

Title

Ethical considerations in qualitative case study research recruiting participants with profound intellectual disabilities

Author

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Abstract

Drawing on the author's experience carrying out qualitative research in the field of occupational therapy with people with intellectual disabilities, this article explores ethical issues inherent in ethnographic and case study research, where study designs can evolve over time. Such qualitative methodologies can enable deep understanding of research topics, but detailed description of methods and of the range of potential experiences participants may have is necessary to ensure that they are fully informed and ethics committees satisfied. Thorough consideration is required of ethical issues related to topic relevance and design, recruitment, collection of data and portrayal of participants in the eventual case report. The article illustrates a way in which research of this type can be explained and justified, including how recruitment can be achieved of participants likely to lack capacity to consent to participation themselves.

Key words

Occupational therapy, intellectual disabilities, capacity, qualitative case study methodology, ethical review

Processes for gaining ethical approval for research, including those in the United Kingdom for researching in the National Health Service, can sometimes seem challenging for research from outside the traditional scientific quantitative paradigm. Those who may lack capacity arguably have a right to have their support needs researched (Dalton and McVilly, 2004; Crook et al., 2016), but an identified notable dearth of research involving people with profound intellectual (or learning) disabilities as informants (Coles 2001) appears to remain with only limited exceptions (e.g. Williams et al., 2007, Griffiths and Smith 2016). This may in part be due to the process of gaining ethical approval for such research appearing insurmountable.

This article explores ethical issues inherent in one qualitative research study in the field of occupational therapy with people with intellectual disabilities. This research used a critical ethnographic case study methodology, with an evolving design seeking to involve an unpredictable number of participants, some very likely not to be able to consent to participation themselves. It illustrates a way in which research of this type can be explained and justified as ethical. The research aimed for a better understanding of occupational therapists' role in improving quality of support. Using a critical ethnographic case study methodology and multiple methods (participant observation, interviews and document analysis), I explored, over the course of one year, a single purposively-selected case in which an occupational therapist worked with five people with severe and profound intellectual disabilities and those supporting them, to increase meaningful engagement in activity at home. An interpretivist and social constructivist stance placed me, myself an occupational therapist, centrally in the research, constructing findings jointly with participants as "*interpreter and gatherer of interpretations*" (Stake, 2008: p.135).

Many inherent ethical issues were apparent from the outset and obtaining ethical and governance approval was to prove complex and challenging. In the nature of case study research, the design evolved and was therefore not straightforward to explain fully in advance. I was encroaching on the potentially sensitive area of interactions between client and professional and the occupational therapy of interest happened in people's homes, where I was seeking to observe and even film. As people with profound or severe intellectual disabilities, Matt, Steve, Becky, Jane and Harold were very unlikely to be able to give informed consent to participate in this research even after taking all steps to maximise their ability to do so. This implied proceeding on the basis that it was in their best interests to have their needs researched. As ethics committees would likely regard such prospective participants as vulnerable, a very strong case was needed to demonstrate that any risks to participation were minimised and that those remaining were proportionate to potential benefits.

The study was approved by the University of Brighton Faculty of Health and Social Sciences Research Ethics and Governance Committee and the National Health Service (NHS) National Research Ethics Service (NRES) (Ref: 12/LO/0319). NRES approval was necessary because occupational therapist Esther was an NHS employee and Matt, Steve, Becky, Jane and Harold were her NHS service users, but also because of the likelihood of

them not having capacity to consent to participate themselves (Department of Health, 2008a). Research governance approval was granted by an NHS Trust to allow recruitment of their staff and service users.

Thomas's conceptualisation (2011) supported construction of a case that is exemplary (a good example of this kind of occupational therapy) and instrumental (providing illustration to facilitate in depth understanding and for readers to make sense of themselves (Simons, 2009)). Interest was sought from occupational therapists proficient in this work and Esther, an experienced occupational therapist from a community team for adults with intellectual disabilities volunteered. We agreed criteria for a suitable case and mutually decided on the potential relevance of her intended work with Matt, Steve, Becky, Jane and Harold in their home Cavendish House, in a suburban area of an English city. A case of occupational therapy supporting this small group of people's engagement in activity at home gradually crystallised, ethnographic in its thick description of culture and structure and critical in its consideration of arguable injustice within the setting (Madison, 2012).

Data collection methods were characteristic of case study and ethnographic research. I spent time in the field with Esther and other participants, an "observer as participant" in Gold's typology of participant observer roles (1958: p.217). Data were collected iteratively over the course of a year: primarily my jottings and field notes, along with interviews, which assisted interpretation of observations through gaining interviewees' additional perspectives. Some interviews were pre-arranged, others relatively quick and informal – more like opportunistic conversations, exploring observed aspects of the case. Filming, in an extractive modality (allowing observation when not present), but, more importantly, in a reflective modality (Haw and Hadfield, 2011), allowed exploration of tacit understandings and reasoning by triggering reflection in interviews. Documents and artefacts created by Esther revealed areas for further exploration. Trustworthiness was promoted by prolonged engagement, persistent observation of emerging issues and opportunity to check data with sources (Simons, 2009).

An emergent, though systematic, inductive analysis allowed a conceptual, rather than purely descriptive, account of the case. Interpreting as much as analysing (Stake, 1995), I constructed findings jointly with participants (Thomas, 2011), notably Esther. Subjective understanding was a strength, but key to ensuring trustworthiness was reflexivity throughout, facilitating distinction between interpretations informed, rather than biased, by my knowledge, values and predispositions (Stake, 2008).

The case's story has two overarching themes: the impact of shifting support and leadership cultures on engagement in activity; and characteristics of occupational therapy seeking to create and sustain cultural change by working with support workers in a collaborative and empowering way. It highlights complexities achieving implementation fidelity (the extent to which professionals' recommendations are implemented as intended by others), with implication for those working with people with high support needs and for their training and education (see further Haines et al., 2016).

Commentary

I now discuss the ethical issues raised by this case study research, focusing in turn on issues related to topic and design, recruitment and informed consent, data collection and participant portrayal. I explain my responses to these issues, justifying arguably controversial aspects of the design in sufficient detail for the reader to be able to judge the integrity of the research, perhaps using the virtues of courage, respectfulness, resoluteness, sincerity, humility and reflexivity, outlined by Macfarlane (2009).

1. Topic and design

Where a research topic is sensitive and methods somewhat invasive, it is particularly important to justify clear relevance and appropriateness to the populations being researched, that is occupational therapists and, in particular, people with intellectual disabilities (Dalton and McVilly, 2004). Consultation with stakeholders is a requirement for all research considered by NHS NRES (INVOLVE and NRES, 2012), but meaningful consultation with those who have profound intellectual disabilities is challenging. Following Tuffrey Wijne, et al. (2008), I therefore consulted with a research advisory group consisting of a small number of people with mild-moderate intellectual disabilities who themselves had previously been research participants. They seemed a nearer equivalent to prospective participants with profound intellectual disabilities, than merely consulting with family and carers. These consultees raised useful points supporting the rationale for addressing the research question, along with recommendations regarding data collection that I followed and refer to further below.

A case study's design can be considerably less pre-determined than many other forms of research, evolving in many ways dependent on the nature of the eventual case (Thomas, 2011). Issues to be explored, nature and exact number of participants, plans for recruitment and methods of data collection can be difficult to describe with complete certainty until case selection, or even later. Ethics committees need sufficient information to

be convinced that an ethical approach will be taken, the NRES committee pressing, for example, for very specific quantification of participant numbers and lengths of involvement that were difficult to give in advance. I provided fairly broad estimates to encompass a range of possible recruitment and participation scenarios, quantifying likely maxima of different types of participants and a predicted total of 18 participants, taking part for anything from a few days to nine months. Although I felt uncertain whether these estimates were meaningful, they satisfied the committee and some did prove reasonably accurate.

2. Recruitment and informed consent

In a study with ongoing recruitment as relevance to the case became apparent, there was a general need to ensure that there was no risk of coercion, of both primary and more peripheral participants. Also, as Matt, Becky, Harold, Jane and Steve were very unlikely to have capacity to consent to participate themselves, careful recruitment procedures were required to ensure compliance with the Mental Capacity Act (GB Parliament, 2005).

Avoiding coercion

The experience of taking part in case study research is complex to describe and particularly detailed explanation was needed to ensure full understanding. To be unambiguous, I designed clearly-worded information sheets specifically for each type of participant, individualised to need where necessary. I supplemented these verbally, to ensure the necessary information to make informed, specific and voluntary decisions, taking into account all possible experiences I could predict a participant might have in the study.

Potential occupational therapist participants were provided with written information about the study and asked to contact me to find out more (avoiding further contact from me that may have created unintended pressure). Once Esther had volunteered, she suggested people with intellectual disabilities on her caseload whose occupational therapy might be relevant to the research question, at this stage not identifying them to me. We then worked closely together to devise a way of recruiting those selected in a manner we both agreed to be non-coercive, with initial approaches to them (or their family or carers) by Esther. I only made contact, to provide further information and answer questions, once initial interest had been shown.

As well as those key participants (Esther and the individuals with intellectual disabilities) an unpredictable number of further participants were purposively and gradually recruited: an occupational therapy assistant

(Sarah); support workers (Jean, Olly, Doug, Tracy, Paula, Gemma, Julie, Robert, Dina and Ivan); a nurse (Adam); a resident of Cavendish House with moderate intellectual disabilities (Mo) and home managers (Sue and Norma). Wherever possible, they were first approached by Esther and then by me only on showing initial interest. I sought consent as soon as their potential relevance to the case became clear and before any data was gathered involving them. I remained aware that some potential participants (particularly amongst the support workers) may have wished not to participate and was explicit that they were under no obligation. What was observed of, or said by anyone who had not consented to participate did not become research data.

Regarding consent as always provisional (Simons, 2009), I adopted the rolling, or process consent model (Dewing, 2007) of on-going and repeated informed consent. This meant regularly checking and re-checking continued wish to remain involved as observations and interviews proceeded and the realities of being a participant (what it felt like to be observed, the amount of time involved) became apparent. Participants were often surprisingly frank in interviews and some may inadvertently have revealed things they did not intend to. Seeking to offer some control over what ultimately became public, I generally, at the end of interviews or observations, asked for permission to use the content or whether anything needed excluding. Observing, for example, the visible discomfort of one support worker during an interview, I offered to pause or terminate it, reminded him that he could withdraw from the study without necessarily having to say why and asked whether there was anything he had said that he wanted me not to transcribe. He did give permission to use his interview, but his body language did not convince me that he genuinely wished to participate and I therefore took the difficult decision of excluding his interview and foregoing that data.

Recruiting adults without capacity

This research sought access to the lives of people with severe and profound intellectual disabilities who were very unlikely (fully at least) to understand the reason for my presence in their home. My justification for this is similar to that used by Tuffrey Wijne et al. (2008): the importance of understanding and gaining insight into the experiences of those who lack capacity in order to develop a research evidence base for how we can best support them. McKeown et al. (2010) describe the:

“hugely missed opportunity if [people lacking capacity] are excluded from the very thing that could be used to gain a fuller understanding” (2010: p.1936).

Sections 30-33 of the Mental Capacity Act 2005 (“MCA”) (GB Parliament, 2005) can enable research to be lawfully carried out in the United Kingdom with people lacking capacity. Steps taken to ensure compliance with these provisions were based on my understanding of the legal position from a number of sources (Department of Health, 2008a; Department of Health, 2008b; Dimond, 2009; University of Leicester and University of Bristol, 2011).

There is no ‘blanket incapacity’ under the MCA and lack of capacity cannot be assumed on the grounds of diagnosis of profound intellectual disabilities. As the person requiring decisions about research participation, it was my responsibility to ensure assessment of each potential participant’s capacity to make the specific decision at that particular point in time. My experience working with people with intellectual disabilities over 20 years, including as an occupational therapist, had given me familiarity with the MCA and experience of presenting information in accessible ways and of judging understanding. As a conflict of interest might be seen to exist were I to assess the capacity of potential participants with profound intellectual disabilities to choose to participate, Esther (similarly used to assessing capacity) took the lead and drew ultimate conclusions regarding this. She used her organisation’s “Mental Capacity under the MCA 2005 Assessment Form”, reaching conclusions in discussion with Norma (Cavendish House Assistant Manager), Sarah (Occupational Therapy Assistant) and myself.

Mo featured in the case in a small way. Unlike her housemates in Cavendish House, she had a moderate intellectual disability and was thought potentially to have capacity to consent to research participation herself. Drawing on information from those more familiar with her communication preferences (her support worker Gemma and speech and language therapy recommendations) and on accessible information guidelines (Department of Health, 2010; Mencap, 2010), we individualised and adapted information about the study. A simplified, “easy read” participant information sheet emphasising only key messages, supplemented with verbal explanation and role play, maximised her capacity to the point where she could indeed herself give informed consent.

Esther concluded, however, that no adaptation to presentation of information could maximise Matt, Becky, Harold, Jane and Steve’s capacity sufficiently for them to be able to decide about participation themselves. Such decisions were therefore made in their best interests in consultation with others in accordance with

sections 30-33 of the MCA. The research related specifically to needs related to their intellectual disabilities, so it was straightforward to meet the initial requirement (section 31(2)) for a clear connection with the “impairing condition” affecting capacity. With a strong underlying presumption of only taking decisions for people when absolutely necessary, section 31(4) requires using participants who *are* able to give consent where possible. Restricting recruitment only to adults with capacity would, however, not have answered the research question, nor would it have allowed anything of the perspective of people with profound intellectual disabilities themselves to be captured. This therefore satisfied section 31(4) and justified proceeding to recruit those without capacity.

Direct personal benefit from being a research participant is not necessary (Dimond, 2009), as the Act allows recruitment where research intends to further knowledge of causes, treatment or care of a condition affecting prospective participants (Department of Health, 2008a). Participating arguably had potential indirect benefit to Matt, Becky, Harold, Jane and Steve (Dimond, 2009): improving the quality of support of people like them; reducing risk of harm, exclusion or disadvantage; and improving understanding of effects of lack of lack of capacity on health and daily life.

Decisions had to be made in participants’ best interests and compatible with what we knew of their broader concerns (University of Leicester and University of Bristol, 2011). Benefits had to outweigh any risks (which needed to be negligible), with no significant interference with freedom of action or privacy, with the research not being unduly invasive or restrictive. It is not unusual for several people to be present at any one time in the environment of settings such as Cavendish House (those living there, support workers, managers, visiting professionals, family and friends). I judged that my presence was unlikely to be experienced as unusual, that research methods were reasonably commensurate with usual experiences and thus that risks would not exceed those of routine support and services (Dalton and McVilly, 2004).

Judging whether benefits outweighed risks required taking time (directly and through consultation with others) to get to know something of prospective participants’ beliefs and values, wishes and feelings, in order to gain some idea of what decision they might make were they to have capacity. Reasonable arrangements are required by the MCA to seek the advice (though *not* the consent) of appropriate consultees about whether participation is in the best interests of individuals lacking capacity. A “personal consultee” was sought for each

prospective participant, someone who knew them well and was interested in their welfare, but who did not care for them in a professional or paid capacity (Department of Health, 2008b). Assistant manager Norma advised about who it might be imagined people would trust to be consulted regarding important life decisions and family members, or friends took on this role for Matt, Becky and Steve. Independent mental capacity advocates unconnected with the project acted as “nominated consultees” for Harold and Jane. Specific information sheets for consultees asked them to consider the broad aims of the research, whether or not the person they were being consulted about would be content to take part and the risks, benefits and practicalities of this. Esther and I together explained what participating would involve, answering any questions.

Respecting their advice, I would not have included someone in the study had consultees advised against this. None took up the option of being present during certain parts of the research e.g. during observations.

Not having capacity to make an informed decision about participation, did not preclude being enabled to participate in decisions, including the acceptability of research methods and my presence. I therefore sought assent from participants, if not consent in the strict legal sense. Following Hubert & Hollins (2007) and Tuffrey Wijne et al. (2008), I paid constant attention to willingness to engage, meeting the additional safeguard in section 33 that nothing should be done to which someone appears to object. Taking into account participants’ ways of communicating, I discussed in advance examples of behaviours that might indicate distress or unwillingness and agreed to respond to these by either removing myself that day or by withdrawing the participant from the study, as appropriate. My experience working in this field assisted in my judgement, but I made such decisions in close collaboration with others, including in particular Esther. In the event no such signs of objection were observed.

3. Data collection

Participant observation in people’s own homes and in depth interviews can be intrusive methods of data collection. Aware that the occupational therapist, support workers and managers could feel that their practice was being judged, perhaps causing them to question their expertise, I sought to observe and question respectfully. Interestingly, some participants, notably Esther and Jean, did report finding interview discussions a valuable opportunity to reflect on their work.

One justification for participant observation was its potential to access something of the views and perspectives of people with profound intellectual disabilities themselves, who otherwise could not verbalise or understand the research issue (Tuffrey-Wijne et al., 2008). Their voices are often silent in research either consisting of psychological or psychometric assessment, or seeking the views of others about their lives:

“Participant observation is the most effective method of collecting data [from] people with little or no speech [providing] the means to discover and interpret ... touch, gesture, non-verbal sounds, eye contact, facial expressions and behavioural manifestations of sadness, joy, contentment, anger, affection and unease.” (Hubert and Hollins, 2007: p.123).

Ware (2004) does caution against merely substituting the researcher’s voice for that of family or carers, which clearly does nothing to reduce marginalisation. Previous experience as a support worker and occupational therapist with people with profound intellectual disabilities had given me experience interpreting non-verbal communication, though I was not initially familiar with these participants. I therefore interpreted nonverbal communication with the assistance of information from others who knew them well and who could say, for example “when he does x/ makes sound y/ makes facial expression z, we think it means that he is enjoying something/ distressed/ tired.” The consultation group of people with mild-moderate intellectual disabilities advised that before observing I should get to know people and explain what was going to happen and that when observing, I should, if possible, sit down rather than stand up. They said that they might find it easier to be observed, if someone known to them were also present (e.g. a member of support staff or family member) and warned that it could get crowded and that I would need to be alert to health and safety risks.

Over a year, a relationship developed between me and participants, including those with intellectual disabilities and extended periods of participant observation can risk expectations that cannot be met of this continuing (Tuffrey-Wijne et al., 2008). I therefore tried to be clear about my reasons for being present and that the relationship would be time limited (or at least to act in a way that did not give another impression). I considered how I might withdraw from Cavendish House and terminate relationships in a gradual, planned and respectful way, seeking in particular not to end contact suddenly or unexpectedly. The nature of the setting,

with different people on shift every time I visited and key members of the staff team leaving before the end of the case did, however, mean that my withdrawal did not follow this plan quite as hoped.

As both researcher and occupational therapist, I had a dual duty of care and responsibility to act on any concerns arising about observed practice, in accordance with my profession's Code of Ethics and Professional Conduct (College of Occupational Therapists, 2015) and local multi-agency policies and procedures for safeguarding adults. This duty included potentially needing to disclose confidential information in order to prevent serious harm, injury or damage to a participant or third party should instances of criminal activity, violence, abuse, neglect or poor practice have been revealed, disclosed, or observed. The possibility of this was highlighted in all information sheets, so that participants were fully aware before consenting to participate. Esther was herself under a similar duty of care in the ordinary course of her role as an occupational therapist. We discussed our mutual concerns about some observed practice, though in seeking to promote good standards of support, her intervention in any case aimed to address these. It felt appropriate therefore to leave further response to her professional judgement and I considered that this fulfilled my obligation to act.

4. Portrayal of individuals

Accustomed to the research norm of preserving participant anonymity and despite some participants' willingness to be identified, I took efforts to ensure that all did remain anonymous. In choosing to be identifiable, participants (or consultees contributing to decisions in others' best interests) might not have thought through all consequences, or might have been anticipating particular findings. I also could not guarantee that future readers of the case would form fair and sensitive judgements.

The issue of anonymity arose specifically in connection to filming aspects of the case, allowing observation when I could not physically be present and participants to watch and reflect on footage during interviews. The consultation group of people with mild-moderate intellectual disabilities were supportive of this filming, even when someone could not agree to it themselves, provided that it was overt. Two consultees said they would be curious about what had been recorded and would want to have their own copy and to see footage before others. One, himself involved in training support staff, thought that recording could be useful for training purposes. As a group they did, however, find it difficult fully to imagine what the research would involve and

suggested that watching filmed excerpts could help with on-going consultation. This prompted me to gain ethical and research governance agreement that certain clips from the video recordings (anonymised using pixilation), could be used in future research consultations.

The consultation group and the MCA consultees of participants lacking capacity supported the choice to film aspects of the case but I remained uncertain that I could justify, or convince an ethics committee to approve, inclusion of filmed data within the research findings, thus potentially identifying participants. I therefore took the cautious approach of not regarding these recordings as primary data sources, but rather as data triggers for my own field notes and for participants' reflections in interviews (Haw and Hadfield 2011), not including film excerpts in the research findings. Some of this footage, however, beautifully illustrates and brings to life the findings and could have supported my aim of keeping people with profound intellectual disabilities visible and central within presentation of the case. Some argue in favour of research participants not remaining anonymous, for example to celebrate the lives of protagonists (Simons 2009) and to promote self-advocacy. In hindsight, I wonder whether a stronger case could have been made for inclusion of some of this as primary data.

Whilst preserving anonymity, I sought to present findings in sufficient detail to retain connection with context, to provide a worthwhile and convincing argument in support of conclusions, to allow readers to consider their own interpretations (promoting transferability) and to provide an adequate audit trail (Thomas, 2011). I quoted actual words of participants, but took care that combinations of incidental details (occupation, location, age, gender and ethnicity) would not inadvertently lead to identification. Where necessary some details were changed to avoid this. I was conscious that participants could feel let down by their portrayal, including in ethnodramatic vignettes (Saldaña, 2011) constructed from data excerpts. Their portrayal could potentially impact on how they saw themselves or were seen by others. As suggested by Basse (1999), I tried to research from a position of respect for all participants, including motivations attributed to what was observed and their portrayal. The findings were constructed by me, but I gave Esther in particular opportunity to respond to the accuracy, relevance or fairness of her portrayal, editing this and adding in some of her comments (Simons, 2009). Sadly, due to the time that elapsed between data collection and write up, along with significant staffing changes at Cavendish House, it did not prove possible to gain the perspectives of all participants on the case report.

Conclusion

The methodology of this research was effective at enabling a deep understanding of the subject. Detailed discussion of the design and inherent ethical issues in this article has provided an illustration of a way of ethically designing and justifying evolving qualitative research of this type, involving participants who cannot consent to participation themselves. This level of detail is necessary for readers – including both prospective participants and those on ethics committees – to be able to judge the integrity of a study's design and whether the benefits of participation can be said, using proportionate reason (Angrosino, 2007) to outweigh residual risks. Rather than merely a “hurdle” to get through, gaining ethical approval was an opportunity to discuss, gain feedback on and improve the research design and I valued these discussions and made use of the committees' comments.

Participants with capacity (and the consultees of those without) were alerted to residual risks by explicit reference in information sheets. The intrusiveness of participating in the research was minimised and the experience for participants with intellectual disabilities was considered not radically different from the way they would usually experience occupational therapy and thus reasonably commensurate with and no riskier than routine support and services. Safeguards were in place to minimise consequences of any risks that did arise.

The research explored in this article relates to the specific fields of occupational therapy and intellectual disabilities in England and reflects ethics and governance processes and the legal position regarding capacity and consent there. Many of the issues arising are, however, considered sufficiently general to have relevance outside England and when considering recruiting other populations who may not have capacity to consent to participation in research, for example people with dementia.

Lessons learned and implications for practice

Ethical issues inherent in some types of qualitative research such as ethnographic or case study research, where study designs evolve and the numbers and exact nature and number of participants are difficult to predict in advance, can make justification and gaining ethical approval challenging. Additional challenges arise when some prospective participants are very likely not to be able to consent to research participation themselves.

It is possible, however, to design research of this type well and thus to gain approval of ethics committees. To do this requires thorough consideration of ethical issues related to topic relevance and design, recruitment (whether by informed consent, or in participants' best interests), collection of data and portrayal of participants in the eventual case report. Extensive detail is needed regarding these matters and the range of possible experiences potential participants in the study may have in order that both they and ethics committees can judge integrity and whether the benefits of participation can be said to outweigh residual risks.

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