

Troubling researcher-led recruitment: the self-selection of brain-injured adults who lack capacity to consent

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Introduction

Respecting and safeguarding individuals, especially those deemed ‘vulnerable’, is essential to research ethics and integrity (Daley, 2015), yet there have long been concerns about the lack of involvement of people with disabilities, and the subsequent silencing of their voices, in social science work (Barnes, 1996; Nind & Searle, 2009; Nind, 2011). Such concerns centre in particular on those who have cognitive or speech impairments and those with profound impairments and multiple needs (Nind, 2011). Methodology has been seen as one major barrier to involvement, for example people with cognitive and speech impairments may be excluded because they have been seen as ‘difficult’ or even ‘impossible’ to interview (Hutchinson et al., 1994).

Reducing methodological barriers to inclusion in social research has been extensively addressed over the past twenty years through the development of new emancipatory approaches and participatory, visual and creative methods and more recent recognition of the applicability of traditional methodologies (such as ethnomethodologies) for the purposes of enabling involvement (e.g. Boahen, 2015; Jepson, 2015). However, the inclusion of people with profound and multiple needs is not challenged by methodology alone; another key challenge is ‘consent’, how it is gained and handled by researchers and ethics committees (Lloyd, 2013).

Many people with profound and multiple needs – including those with learning disabilities acquired brain injuries, dementia or other progressive neurological diseases lack the capacity to consent to involvement in research on their own behalf and key legislation is in place to both protect and enable these people (Parker et al., 2010). The Mental Capacity Act 2005 (MCA) established a legal framework for assessing cognitive capacity, a process for making decisions on

behalf of incapacitated adults and conditions under which these adults can be lawfully included in research (see sections 30–34).

The use of research interviews and observation (all ethnographic and participatory methodologies) with people who lack capacity to consent on their own behalf, is included in that which is considered as ‘intrusive’ under section 30 of the MCA (Johns, 2007; Jepson, 2015). Under the requirements of the MCA (2005) researchers wanting to involve people who lack capacity to consent must obtain approval from an ‘approved research ethics committee’ and demonstrate that the research relates to the ‘impairing condition’ that causes the lack of capacity and/or that the research will increase knowledge of the care or treatment of people with that condition. They must also have an understanding of the Act’s principles and its Code of Practice and be able to demonstrate this through the design and proposed conduct of their research.

A significant safeguard relating to the recruitment of individuals who lack capacity is that the researcher must seek a suitable ‘consultee’ to both ‘consult as far as possible’ with the individual, and taking into consideration any prior expressed values and beliefs, advise the researcher whether or not the person would or would not be content to take part in the research (MCA, 2005).

Throughout the MCA (2005) there is an emphasis of ‘protection’ of the person who lacks capacity, and this is given priority ahead of aiding and maximising participation. The focus on protection in research governance is noted within ethical guidelines guarding the involvement of other ‘vulnerable’ groups in research, such as children (see Daley, 2015). Subsequently, protection is foregrounded within research practice, especially with those who lack capacity and research is conducted through and with multiple safeguards in place. However, there are challenges in practice to conducting research under such requirements.

Emerging literature has begun to highlight complexities of micro-ethical negotiations in fieldwork relations and problems with putting into practice the research governance and ethical components of the MCA (2005). For example, on the one hand, issues surrounding the involvement of those who might be ‘suggestable’ arise for some researchers working with people with learning disabilities and the historical argument of the researcher as powerful and potentially exploitative, however well-meaning, is rehearsed in such cases (Boahen, 2015). On the other hand, there are suggestions that ethics and research regulations regarding consent can be so heavily focussed on

‘safeguarding’ that they act as a barrier to involvement and *prevent* participation (Daley, 2015). In the case of social research, this argument is extended further to suggest that setting ‘informed consent’ as a key ethical principle privileges certain methods and prevents the use of others such as covert methodologies (Calvey, 2008), and Dingwall (2008) goes so far as to argue that ethical scrutiny is ‘fundamentally wrong’ due to the potential for damage to knowledge production.

Although extreme ends of these arguments are presented, a middle ground is also offered within the literature. While the need for research governance and ethical regulation is acknowledged, equally there are calls for the recognition of practice-theory gaps in applying guidelines and legislation in the field, and the potential for ethical requirements to hinder participation through the bureaucracy of over-protection.

Despite the development of emancipatory and participatory approaches to research which acknowledges the disabled and ‘incapacitated’ adult as ‘holder of opinions and worthwhile insider insights’ (Nind, 2011: 350) and capable of being competent actor in their own right, the protective emphasis within ethics guidelines continually constructs and presents participant selection and recruitment as linear, researcher led and initiated.

Through telling the story of a brain injured woman, Riya, and her participation in a PhD research study I contribute to these debate in two main ways:

- 1) Focusing on experiences of conducting an ethnographic study and the recruitment of people with severe brain injuries, I problematize the notion of recruitment as linear and a researcher led process as dictated by the MCA (2005).
- 2) Arguing that the research governance guidelines within the MCA (2005) regarding recruitment and inclusion appropriately assist the inclusion of some people who lack capacity to consent by providing a clear process to be followed. However, I highlight practical difficulties in establishing and selecting nominated consultees in some cases – a critical part in the process – and ask whether, in practice, a new sub-category of those who lack capacity is now being created – a group of people who are unable to be involved in research and whose voices are therefore remaining silent.

The study

My PhD is concerned with exploring how the futures of people with severe brain injuries are shaped during rehabilitation. The core research involved a five-month ethnography in two independent sector (non-NHS) inpatient neurological rehabilitation settings in England: 'Bracken Lodge' and 'Goodleigh Hall'. This included observation on wards where people with severe acquired brain injuries were being cared for, combined with informal discussions and formal audio-recorded interviews with resident, families, health care workers and other staff working in these centres. Data collection was conducted over three months at 'Bracken Lodge' (August to October 2014) and over two months at 'Goodleigh Hall' (February to April 2015). Thirty-six separate fieldwork visits were made, averaging three days a week throughout the research period.

I aimed to include residents with differing types and severity of impairments. In practice however, selection was also guided by those who made any attempt to interact with me during periods of 'broad observation'. This proved important because first, the main tool of an ethnography is the ethnographer. It is critical that those being observed are not overly disconcerted by the presence of the researcher as if this disrupts the 'goings on' too much, the phenomena under study may be lost. Demonstration of comfort with or willingness to interact with the researcher provides an indication that the individual might be able to tolerate being more closely observed and not become distressed through their participation. This is particularly important in the context of working with people with severe brain injuries, whose injuries can impair reasoning abilities and perception for example and cause the development of emotional, psychological and behavioural changes such as aggression, anxiety and hallucination.

Eight residents with severe brain injuries were recruited for interview and/or close observation. 'Close observation' in this case consisted of between six to eight sessions of (up to) two hour observations. This time included observation of therapy sessions, review meetings, personal care and time with family. Four of the eight patients involved in this way lacked capacity to consent on their own behalf.

The ethnography began with a period of 'broad observations', a period of time where I was not focused on individuals but on general happenings within the setting. Broad observations continued throughout the ethnography in-between interviews which helped me to become a regular and recognizable face as I sat in open spaces: receptions, lounges, gardens etc. It is an interaction

experienced while conducting such broad observation that I now focus on here.

Observing and being observed – capturing one another

During my time at Bracken Lodge, I would sit at the far end of the communal lounge and observe everyone that sat in and passed through that space for up to an hour at a time. Riya, a brain injured woman was one of six residents who was often sat there. Riya could speak at least two languages and would often speak in a mixture of them. English would break through when she was cross, felt ignored or made a demand. Riya could be fun-loving and seek to interact with those around her, but she was also easily angered and at times, would wail in distress. Her happiness, anger and distress was not evidently stirred by anything in particular and her emotions and 'behaviours' could change suddenly.

Riya was able to make some decisions for herself, for example deciding what to eat given two options to choose between. However, she lacked the ability to remember and assess information in order to make decisions about more complex issues. This applied to making a decision about her involvement in the research. Riya lacked the capacity to give informed consent to participate in my study.

Riya had one visitor, who visited infrequently, and I did not speak her language. No other family members or friends were in contact with her. This meant, that because I did not have funds for a translator¹, there was no personal consultee I could talk to regarding the potential of Riya's participation in the research. Riya was not well known by staff, her history was unclear and no one could tell me much about her. No individual member of staff seemed to have a better rapport with her than others although many knew her well in terms of her behaviours and preferred care routines. In theory, a health care professional working with any such resident would often be fully appropriate to act as a nominated consultee, in the case of Riya, it seemed that no one knew her well enough.

¹ Ethical approval for this doctoral study was gained from the Social Care Research ethics committee, who granted approval in the knowledge that the study would include only those who could communicate through the English language. The Health Care Authority does consider 'cost' as a 'fair' reason for the exclusion of those who may have 'difficulties in adequate understanding of English', particularly in student/educational research (see hra.nhs.uk). However, language as a barrier to consultation for the enablement of Riya's participation does raise ethical issues. In theory it may have been possible to access local services, but in practice it is likely that such attempts would have outrun the data collection period. At one setting I observed long waits and high costs for translators required for patient communication directly relating to their care, let alone decision-making or for research purposes.

Within the space of the lounge from one side of the room to the other, Riya attempted to interact with me on many occasions but, because of the distress that Riya displayed at times and because there was no ‘personal’ or no truly appropriate ‘nominated’ consultee her inclusion in my research was not taken further.

Even though I could not observe Riya closely, speak with her in terms of conducting any type of interview or learn her personal routines, she formed a critical part of the everyday within that place. She contributed to my understanding of the setting that I would later describe. Unable to involve her further I appropriately kept my distance, not to intrude upon Riya. However, towards the end of data collection at Bracken Lodge I was walking through the lounge one morning passing Riya who was seated in a wheelchair at the end of the room, and the following occurred.

Riya stretched out her arms towards me, grabbed my hand and then arm and pulled me towards her. Her grip was strong and she took more and more of my arm to such an extent that I was held captive in her firm but friendly grasp. Bringing my face close to hers she began to chatter to me in a whisper, with all the expression and sound of divulging deepest secrets and imparting the latest gossip. Riya is brain injured and although she has speech it is a mix of jargon (of made-up words) and the multiple languages and dialects she speaks that I do not. Riya holds me close and chatters away. I look at her and smile while she tells me all she wishes. Standing in an awkward and uncomfortable position pulled down and in by Riya I gently try and release myself from her grasp but every time I try she pulls me closer still. I nod towards the chair by her side and tell her I need to sit down. She releases her grasp just enough to let me move, hovering her hands over my arms as I move towards the chair, ready to pounce and grab me tight again if I attempt to move away. Once seated Riya grips me tight once more and pulls me in to her and returns to her whispers, apparently sharing her deepest thoughts, all the gossip, chatting and giggling with me. Jane, a health care assistant walks past us:

Jane: “She won’t let go of you now! Riya let go of her, you don’t even know her!”

Riya looks up at Jane, speaks to her in another language, sternly and with exclamation. She looks back at me and gently strokes my face and looks back up at Jane crossly, pulls me closer still and carries on talking to me.

I do not know what Riya has said to Jane, and Jane does not know either, but through the tone of her voice and the action of stroking my face, I interpret her to have told Jane that of course she knows me, that I've been there for months, how can she say that she does not know me?

(Extract from Field Notes)

Following my purposeful and careful avoidance to remain at distance and not to 'intrude' on her, Riya 'captured' me herself. She brought me to her and held me in an interaction. While I was, at a distance, trying to 'capture' her world and unsure whether I should or could encroach into it any further, Riya answered that herself by bringing me to her. Riya chose to be participant. She saw me, not as a stranger, but as a familiar face and one with which she chose to interact.

Analysis and discussion

The MCA (2005) and research committees frame those who lack capacity as unable to 'act' in the recruitment process. Recruiting such participants is a process that is presented as researcher-led, impregnated with formal sets of safeguards – the involvement of a consultee, to name but one. Here however, through ethnography, I demonstrate how 'recruitment', the choice of interaction and involvement between participant and researcher is more fluid and can be more participant-led than the one way, mainly researcher-led focus of research governance guidelines prescribe.

In all cases in my research, potential participants who lacked capacity (and were conscious) but often severely impaired, with complex and multiple needs, actively demonstrated whether or not they were willing to be observed. The extreme example of Riya is but one. People with impairments ranging from mild to severe also chose whether or not to interact with me. Those who were mobile through any means and able to converse verbally, did so spontaneously, enquiring about me and engaging in conversation. Those who were unable to communicate verbally and whose close family had acted as personal consultees and advised their will for involvement, responded to my presence and to me through gesture and behaviours. Their responses to me were then checked and interpreted by family and staff members who knew them well. Equally, several residents who lacked capacity to consent but whom I would have selected to explore the potential of their becoming 'participant', demonstrated to me that I was not welcome or wanted in their space. With scowls and physically turning

away, they made it known that my presence and watchful eyes was considered intrusive to them. In those cases I moved away and did not pursue their participation.

In practice then, many residents ‘self-selected’ by either coming towards me and interacting with me or de-selecting, by making it evident they did not want me around. While I do not wish to suggest that ‘interaction’ equals consent it does provide a key indicator of willingness to interact, or not. In research which utilises methods such as ethnography, where the presence of the researcher must be at the very least, well tolerated, the gathering of interactive potential and the tolerance of presence is critical for the appropriate participation of those who lack the capacity to consent on their own behalf.

My interaction with Riya however raises two further considerations. Although in theory there were many health care professionals who could have acted as a ‘nominated consultee’ for Riya, there was no one who knew her well, or who had a particular level of rapport above that of others. The MCA Code of Practice and Department of Health supporting documentation (DoH, 2008) places the onus on the researcher to satisfy the ‘approved ethics committee’ that the process of seeking out nominated consultees is contextually appropriate and offers extensive explanation regarding what nominated consultees are and who can potentially fulfil the role. A nominated consultee can be someone who does not know the individual at all. They can, for example, be outside of the care team and part of a locally organised panel that has been set up for supporting research with people who lack capacity to consent (DoH, 2008). However, although the nominated consultee may not know the individual they are being consulted about, or know them well, they are entirely reliant upon gathering information about the person. The nominated consultee must seek out any prior expressed values and beliefs and/or ‘how the wishes and interests of the person who lacks capacity would incline them to decide if they had the capacity to make the decision’ (DoH 2008: 10). This therefore relies upon *someone* knowing that information.

Although information about Riya was available and could have been sought from her visitor through a translator, there were many other residents at Bracken Lodge and Goodleigh Hall who did not have any visitors and the person’s preferences, beliefs and wishes were largely unknown. Are there then, a subset of people who are ‘unknown’ or not known well enough for consultation to ever be appropriate to enable their involvement in research? Does the guidance surrounding the role of the ‘nominated consultee’ need to be

expanded further to include taking into account the practical possibility of meeting those about which little is known?

The information gleaned about Riya came from the broad observation period of my data collection, where gaining individual ‘consent’ was not practicable nor required under the ethical approval I had for that part of the ethnography. Using Riya’s data to talk about her medical care or her ‘future’ (as is the focus of my PhD) would be unethical, however Riya repeatedly demonstrated a will to interact with me. When she got the opportunity to bring me to her she literally reached out and took it, and expressed familiarity, and even tenderness. It would be unethical for me not to write about her in any way. I cannot leave her out when she made so sure that I saw her and that I knew she had seen me.

Conclusion

Some barriers to involving those who have profound impairment and multiple needs have been tackled through the creation of new methodologies and political and ethical arguments of emancipation have been well aired and taken seriously so research now includes those who are under study. However, new barriers to involvement, namely that of gaining ‘informed consent’ may have been created by the safeguards written in to the MCA (2005).

Although the recruitment process is framed as a one-way process, research initiated and led, here I have shown that those who lack capacity can have the potential to take ownership of interactions themselves. They have choices which they make – not based on weighing up information provided to them or necessarily an understanding that research is in process, but in response to people, in this case, to a person. This type of self-selection may be fleeting and yet still meaningful.

The demonstration of willingness to engage with the researcher is an important and helpful first step towards involvement in research of some of this vulnerable group, and can be followed through with the appropriate consultation process as prescribed by the MCA (2005). The problem however comes, when consultation cannot be easily found or established.

Although the MCA (2005) enables the participation of many who, without this legislation would be more likely to be excluded from research, there is the potential for the creation of a sub-category of those who are to be excluded *because* of the safeguarding processes within the legislation. The experiences of those who are disconnected from families and those not known well enough

by those who care for them could become under-represented when truly appropriate nominated consultation becomes difficult to secure in practice.

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