic level, the prolonged duration of the project spanned considerable staff turnover and it proved difficult to sustain relationships with them through the final dissemination phase of the research. Dissemination to the wider research community took the form of several publications and presentations – a time consuming phase of research that required considerable forward planning and consideration.

For the residents in this research, care staff provided most, if not all of their social contact. The relationships between them, in which both practical assistance but also companionship are important, are of huge significance to the quality of life of the residents. Day to day interaction can enhance empowerment and choice in residents' lives, but it can also disempower and control them; this research provided evidence of both occurring, in a fluid dynamic imperceptible to the participants.

People with learning disabilities are amongst the most disempowered in our society, and policies and services provided to them have often been accused of reinforcing this situation. Meaningful participation in decisions about their own lives is a particular challenge for people with the most severe learning disabilities: choice and control are unavailable when there is no communication.

Research on communication has so far concentrated its attention on language, while failing to address issues of power. And yet this research demonstrates that residential care homes like these often reflect, to an extent, societal conditions of oppression of people with disabilities. Training for staff in interaction techniques should also address staff values and attitudes and raise awareness of the power relations within interaction.

Only by ensuring the inclusion of people with communication impairments in research can we get a better understanding of the challenges they face in their day-to-day lives (Dee-Price et al 2021). Through communication, individuals exercise

choice and control over their lives, build relationships, and express themselves. Communication is a human right.

Activity

All research proposals must be realistic. Starting with your research idea or topic, begin considering the practical details including:

- What settings will be your research sites? How many participants do you hope to recruit? What data collection methods will you use? What are the ethical issues?
- Make a list of the possible barriers or limitations you may encounter in conducting your research.
- Note down how you will address any challenges that arise.

[Link to the full research study](#)

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