Paper Title: More than words: The use of video in ethnographic research with people with intellectual disabilities.

Abstract

There is a tendency to exclude people with intellectual disabilities from participating in research about their own lives. Whilst the use of participatory research approaches is increasing, the methods used for engaging people with intellectual disabilities in research are generally limited to interviews and focus groups. Yet a focus on the spoken or written word can present a challenge for those who may prefer to use alternative forms of communication. The purpose of this article is to share the methodological insights gained from a visual ethnographic study that sought to explore the experiences of people with intellectual disabilities engaged in nature based (or 'green care') therapeutic interventions for health and wellbeing. If used within carefully negotiated relationships we suggest that video can be an empowering visual medium for doing research that can help to elicit the experiences of people with intellectual disabilities first-hand, without having to rely on the views and perspectives of other people.

Introduction

People with intellectual disabilities have typically been given few opportunities to participate in decisions made about the services they use and there is a tendency to exclude this particular group from participating in research about their own lives (Goldsmith & Skirton, 2015). Indeed, up until the 1980's people with intellectual disabilities were largely not involved, as active participants, in studies that were about them (Gilbert, 2004). While there continues to be an overreliance on the views of health and social care providers (as well family members and carers) in research, there is an increasing awareness that people with intellectual disabilities should be more actively involved in health and social care planning and in research (Strnadova et al, 2014; Read & Maslin-Prothero, 2018). For example, the UK Government White Paper 'Valuing People Now' states that organisations should no longer view people with intellectual disabilities as passive recipients of services, but as active partners (Department of Health, 2009). However researchers have identified limitations to this process when it comes to including the views and experiences of people with intellectual disabilities (Hollomotz, 2018). These have to do with abelist structures and processes that perpetuate unequal power dynamics that often exist between the (non-disabled) researcher and disabled research participant (Milner & Frawely, 2018). For example, a continued reliance on discussion based interviews and focus groups in qualitative research privileges certain 'patterns of able-bodiness' (Lester and Nusbaum, 2018 pp. 4), namely, people who use spoken or written language. Yet a focus on the spoken or written word can present a challenge for those who may prefer to use alternative forms of communication (Rojas and Sanahuja, 2012). These observations demand an open, flexible and proactive approach when doing health and social care research with people who may be considered marginalised or lacking 'voice'. To this end, there have been a proliferation of studies that have sought to engage people with intellectual disabilities in research through the use of creative and visual methodologies (Nind and Vinha, 2016; McLaughlin and Coleman-Fountain, 2018; Teachman et al, 2018).

Among the more common visual methods used in inclusive research with people with intellectual disabilities are photographic participation and elicitation techniques (e.g. Aldridge, 2007; Booth & Booth, 2003; Boxall & Ralph, 2010; Cluely 2017; Mathers, 2008; Povee, 2014). These methods have been used as a way for participants to document their

own lives and the people, places, interactions or events that are important to them. In this way, the use of photographic participation methods have been argued to shift the balance of power by offering people with intellectual disabilities more control over how they represent themselves and how they depict their situation (Booth & Booth, 2003).

The use of photographic methods is becoming increasingly common in research with people with intellectual disabilities, however the use of video as a methodological tool is far less common. Indeed, there are only a handful of studies that have utilised this approach in this field (e.g. Sitter 2015; Burford and Jahoda 2012; Rojas and Sanahuja 2012). However, as Rojas and Sanahuja (2012) argue in their paper, video can be an extremely useful methodological tool in research with people with intellectual disabilities. This is because video is able to capture non-verbal methods of expression, such as body language, facial expressions, voice intonations and physical interactions, which have important communicational value (Rojas and Sanahuja 2012). In this way, video has the potential to make visible the perspectives of people with intellectual disabilities who may prefer to use non-verbal forms of communication.

The purpose of this article is to share the methodological insights gained from a visual ethnographic study that sought to explore the experiences of people with intellectual disabilities engaged in nature based (or 'green care') therapeutic interventions for health and wellbeing. While there has been a long tradition of ethnographic research concerning people with intellectual disabilities (e.g. Gleason 1993; Pockney 2006; Tuffrey-Wijne and Davies 2007; Bromley et al. 2012; Niemeijer, Depla, and Frederiks 2015), there are a distinct lack of studies that incorporate video in ethnographic research with this group. As Davies (2000) observes, the challenge when doing ethnographic research with people with intellectual disabilities resides in the temptation to rely on others (such as staff or family members) to interpret participants' cultural world (Davies, 2000). To this end, ethnographers need to ensure that people with intellectual disabilities are treated as competent social actors, able to make decisions about when to communicate, and with whom (Nind, 2008).

Building on these insights and observations, this article critically examines the role of video in ethnographic research, and what this approach has to offer researchers working in the field of intellectual disability. If used within carefully negotiated relationships and viewed as a set of collaborative performances (rather than a set of realist or objective claims to knowledge), we suggest that video can be an engaging visual medium for doing ethnographic research, one that can help to elicit the experiences of people with intellectual disabilities first-hand, without having to rely on the views and perspectives of other people.

The empirical research

Setting the scene: researching the benefits of green care activities for people with intellectual disabilities.

There is now a whole body of evidence indicating that access to outdoor environments can have a beneficial impact on human health and wellbeing (e.g. Kaplan and Kaplan 1989; Pretty et al. 2007; Pretty et al. 2005; Ulrich, Roger 1984). As a result there have been an increasing number of initiatives, seeking to encourage marginalised groups to access outdoor environments to improve physical and mental health (One such initiative growing in popularity in the UK is that of green care in agriculture (or care farming).

Care farming is defined as the use of commercial farms or agricultural landscapes to provide health (both physical and mental), social or educational benefits through farming (Hine et al., 2008). People attending a care farming intervention generally follow a facilitated or structured programme on a regular basis, where the service is usually commissioned by health or social care, or through the use of personal budgets and direct payments. All care farms therefore seek to offer a balance of 'farming' and 'care', where the latter is typically delivered through therapeutic contact with farm livestock, food growing and/or horticultural activities (Hine et al, 2008). Care farming is therefore situated within a broader 'green care' movement, a collective term for activities that utilise plants, animals and landscapes to create interventions to improve health and wellbeing (Bragg, & Atkins, 2016).

In our study, we observed how the methods deployed in existing studies on the health and wellbeing benefits of care farming (e.g. standardised interviews and surveys) often fail to meet the needs of people with intellectual disabilities. Given this, there has been very little research to date that has offered an in-depth exploration of the health and wellbeing effects of care farming for this particular group (although there are some notable exceptions- see (Rotheram, McGarrol, & Watkins, 2017). This poses a very specific problem. Indeed, care

farming is increasingly being advocated as a viable alternative to more traditional forms of health and social care, and over 90% of care farms in the UK are currently providing services for people with intellectual disabilities (Care Farming UK, 2017). Yet the views and experiences of people with intellectual disabilities (the UK care farm industry's main service user) have rarely been sought. This reflects a more general tendency to exclude people with intellectual disabilities in research about their own lives (Milner and Frawley, 2018).

Given the current lack of evidence, this ethnographic study aimed to fill this gap through an in-depth exploration of the wellbeing effects of care farming for people with intellectual disabilities. Observations on the relative limitations of the methods used in previous studies suggested the need for more innovative and inclusive methods, including the use of video methods, through which to explore the views and experiences of the people who took part in this study.

Study design

The care farms

For this study, 3 care farm organisations delivering services to people with intellectual disabilities were recruited to participate in the research. These settings were selected to reflect the different types of care farms currently in operation in the UK, from commercially orientated or 'real' farms (where care farming constitutes an additional source of funding alongside food production) to farms that offer care services as their main, or sole activity, delivered though charitable organisations or social enterprises.

Participants

The study adopted an in-depth and intensive 'case study' approach where individuals were viewed as the 'case studies'. This particular approach was chosen as it allowed the researcher to explore the experiences of people with intellectual disabilities engaged in care farming activities in extensive detail, using a variety of qualitative data sources. Case study participants were selected on the basis that they had recently been enrolled on a care farming programme and were identified as having an intellectual disability (7 case study participants

in total). The study also recruited additional individuals that made up case study participants' wider networks of professional and personal relationships. This included staff based at the care farms that participants attended as well as family members and/or paid carers with primary responsibility for supporting case study participants (usually three additional participants were recruited per case study, thirteen additional participants in total)

Data Collection

Data was collated longitudinally over a period of 10 months to ascertain the impacts of care farming on the lives of people with intellectual disabilities over a sustained period of time. The fieldwork phase of this study comprised of two rounds of data collection. The first took place from July 2014 to October 2014, followed by a repeat round approximately six months later, from January to April 2015. This particular research strategy was designed to track participants' progress during their first year on a care farming programme and to gather subjective data on participants' experiences of care farming and any wider impacts of these kinds of activities. To this end, a range of qualitative methods of data collection was used for each case study. These are outlined in more detail below.

Figure 1. The case study design

[insert figure]

Participant observation

During fieldwork, a significant period of time was spent at each of the three care farm settings (approximately 30 days, 10 days at each setting). During these visits the researcher collated extensive observational field notes on participants (and the researcher's) behaviour, thoughts, feelings and actions, where these observational field notes primarily performed a supportive and guiding element to the interpretation of interview and visual material and as a resource for researcher reflexivity.

Video data collection

Video-data was collated over a period of 10 months, where time was spent with each of the case study participants at the care farm they attended (approx. 6 days with each individual),

video recording them as they went about their normal daily activities. The purpose of this part of the research was to capture participants' embodied and multi-sensory experiences when spending time at these farm settings. It also provided a means through which to understand the meanings that people attached to these experiences and how they contributed (or not) to wellbeing. Following the work of contemporary visual ethnographers (e.g. Pink, 2001; 2004, Banks, 2001; Grasseni, 2004) the researcher sought to ensure that the video ethnographic sessions were as collaborative and participatory as possible and that the audio-visual data collated reflected the intentionalities of both the researcher and participants. To this end, participants were also encouraged to 'direct' the content of these videos in ways that reflected their own interests and preferences and were frequently consulted about filming progress, editing options and future activities.

Visual elicitation interviews

Participants were invited to take part in two qualitative visual elicitation interviews. These took place soon after the video data collection sessions (within approx. 1-2 weeks) in order to ensure that participants had relatively fresh memories of the events, activities or social interactions being presented to them. The primary purpose of presenting participants with edited versions of the video footage was to provide them with certain visual cues designed to guide the interview process, prompt discussion and provide a basis for reflection. The first stage of the interview involved inviting participants to watch edited versions of their video footage. Selected scenes included those where an individual was perceived by the researcher to be gaining some form of enjoyment or benefit from participation in a particular activity, certain events that may have constituted a negative experience for participants, or scenes that evidenced a change in behaviour or relational capabilities. Participants were asked to describe in their own words what was taking place, how they felt emotionally during these scenes and whether (and in what ways) care farming had helped them to think and feel differently.

Photographic participation

In addition to the video data, case study participants were given disposable cameras and asked to take photographs that captured the things that they did and/or places they visited

during a 'normal' week. This part of the research was designed to help the researcher access participants' broader set of place experiences, beyond the care farm, in order to ascertain the wider impact that these kinds of encounters had on the everyday lives of participants. It was our intention that this part of the project was to be as user led as possible. Participants were therefore encouraged to take photographs of anything that was of interest to them. Participatory methods such as these have therefore been argued to give marginalised people more control over how they represent themselves and depict their situation (Cluely, 2017). These photographs were also discussed during the visual elicitation interviews.

Interviews with wider 'network'

Case study participants' family members and/or carers, as well as care farm staff were asked to participate in two semi-structured qualitative interviews (n=13, 26 interviews in total) over a 10 month period. These interviews sought to gain the perspectives, views and experiences of case study participants' 'wider network'. Topics discussed included the perceived impact of care farming on case study participants' wider lives, including any perceived changes in mood, behaviour or relational capabilities; social networks (or lack thereof); the impact on relationships with friends or family; participants' emotional wellbeing and any perceived lifestyle changes or improvements to health.

Data analysis

Both the text based and visual data were analysed using ATLAS ti. Data was analysed using an inductive and interpretive approach which proceeded by carrying out a preliminary reading of the data marking all significant sections of the interviews/video logs, annotating the transcripts and visual material (this included a commentary on non-verbal data i.e. body language and movement, hand gestures and facial expressions). The data was then coded in ATLAS ti using a grounded approach (i.e. allowing codes to emerge from the data, rather than coding a priori) where participants' data was analysed carefully and in substantial detail in order to ensure sufficient levels of interpretative engagement with the text. The final set of codes were subsequently analysed and re-grouped into categories based on their common properties. Each case study was analysed separately using this process, in order to ensure that the complexity of individual cases was not lost or subsumed under overarching themes

too early. This was followed by a cross case analysis which involved looking for patterns across cases as well as divergences in the data sets. The final set of themes identified was drawn from topics that occurred through the qualitative interviews, ethnographic field notes, video logs/transcripts and theoretical ideas from the literature review.

Ethical considerations

Permission to contact potential case study participants was sought through the care farm settings included in this study. After this initial meetings were set up with prospective participants (accompanied by a family member/carer where requested), either at the care farm setting which they attended or at another location of their choosing. If an individual did decide to take part in the research, they were then asked to sign a written consent form, produced in an accessible format where necessary.

The study was reviewed by the [Faculty] research ethics committee and approved by the University Research Ethics committee at [Institution]. Permission to use participants' identifiable visual images was sought prior to their usage in publications (see 'challenges' section for more detail).

In the remainder of this article we focus on the video element of the study. Specifically, we discuss the strengths and challenges of this approach, and what video ethnographic methods have to offer researchers working in the field of intellectual disability.

Doing participatory video with people with intellectual disabilities

Making ethnographic videos

Observing and video recording human experience and behaviour is an established technique in ethnographic research, and video is advocated as a useful ethnographic tool because of its ability to capture aspects of lived experiences that may otherwise be lost during observational field noting (O'Reilly, 2012). Whilst all participatory research seeks to be inclusive in some way, we argue that video methods are especially well placed in this regard when utilised in a study with people with intellectual disabilities. This is because video has the potential to generate an 'ethnographic awareness of largely unspoken processes' (Grasseni 2004, 12) such as facial expressions, gestures, voice intonations and other bodily movements, all of which have important communicational value.

In this study, the researcher wanted to explore how activities undertaken on care farms contributed to people with intellectual disabilities' personal development and overall wellbeing. Although the researcher's field diary and qualitative interviews proved to be a valuable source of knowledge in this regard, the ethnographic videos added a richness and depth to the qualitative data that would not have been possible to achieve through other methods. Figures 2 and 3 depict participants engaged in different care farm activities. These videos were made at participants' request because they depicted activities that they particularly enjoyed and had become very good at during their time at these settings.

[Figure 2]

[Figure 3]

Re-watching these videos helped the researcher to focus on different aspects of the events witnessed (e.g. the rhythmic motion of sanding wood, laughter between friends, a reassuring gesture or touch or feelings of physical exertion) and how these contributed to an experience that was both pleasurable and rewarding. Given participants' disability however, it was not always possible for them to verbally communicate these aspects of their experiences to the researcher. However by making videos about their experiences, they were able to show the researcher what they had learned and what they enjoyed about a particular activity. What is more, video recording people's experiences allowed the researcher to capture fleeting aspects of behaviour (e.g. smiles, gestures and other body language) that may not have been noted at the time of the event, but which seemed significant upon re-viewing the data. By focussing on person's interactions, skilled practices and learned behaviours we therefore concur with Rojas and Sanahuja (2012) that video can 'make visible the demands of those who prefer to use alternative forms of expression to the articulated word' (ibid. 32). In this way, offering people with intellectual disabilities the opportunity to show their experiences through video (rather than just talk about them) invited new ways of working with participants that valued their contribution to the research process.

'The thing with observation of filming him with the animals, you can gain a sense of what level of enjoyment and value he's getting out of it without him having to articulate that, which I think is really good' Sian, Farm Manager, Follow-up Interview).

It is argued that the use of video in research with people with intellectual disabilities has the potential to elicit their views and experiences, however others caution that it runs the risk of producing knowledge claims that are 'voyeuristic, distanced and disembodied' (Kindon 2003, 142). This is because making videos of people with intellectual disabilities for research purposes permits staring and legitimises the viewer's extended gaze (Garland-Thomson, 2002). This may be exacerbated by researchers maintaining control of the video recording technology, and feminist researchers have critiqued video as being a tool of the masculinist gaze, a gaze of objectification and unequal power relations (Carroll, 2014)

In view of these concerns, the researcher sought to develop a more ethical approach to video research, one that was collaborative, reflexive and that represented the voices of participants. From the outset, this required the researcher to be transparent about who was in control of the visual technology, what was being captured and how these images were produced and represented. Although it was the researcher who had control of the video recording technology (motivated by a desire to include participants themselves in these ethnographic videos), this did not mean that participants could not share control of the filming process as whole. To this end, participants were encouraged to 'direct' the content of these videos in ways that reflected their own interests and preferences. In doing so it was therefore intended that these videos would offer participants more control over how their experiences were represented (see Figure 4).

[Figure 4]

It is important to note here that encouraging research participants to collaborate in the film making process need not be limited to decisions made about what to film and when. Indeed, good participatory video should seek to ensure that participants have an active role prior to and *during* filming. In this study, this involved encouraging participants to engage with the video camera in ways that ensured their agency as co-producers. The video scene depicted in

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Figures 5 provides an example where the researcher and participant are engaged in a dialogue during filming.

[Figure 5]

Researcher: Oh I think it's too dark to film in here. **Neil**: Can't you see me? **Researcher**: No, not really. **Neil**: Go that way (points to door). **Researcher**: Over here. **Neil**: Yeah (Dialogue during a video data collection session)

As the video frame and interview excerpt above illustrate, encouraging participants to describe events as they are taking place, and to comment on things like camera angle and lighting can help participants to take a more active role in the film making process, thus blurring the boundaries between film maker and subject. Indeed, cameras, video and T.V. play an important role in our modern society and as such, are accessible to many different people. The people in our study knew how to use video recording technology and understood its purpose. Indeed, a number of participants had cameras on their smartphones that they regularly used to take photographs or make videos of their own. Video can, therefore, enable people to participate in research in a way that more traditional methods (e.g. interviews or focus groups) do not. This can help marginalised groups, like people with intellectual disabilities, to feel more empowered when doing research and to feel more confident about communicating their preferences.

Talking about ethnographic videos

As we have argued, video can be an engaging and inclusive visual medium during the data collection process. It can also serve as a useful tool in qualitative interviews with people with intellectual disabilities. The semi-structured interview is an established method in qualitative research, however, researchers who use this method with people with intellectual disabilities are often faced with certain challenges. These are to do with the fact that researchers often fail to elicit the depth of response that is typical of qualitative research (Hollomotz, 2018; Lewis & Porter, 2004). This may be linked to issues around low self-esteem, unequal power dynamics or barriers to communication (Clarke, Lhussier, Minto, Gibb, & Perini, 2005). The challenge therefore, becomes how researchers elicit qualitatively rich data without having to

rely on other people to articulate the views, perspectives and experiences of people with intellectual disabilities.

Inviting participants to directly engage with the visual data in which they feature is an established technique in participatory research (Pauwels 2015). Indeed, the use of photographs in qualitative interviews, otherwise known as photo interviewing, or photoelicitation, has become an increasingly popular methodological technique for accessing the views, experiences and beliefs of populations who might otherwise be excluded from participating in social research (Aldridge, 2007; Wiles et al., 2008). Although the use of video as an elicitation technique in qualitative interviews is far less common, this method has been utilised in several studies to generate participants' accounts of an event, gain insight into a particular point of view or learn more about the practices and meanings that relate to a particular setting (Forman, & Fetters, 2011; Henry & Fetters, 2012).

Asking people with intellectual disabilities to watch and discuss the videos in which they featured proved to be an effective method of engaging participants more fully in the interview process. Indeed, it is argued that video material can serve as a good ice-breaker when trying to talk to people about their feelings and emotions, particularly if it concerns their immediate environment or a subject of interest to the viewee (Pauwels, 2015).

[Figure 6]

Neil: I'm always wearing the same t-shirt. And I'm wearing the same hat that I've got on now and trainers, but different trackies I just got.... I got a beard growing.....I always have my hood up and my trousers down low. **Researcher**: So why is that? **Neil**: Dunno, it's the fashion. **Researcher**: So do you like to be fashionable? **Neil**: Yeah (Neil, Followup elicitation interview)

As the video frame and accompanying excerpt in Figure 6 illustrate, the people who participated in this study enjoyed watching and talking about videos of themselves. This helped to sustain participants' interest and engagement throughout the course of the interview, where the audio-visual material provided a structure for the interview that was enjoyable for participants, rather than dull or irritating. This also helped participants to feel

less anxious about the research process and about answering researcher questions, and encouraged them to be more confident about expressing their views. Incorporating videos in qualitative interviews can therefore foster good researcher-interviewee relationships, where the latter feels enabled to participate in ways that were meaningful and interesting for them.

Other studies that have used video elicitation techniques during the interview process suggest that the researcher should watch the videos with participants in one sitting and discuss these afterwards (Henry and Fetters 2012; Burford and Jahoda 2012). However, when interviewing participants who took part in this study it became apparent that the most effective interview method involved talking with participants while watching the videos together, as well as pausing the video at specific points to allow for further comment. This helped participants to focus on the specific events and activities as they were being presented to them and, by breaking up it up in this way, made the interview process more manageable and engaging.

Importantly, the use of video in interviews need not be restricted to a discussion of the events and experiences being presented. Indeed, use of this technique can help to broaden the interview by encouraging participants to relate these experiences to other experiences or significant life events.

[Figure 7]

Researcher: So you're all working together here to make the fire? **Robert:** As a team **Researcher:** As a team yes. Do you like working as part of a team? **Robert:** Yeah I've done it before. Made our own BBQ at our last place. **Researcher:** OK. So you're quite used to working as part of a....**Robert:** Team, yes. **Researcher:** And how does it feel, working as part of a team? **Robert:** Very good. **Researcher:** And why is that do you think? **Robert:** If you work in a team its.....if you work by yourself it's not so good....Cause when I'm at home I find some people hard to get on with. **Researcher:** And why is that do you think? **Robert:** Cause they're shouting and screaming. **Researcher:** So there are some arguments that happen at home? **Robert:** Yes. And it's hard to concentrate. Just try to stay out of it. (Robert, baseline visual elicitation interview)

In the example above we observed how the discussion moves from the current event being witnessed to broader issues relating to social relationships and the value of 'team work' as well as problems at home. Participants often found it difficult to conceptualise their emotional state in more generalized or abstract terms, however having something material and concrete to watch and discuss provided a useful focal point through which to explore complex issues. The use of videos in the interview process can, therefore, help to elicit deeper, or more abstract, perceptions and values from interview participants and may be particularly useful for a study that seeks to include the views and experiences of people with intellectual disabilities, who may find it difficult to articulate their feelings or emotions.

Analysing ethnographic videos: (Re)presenting experience

For this study, digital video was a valuable tool through which to engage the full sensuality of participants' experiences, that is, the sights, sounds, smells, tastes and tactile sensations that characterise interactions between people and places. Watching the videos back helped the researcher to access the sensed or felt qualities of those interactions and the way in which these experiences facilitated (or inhibited) therapeutic gain. Of course, we are not claiming here that video was able to directly record things like smell or touch, merely that the audio-visual data provided a route through which the researcher could empathise with participants' multisensory and embodied experiences beyond the aural or visual (Pink, 2001).

Although video has the potential to enhance ethnographic awareness, video does not (and cannot) offer the researcher unmediated access to people's lived experiences. A video recording is just that, a recording. It presents the viewer with a representation of experience, not experience itself. Rather than viewing video as a means of recording human experience in any direct or objective sense, we therefore follow Pink (2001) in arguing that 'reality is subjective and is known only as it is experienced by individuals' (ibid, p. 36). Inviting people with intellectual disabilities to directly engage with the visual data during qualitative interviews proved to be an effective method when asking participants to talk about their experiences. Watching and discussing their research videos helped participants to remember

'what-it-felt-like' to be doing a particular task or activity and provided them with the means to recall aspects of their experiences (e.g. encounters, sights, sounds, feels and tastes) that might not have been possible to elicit otherwise. The knowledge produced during the interview process therefore helped to deepen the researcher's own understanding when analysing these videos, and significantly influenced how they chose to represent the experiences of those who participated in the research.

[Figure 8]

Researcher: Can you remember what you're doing here? **Simon:** I remember this, picking blackberries. **Researcher:** Yes that's right. Do you remember you made the jam? **Simon:** Yep. Ate it all, yum! Get prickled (points to video). **Researcher:** Yes that's right, you pricked your finger whilst we were picking the blackberries. **Simon:** And you ate it all. **Researcher:** (laughs) Yes I ate them all so I wasn't being very helpful was I. **Simon:** And the dogs. **Researcher:** That's right yes, we met some dogs on the walk didn't we and you stroked them. **Simon:** Yeah and spoke to them people, that was fun. (Simon, baseline visual elicitation interview, October 2014)

Our approach to data collection and analysis sought to be as reflexive as possible. This required the researcher to critically reflect on the way in which researcher subjectivity and the process of doing research impacted on the knowledge that was produced (Davies, 1999). Although this is a concern for all social research, good reflexive practice is especially important in ethnographic research where the researcher is typically required to spend a significant amount of time with the society or culture being studied. Indeed, the relationships that are formed between ethnographers and participants have a crucial role to play in the research process whereby ethnographers typically 'help to construct the observations that become their data' (Davies, 1999, p. 32).

To this end, the audio-visual data was treated as contextual ethnographic knowledge that is co-produced (rather than a realist set of observations) (Grasseni, 2004). This involved scrutinizing the relationships between the meanings given to these videos during fieldwork and academic meanings later invested in the same images. This approach therefore acknowledges that videos are interpreted in different ways and by different people at different points in the ethnographic research process (Mitchell, 2011). Data analysis was not, therefore, a simple matter of interpreting the visual content of the video data, but involved examining how different producers and viewers of these images give subjective meaning to their content and form (Trena, Paulus, & Dempster, 2014).

It has been suggested that the use of video elicitation techniques also provides a useful way for researchers to cross reference and/or validate their own interpretations of the video data (Henry and Fetters 2012). This was important for the methodological approach adopted in this study, which recognised that there was no 'correct' way to interpret the audio-visual data, and that these images may well be given different meanings depending on who is viewing them.

[Figure 9]

Researcher: So what do you do when you need help, do you ask for it or can Liz or Lee normally just tell if you need help? **James**: Just tell 'em I think. **Researcher**: So when you're standing here (points to video) is this a time when you feel you need help? **James**: No, I was flattening 'em. **Researcher**: Oh I see so you were standing there to flatten the mole hills? **James**: Yeah. **Researcher**: So I thought you were just waiting, but you were busy doing something. **James**: Yeah. **Researcher**: So you seem to be working quite well on your own here then? (points to video). **James**: Yeah (James, follow-up visual elicitation interview).

As the above example demonstrates, James offered the researcher a different explanation of what was taking place during this segment of video data. Past observations had led the researcher to believe that this was one of those occasions where James was feeling uncertain and needed direction from a staff member, when in fact James was performing the task he had been instructed to do perfectly well. This is, therefore, a good illustration of how past experiences and biases can lead the researcher to interpret the audio-visual data in a particular way. It seems appropriate then, that participants should be given an opportunity to voice their own opinion, particularly when it is their actions and behaviours that are the subject of scrutiny. Asking participants to collaborate on the analysis of their ethnographic videos in this way, therefore helped to create a shared sensed of ownership over the audio-

visual data and offered people more say over how their experiences were represented. This denotes a commitment to visual research that 'looks with' or alongside participants rather than 'at' them (Kindon, 2003). When utilised in a study with people with intellectual disabilities we argue that this reflects a paradigmatic shift from research *about* to research *with and by* participants, and seeks to destabilise some of the hierarchical relationships that exist between research subjects and academics (Milner and Frawley, 2018).

Video ethnography: practical and ethical challenges

In this article, we have sought to demonstrate the added value of using video in ethnographic research that seeks to include the views and experiences of people with intellectual disabilities. There are, however, certain challenges associated with this approach that must be given due consideration here. Firstly, it is important to acknowledge that people given the label of 'intellectual disability' are not a homogeneous group of people and may be described in many other ways (e.g. friend, community member, son, partner, co-researcher). Given this, although video methods may work well for some people, for others there are likely to be better forms of communication. This demands flexibility through the research design to allow for a variety of forms of participation.

Related to this point, is the need to consider how the use of video in qualitative interviews could be adapted to include the views and experiences of people with little or no verbal communication. The participants in our study demonstrated a variety of communication styles (with some people being rather more verbose than others). In this respect, the use of video provided a useful and engaging object of reference through which to elicit a greater depth of response from those who were already able to communicate verbally, to varying degrees. However, as Aldridge et al (2007) acknowledge in their study, depending on the severity of participants' intellectual disability, eliciting verbal responses may not always be possible. This demands an open and inclusive approach when deciding 'what counts' as respondent engagement in qualitative interviews. To this end, recent research that has used visual methods (normally photographs) advocate a mediated and flexible approach to inclusive research that embraces and supports the needs of all involved (Boxhall, 2011; Cluely, 2017). In this vein, we argue that the use of video as an elicitation tool in qualitative interviews can open up new channels of communication in research not previously considered. For

example, by treating non-verbal responses to video footage (e.g. looks, gestures, or other behaviours which signify a preference (or dislike) for certain video scenes) as valid and worthwhile modes of engagement, in their own right.

In our study we observed that the video camera can be a very useful methodological tool, at certain times, and for certain people. However it can also be barrier to engagement. This is because a video camera's operation significantly limits the ethnographer's ability to physically participate in the everyday lives of the people being studied, given that their hands, and entire body, are otherwise occupied. Moreover the video camera is an ever present object during fieldwork and can, therefore, contribute to a physical (and symbolic) separation between the researcher and research subjects. Given this, time spent making research videos should be balanced against time spent simply 'being there,' getting to know participants, talking to them and engaging with them. This kind of approach can, therefore, help participants to feel more comfortable in the researcher's presence (and the video cameras) and enable them to feel more confident about communicating their preferences and what they want the video sessions to achieve, for themselves. Similarly, although video can be an effective research tool when used in public spaces or settings, it may not always be possible to replicate this in other places, such as individuals' homes. This is because observing and video recording people in their homes, or other more private spaces, has the potential to make people feel uncomfortable and may, therefore, feel too intrusive. In our study, we decided to give participants disposable cameras so that they might take photographs of the people and places that were important to them. This helped the researcher to capture important aspects of participants' life worlds where it was deemed ethically and/or organisationally problematic for the researcher to be physically present. While the decision to provide participants with disposable cameras was motivated, in part, by budgetary constraints, we see no reason why this process could not be replicated using video cameras, provided that there was a sufficient budget and time to train participants on the usage of the video recording technology.

It is important to acknowledge here that the participants who took part in our study were not given the opportunity to use the video recording technology themselves. As we have argued, the use of video in ethnographic research offers the researcher a unique opportunity to witness and record people's experiences as they unfold in real-time. Given this, it was very important for our study that participants themselves featured in these videos. On a more practical note, we did not have the resources to supply all of our participants with the necessary training and equipment. That said, the participatory process could arguably have been enhanced had participants been allowed to do some filming of their own. We therefore encourage researchers interested in video methods to explore all the available options when working with people with intellectual disabilities, as part of their research.

Despite developments in participatory research approaches, participatory data analysis has been underexplored when compared to other aspects of the research process. In an attempt to understand what it means for data analysis to be participatory, Nind (2011) advocates a flexible and pluralistic approach, citing many different examples of participatory data analysis that demonstrate a role for the participant as a 'sense-maker of data' (Nind, 2011 pp. 359). In our study, we collated many hours of video footage (approx. 30 hours per participant) as part of the research process. Given the impracticality (and implicated time constraints) of asking participants to view and comment on this amount of video footage, participants were presented with only substantially edited versions. While this aspect of the research was able to generate new and interesting insights into the specific events and social interactions presented, participants were not, therefore, being asked to collaborate on the analysis of the visual data as a whole. As a commitment to researcher reflexivity, it was therefore necessary to critically reflect on the decision-making process with regards to the selection of video scenes and the extent to which these were motivated by the researcher's own intentions and preferences.

Finally, the use of video methods raises some important ethical concerns with regards to participant anonymity and confidentiality. This is because much visual material makes the anonymization of individuals or locations problematic, if not impossible. Moving visual images portray clearly identifiable individuals, where these sorts of images can only be anonymised by altering the image in some way so as to obscure participants' identity. As we have argued in this paper, video methods have the potential to portray something additional to text alone. Given this, to tamper with images in ways that obscure certain important details, such as people's facial expressions, makes the purpose of collecting visual data questionable. Obscuring faces affects the viewer's ability to make sense of visual data because faces are necessary to enable us to interpret physical, psychological, social and emotional aspects of individuals (Pink, 2014). Moreover, many people who participate in visual research may

actually want to be identified by their visual images (Prosser & Loxley, 2008). This may be especially relevant for people with disabilities who advocate for their right to be made visible (Aldridge 2006; Booth and Booth 2003). It is therefore suggested, that audio-visual material should be presented in its entirety, enabling individuals to be identified with their consent. When doing research with people with intellectual disabilities, this requires the researcher to ensure that participants have fully understood what the implications of identifiable images being disseminated might be. This may require the researcher to present this information in an accessible format where special care is taken to ensure that participants have fully understood what is being asked of them and that consent to use visual images in this is way is voluntary and fully informed.

Conclusion

There is a tendency to exclude people with intellectual disabilities from participating in research that is about their own lives and it is only relatively recently that people with intellectual disabilities have begun to claim the right to participate in research 'about them'. However, the methods used for engaging people with intellectual disabilities have not always been sufficiently adapted to meet their needs. In this paper we have set out an innovative way of doing ethnographic research with people with intellectual disabilities. For us, the added value of video method lies with its potential to elicit the experiences of people who may prefer to use alternative forms of communication to the spoken or written word. This is because video values non-verbal forms of expression and offers people the opportunity to communicate their experiences by moving their bodies, as well as by using their words. Asking people with intellectual disabilities to engage with the videos in which they feature can also be an effective method of engaging participants more fully in the interview process, and can help to elicit a greater depth of response from those who may find the traditional interview format a challenging or uncomfortable experience. By focussing on the capacities of people with intellectual disabilities (rather than on their limitations) we therefore suggest that video can be an empowering visual medium for doing research and invites new ways of working with people with intellectual disabilities that values their contribution to the research process.

References

- Abell, S., Ashmore, J., Beart, S., Brownley, P., Butcher, A., Clarke, Z. & Wilson, D. (2007).
 Including everyone in research: The Burton Street Research Group. *British Journal of Learning Disabilities*, 35(2), 121–124. https://doi.org/10.1111/j.1468-3156.2006.00425.x
- Aldridge, J. (2007). Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disability & Society*, *22*(1), 1–17. https://doi.org/10.1080/09687590601056006
- Atkinson, D. (2004). Research and empowerment: involving people with learning difficulties in oral and life history research. *Disability & Society*, *19*(7), 37–41. https://doi.org/10.1080/0968759042000284187
- Booth, T., & Booth, W. (1996). Sounds of Silence: Narrative research with inarticulate subjects. *Disability & Society*, *11*(1), 55–70. https://doi.org/10.1080/09687599650023326
- Booth, T., & Booth, W. (2003). In the Frame: Photovoice and mothers with learning difficulties. *Disability & Society*, *18*(4), 431–442. https://doi.org/10.1080/0968759032000080986
- Boxall, K., & Ralph, S. (2010). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual & Developmental Disability*, *34*(1), 45–54. https://doi.org/10.1080/13668250802688306
- Boxall, K., Carson, I., & Docherty, D. (2004). Room at the academy? People with learning difficulties and higher education. *Disability & Society*, *19*(2), 99–112. https://doi.org/10.1080/0968759042000181749
- Bragg, R., Atkins, G., Bragg, A., & Atkins, G. (2016). A review of nature-based interventions for mental health care.
- Bromley, E., Mikesell, L., Mates, A., Smith, M., & Brekke, J. S. (2012). A video ethnography approach to assessing the ecological validity of neurocognitive and functional measures in severe mental illness: results from a feasibility study. *Schizophrenia Bulletin*, *38*(5), 981–91. https://doi.org/10.1093/schbul/sbr002
- Burford, B., & Jahoda, A. (2012). Do video reviews of therapy sessions help people with mild intellectual disabilities describe their perceptions of cognitive behaviour therapy?

Journal of Intellectual Disability Research : JIDR, 56(2), 179–90. https://doi.org/10.1111/j.1365-2788.2011.01450.x

- Carroll, K. (2014). Outsider, insider, alongsider: Examining reflexivity in hospital-based video research. *International Journal of Multiple Research Approaches*, *3*(3), 246–263. https://doi.org/10.5172/mra.3.3.246
- Cluley, V. (2017). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities*, 45(1), 39–46. https://doi.org/10.1111/bld.12174
- Collier, J, J. (1986). *Visual Anthropology: Photography as a Research Method*. University of New Mexico Press.
- Davies, C. (1999). *Reflexive Ethnography: a guide to researching selves and others*. London: Routledge.
- Department of Health. (2009). Valuing People Now: A New Three Year Strategy for People with Intellectual Disabilities, Making it Happen for Everyone. London.
- Garland-Thomson, R. (2002). The Politics of Staring: Visual Rhetorics of Disability in Popular Photography. In L. Snyder, Sharon, J. Brueggemann, Brenda, & R. Garland-Thomson (Eds.), *Disability Studies: Enabling the Humanities*. Modern Language Association of America.
- Goldsmith, L., & Skirton, H. (2015). Research involving people with a learning disability methodological challenges and ethical considerations. *Journal of Research in Nursing*, 20(6), 435–446. https://doi.org/10.1177/1744987115591867
- Gilbert, T. (2004). Involving people with learning disabilities in research : issues and possibilities Correspondence, *12*(4), 298–308.
- Gleason, J. (1993). The Creation of Meaning: What Persons with Severe or Profound Multiple Developmental Disabilities Do in Context. *Austrailia and New Zealand Journal of Developmental Disabilities*, *18*(3), 157–57.
- Grasseni, C. (2004). Video and Ethnographic Knowledge: Skilled vision in the practice of breeding. In S. Pink, K. Laszlo, & I. A. Ana (Eds.), *Working Images: Visual Research and Representation in Ethnography*. London: Routledge.

- Harper, D. (2002). Talking about pictures: a case for photo elicitation, *17*(1). https://doi.org/10.1080/1472586022013734
- Henry, S., Forman, J., & Fetters, M. (2011). How do you know what Martha looks like? A video elicitation study exploring tactic clues in doctor-patient interactions. *Journal of Evaluation in Clinical Practice*, *17*(5), 933–9.
- Henry, S. G., & Fetters, M. D. (2012). Research Method for Investigating Physician-Patient Interactions, 118–126. https://doi.org/10.1370/afm.1339.Department
- Hine, R., Peacock, J. and Pretty, J. (2008) *Care farming in the UK : Evidence and Opportunities.* London: NCFI.
- Hollomotz, A. (2018). Successful interviews with people with intellectual disability. *Qualitative Research*, *18*(2), 153–170. <u>https://doi.org/10.1177/1468794117713810</u>
- Juhasz, A. (2000). No Woman Is an Object : Realizing the Feminist Collaborative Video. *Camera Obscura*, *18*(3), 71–97.
- Kaehne, A., O'Connell, C., & Connell, C. O. (2010). Focus groups with people with learning disabilities. *Journal of Intellectual Disabilities*, 14(2), 133–145. https://doi.org/10.1177/1744629510381939
- Kaplan, R., & Kaplan, S. (1989). *The experience of Nature: A psychological perspective.* Cambridge: Cambridge University Press.
- Kindon, S. (2003). Participatory video in geographic research : a feminist practice of looking ? Area, 35(2), 142–153.
- Lewis, A., & Porter, J. (2004). Interviewing children and young people with learning disabilities: guidelines for researchers and multi-professional practice, 191–197.
- Lester, J. N., & Nusbaum, E. A. (2018). "Reclaiming" Disability in Critical Qualitative Research: Introduction to the Special Issue. *Qualitative Inquiry*, 24(1), 3–7. <u>https://doi.org/10.1177/1077800417727761</u>
- Mathers, A. (2008). Hidden voices: the participation of people with learning disabilities in the experience of public open space. *Local Environment*, *13*(6), 515–529. https://doi.org/10.1080/13549830802259912

- McLaughlin, J., & Coleman-Fountain, E. (2018). Visual methods and voice in disabled childhoods research: troubling narrative authenticity. *Qualitative Research*, 146879411876070. https://doi.org/10.1177/1468794118760705
- Milner, P., & Frawley, P. (2018). From 'on' to 'with' to 'by:' people with a learning disability creating a space for the third wave of Inclusive Research. *Qualitative Research*, 146879411878138. https://doi.org/10.1177/1468794118781385
- Niemeijer, A. R., Depla, M. F. I. A., & Frederiks, B. J. M. (2015). The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care, *22*(3), 307–320.
- Nind, M. (2008). Conducting qualitative research with people with learning , communication and other disabilities : Methodological challenges. Southampton: NCRM.
- Nind, M., & Vinha, H. (2016). Creative interactions with data: using visual and metaphorical devices in repeated focus groups. *Qualitative Research*, 16(1), 9–26. https://doi.org/10.1177/1468794114557993

O'Reilly, K. (2012). Ethnographic Methods. Abingdon: Routledge.

- Pauwels, L. (2015). "Participatory visual research revisited : A critical-constructive assessment of methodological and social activist tenets. https://doi.org/10.1177/1466138113505023
- Pink, S. (2001). Doing Ethnography: Images, Media and Representation in Research. Sage.
- Pink, S. (2011). Multimodality, multisensorality and ethnographic knowing: social semiotics and the phenomenology of perception. *Qualitative Research*, *1*, 261–276.
- Pink, S. (2014). Doing Visual Ethnography. London: Sage.
- Pink, S., Laszlo, K., & Afonso, Ana, I. (2004). *Working Images: Visual Research and Representation in Ethnography*. London: Routledge.
- Pink, S., Leder Mackley, K., & Morosanu, R. (2015). Researching in atmospheres: video and the "feel" of the mundane. *Visual Communication*, 14(3), 351–369. https://doi.org/10.1177/1470357215579580

- Pockney, R. (2006). Friendship or facilitation: people with learning disabilities and their paid carers. *Sociological Research Online*, *11*(3).
- Pretty, J., Peacock, J., Hine, R., Sellens, M., South, N., & Griffin, M. (2007). Green exercise in the UK countryside: Effects on health and psychological well-being, and implications for policy and planning. *Journal of Environmental Planning and Management*, *50*(2), 211–231. https://doi.org/10.1080/09640560601156466
- Pretty, J., Peacock, J., Sellens, M., & Griffin, M. (2005). The mental and physical health outcomes of green exercise. *International Journal of Environmental Health Research*, *15*, 319–337.
- Prosser, J., & Loxley, A. (2008). ESRC National Centre for Research Methods Review Paper: Introducing Visual Methods.
- Read, S., & Maslin-Prothero, S. (2011). The involvement of users and carers in health and social research: The realities of inclusion and engagement. *Qualitative Health Research*, 21(5), 704–713. https://doi.org/10.1177/1049732310391273
- Rojas, S., & Sanahuja, J. M. (2012). The image as a relate: video as a resource for listening to and giving voice to persons with learning disabilities. *British Journal of Learning Disabilities*, 40(1), 31–36. https://doi.org/10.1111/j.1468-3156.2011.00679.x
- Rotheram, S., McGarrol, S., & Watkins, F. (2017). Care farms as a space of wellbeing for people with a learning disability in the United Kingdom. *Health and Place*, *48*(October), 123–131. https://doi.org/10.1016/j.healthplace.2017.10.001
- Sitter, K. C. (2015). Participatory video analysis in disability research. *Disability & Society*, *30*(6), 910–923. https://doi.org/10.1080/09687599.2015.1057319
- Strnadová, I., Walmsley, J., Johnson, K., & Cumming, T. M. (2014). Diverse faces of inclusive research: reflecting on three research studies. *Scandinavian Journal of Disability Research*, (April 2015), 1–13. https://doi.org/10.1080/15017419.2014.964766
- Teachman, G., McDonough, P., Macarthur, C., & Gibson, B. E. (2018). A Critical Dialogical Methodology for Conducting Research With Disabled Youth Who Use Augmentative

and Alternative Communication. *Qualitative Inquiry*, 24(1), 35–44. https://doi.org/10.1177/1077800417727763

- Trena, M., Paulus, J., & Dempster, P. (2014). Analysing Image, Audio, and Video Data. In M. Trena, J. Paulus, & P. Dempster (Eds.), *Digital Tools for Qualitative Research*. Sage.
- Tuffrey-Wijne, I., & Davies, J. (2007). This is my story: I've got cancer. *British Journal of Learning Disabilities*, 35(1), 7–11. https://doi.org/10.1111/j.1468-3156.2006.00421.x
- Ulrich, Roger, S. (1984). View Through Surgery Window May Influence Recovery from. *Science*, 224(21).
- Wiles, R., Prosser, J., Bagnoli, A., Clark, A., Davies, K., Holland, S., & Renold, E. (2008). Visual Ethics : Ethical Issues in Visual Research, (October).