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when researching with people living with dementia**

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A Novel Approach to Support the Use of Visual Methods when Researching with People Living with Dementia

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Abstract

Accepted methods of enquiry to address qualitative research questions are focus groups and interviews, enabling access to the experiences, opinions, and perspectives of participants. However use of these methods with people with dementia is problematic because this condition can impair verbal communication in addition to other domains. These challenges can have a significant impact when trying to obtain insight from an individual through conversation and discussion. As researchers, we should be creating alternative methods that place equal importance on behaviour that is non-verbal as well as verbal. This contribution highlights the need for the advancement of creative qualitative methods drawing on lessons learned of the benefits and challenges during the development of a novel approach to support the use of visual methods in dementia research.

By focussing on all that is retained and done well, emphasising individual strengths and abilities, offers an increasingly prevalent alternative to existing loss-deficit models that have characterised dementia research in the past. This approach highlights the importance and appropriateness of visual methods in enabling meaning and transparency throughout the research process from ethical approval and consent procedures through to the collection, analysis, dissemination, and impact of the research data.

Keywords

dementia, visual methods, participation, ICT, enjoyable activities

Introduction

In recent years there has been a noticeable and positive increase in awareness regarding the ways society engages with people living with dementia and increasing emphasis on their advocacy needs (Department of Health, 2015a; 2015b; World Health Organization, 2021). Equally, there is a much-needed shift underway and hearing the ‘voice’ of people living with dementia is becoming common practice in research (Bartlett, 2012a; 2012b; Bowker, Calvert, Allcroft, et al., 2019) and policy and practice organisations (Pickett et al., 2018; Williamson, 2012). In the UK, supporting people to live well with dementia continues to be a priority currently driving national policy (Wittenberg et al., 2019). This is with the growing awareness that interventions that aim to promote quality of life and wellbeing are vital. Since the work of Bartlett and Connor over 15 years ago, there continues to be a positive change from the concept of ‘inclusion’ of the person with dementia

towards their active ‘participation’; a movement referred to as ‘social citizenship’ that acknowledges the potential contribution that people living with dementia can bring to every day social situations including self-advocacy groups, community groups and research studies (Bartlett & Connor, 2007). This is reflected in the increasing quantity of international evidence that is now being published focusing on the involvement of people living with dementia in

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advising and taking part in research (Bethell et al., 2018; Biglieri, 2021; Gove et al., 2018; Miah et al., 2020; Poland et al., 2019; Waite et al., 2019).

Until recently, people living with dementia were excluded from the research process, apart from as passive participants, possibly due to the stigma and negative consequences that are often associated with cognitive decline (Kim et al., 2019). Researchers have relied on proxy accounts provided mainly by the individuals' spouse, informal or formal carer rather than seeking the views of those with the diagnosis. Although the views and opinions of carers are vital in gaining a comprehensive understanding of the caring role, it is problematic to rely solely on these opinions for three reasons: first, the perspectives and opinions of the person with dementia do not consistently correspond with those of the person in a caring role (Beard et al., 2012), second, there is a danger that the needs and requirements of the person with a diagnosis may be overlooked in favour of the carer, rendering the individual powerless and side-lined (Mountain & Craig, 2012) and third, without hearing the voice of the person with dementia, this group will continue to be marginalised and stigmatised within society (Bartlett & Connor, 2007). This in consequence may lead to assumptions concerning the individual's decreased interest equating to an inability to participate effectively in society. However, there is increasing evidence that suggests the importance of directly accessing the individual experiences of people living with dementia (Genoe & Dupuis, 2012; MacRae, 2011; Phinney & Moody, 2011) and the reciprocal value of promoting this participation.

It is also important that whilst still recognising impairment, we move beyond what is lost and begin to focus on the strengths of the person with dementia. Positive Psychology offers an alternate approach to existing loss-deficit approaches that have characterised dementia research in the past *'to consider the possibility of living positively with dementia we must recognise the influence of biomedical discourses of loss and pathology that usually surround the condition. Such discourses imply that dementia automatically dominates and devastates a person's everyday life. As such, people living with dementia are seldom asked if (and how) they still experience achievement, enjoyment, love, hope, humour, growth, and spirituality. The assumption that people with dementia do not and cannot have these kinds of experiences is therefore maintained'* (Clark & Wolverson, 2016, p. 12).

There are some good examples of ethnographic methods being utilised in health research settings around the topic of dementia (Hillman, 2017; Hung et al., 2018; Prorok et al., 2013) yet it remains that many qualitative methods rely on the coherent articulation of the experiences of people living

with dementia and their views of health. The skills required for communicating through writing, reading, and speaking can be compromised in people living with dementia (Downs & Collins, 2015) which only highlights the need for enhanced research skills in both qualitative and quantitative research. The importance of novel, stimulating and creative methods come to the fore when researching with people living with dementia and the development of these methods is the responsibility of the researcher. Zeilig (2016) stresses that dementia research should always include people living with dementia, which is essential, but also be inclusive with regard to the methods used. In order to understand the experience of living with dementia a deeper level of knowledge is required that depends on very carefully considered methods (Zeilig, 2016). Equally, Dupuis et al., (2012) have argued that *'Listening and hearing the perspectives of persons with dementia is not enough. We must actively involve them in decision-making to the fullest of their abilities and support their involvement using whatever means necessary'* (p. 433).

We know that people living with dementia can provide their own accounts of their lived experiences. Due to the sharing of views and perspectives in this way, we can engage and support people living with the condition throughout the research process by devising methods collaboratively ensuring they are acceptable to them. Designing and developing ways to capture, define and assess lived experience requires methods that are sensitive and flexible to change. Rather than asking people living with dementia to reflect on their recent experiences, capturing 'in the moment' data is important and necessary as we know that a person's experience of the condition can and will fluctuate (Clare & Nelis, 2014). This means that reflection and self-report of the past month or even week can be challenging and misremembered, and it is vital that researchers are aware of this. Nevertheless, despite an increasing interest in the active participation of people living with dementia in research, there remains little to no new knowledge on the most appropriate ways to achieve this, although this is now changing (Beresford-Dent et al., 2022; Smith et al., 2022). In order to meaningfully include the views, feelings, and opinions of people with dementia that are sensitive and appropriate, the methods underlying research studies still require careful attention.

This paper highlights the essential need for creative qualitative methods that can meaningfully capture the lived experiences of people living with dementia that are relevant and acceptable to them. The appropriateness of using visual methods throughout the whole research process will be discussed using examples from a video-based participant observation study.

Summary of the Video-Based Participant Observation Research Study

An approach has been created from the findings of a study involving people living with dementia and their participation with smart technology. This highlights that, for certain projects, the appropriateness of visual methods throughout the research process from ethical approval and consent procedures through to the collection, analysis, dissemination, and impact of the research data. This research explored the potential of touch screen computer technology in facilitating enjoyable activities with people with dementia who live in the community. The project premise that technology may facilitate enjoyable activity by those with a dementia diagnosis was explored through two successive studies. The first involved attendees at a community day care centre, 12 participants in total, 9 women and 3 men. They were living with moderate to later manifestations of the condition but still lived in the community, some alone. The second study involved people with a recent diagnosis of dementia, possibly experiencing mild to moderate manifestations of dementia, who were visited by the researcher in their own homes. Sixteen participants in total, 10 had a diagnosis of dementia and 6 were in a supporting role. Data collection methods comprised of video-recorded participant observations and in-depth interviews. The findings suggested that people living with dementia who took part in both studies were competent in their technology interactions when engaging with enjoyable activities, if appropriately and consistently supported (Smith et al., 2018).

Rationale for Using Visual Methods in Dementia Research

There is heightened awareness of the possibilities of the 'visual', in all areas of society including academia, that may be explained by various contributing factors which include: easy access to reasonably priced but sophisticated technologies that enable such methods to be utilised and the ever-increasing engagement with these technologies by researchers for data collection, data presentation and interpretation, photo-elicitation for example. Equally, the reputation of science regarding the ways social phenomena may be visually portrayed to the public; and the varying ways research data is now collected, analysed, and disseminated in academia which has been accompanied by the advent of contemporary digital technologies (Smith et al., 2015).

At the time of conducting this research, a scoping review identified that aside from comprehensive textbooks, published articles that report primary research including working with images, and the process of collecting, analysing, and describing results were limited (Smith et al., 2015). Moreover, even less evidence could be located for the use of visual methods in dementia research, aside from a few notable exceptions (Alm et al., 2007; Astell et al., 2010; Genoe & Dupuis, 2013; Bartlett, 2015; Capstick, 2015). This is despite the potential of visual

methods having the ability to present complex information in ways that conventional texts may not (Zeilig, 2016) and the ability of these methods to convey emotional messages succinctly and powerfully (Bartlett, 2012a; 2012b).

Visual methods were utilised throughout this work for three essential reasons; first, video recordings prove to be an effective method for capturing verbal and non-verbal participation 'in the moment' that can often be missed using other methods. Second, visual methods enabled the researcher to facilitate individual or group participation without the explicit writing of field notes, and primarily acted as an aide memoire. Third, by maintaining the focus on participants' strengths and achievements, visual methods enable others to 'see' individual participation rather than solely 'reading' about it. This approach was effective and sensitive because the methods of data capture and analysis were developed in tandem and designed specifically for this area of work (Smith et al., 2015).

Ethical Issues in Using Visual Methods in Dementia Research

There is limited use of visual methods in dementia research, possibly due to the complex ethical considerations involved when utilising photographs or video recordings involving people living with dementia. Using visual methods would of course not be appropriate for all qualitative dementia research topics and an emphasis on impairment, loss or deficit would surely add to existing issues around stigma and marginalisation that people living with dementia face every day. Yet topics that focus on positive outcomes including achievements, active participation, engagement, laughter, and friendship can illustrate, through visual means, all that is retained, enjoyed, and done well. It could be viewed as unethical not to highlight an individual's strengths through use of the visual as long as a clear and thoughtful rationale for doing so is in place. The following sections identify the ethical issues that should be considered.

Issues Concerning Identifiable Images

Traditionally, societies have viewed people living with dementia as a vulnerable population (WHO, 2017) often due to the degenerative nature of the condition but also the stigma and marginalisation that can be experienced. Yet some would argue that being 'vulnerable' is just another label that has been placed on people living with dementia when actually it is more about the persons awareness of the changes they are experiencing (Bartlett & Brannelly, 2019). In this sense, the research will necessarily require a heightened and detailed rationale for using visual methods as the biggest potential challenge to consider is that research participants may be identifiable when using visual methods in research. This is not to say that participants are vulnerable but purely identifiable, which does require acknowledgement. However, during this

study, it was found that as long as participants understood and consented to their images of participation being used, it became a really positive aspect of the research design. In order to strengthen these understandings, transparent conversations between participants and the researcher took place with the images (stills taken from the video recorded data) acting as ‘aid memoirs’ to prompt understanding of consent. We collaborated in making decisions regarding which images to use throughout the process and this provided participants with ownership and a real investment in the research and the ways it was disseminated.

The Ethics Review Process

A further consideration when using visual methods in dementia research is the ethics review process, whether gaining approval from University or HRA committees. There were many relevant and considered questions from the Review Panels when seeking Ethical approval and certainly, issues around participants being identifiable through the use of their images was front and centre. The University Ethics panel was comfortable with the use of images from study 1 which was undertaken in a charity day centre and granted approval. Although the HRA approval committee questioned whether it would be possible to pixelate or distort the images so that participants could not be identifiable (see [Image 1](#) for an example of a pixelated image). Yet this was the primary reason for using visual methods in this project, to communicate visually how people living with dementia remain capable in their participation, despite a diagnosis of dementia. It was emphasised strongly to the committees that pixelating the participants faces was counter intuitive to the aims of the study. Visual methods were utilised to capture the non-verbal behaviours as well as the spoken word, including facial expressions whilst engaging with the research (see [Image 2](#) for the same image unpixelated).

A solution to this was to provide example images of people living with dementia previously engaging with the technology from study 1 to illustrate participation to the HRA Ethics committee. This provided a clear way of communicating the rationale to ethics committees in order for a favourable ethical opinion to be reached.

The Process of Obtaining Consent

Researchers are required to apply enhanced understanding of capacity and consent when undertaking ethically sound dementia research. Detailed yet clear information sheets and consent forms were required to enable informed decisions to be reached by all those involved in the research. From the outset, the use of visual methods and images depicting individual participation should be explicitly detailed in all documentation. The goal throughout this research was for the person with dementia to provide independent informed and

maintained consent with a full understanding of the nature and purpose of the research. Visual methods played a key role in the stage of obtaining ongoing consent, more so for people whose recollection of events from the previous week was compromised. The importance of gaining on-going consent is essential when researching with people living with dementia and visual methods enabled and supported this process as described below.

The ‘process consent model’ provided essential direction offering five key elements for effectively gaining and maintaining meaningful consent with people living with dementia ([Dewing, 2007](#)). Each element was drawn from and adapted for the purposes of this research to develop the use of visual methods in gaining consent. Preparation and background required the researcher to be transparent with carers (formal and informal), staff and clinicians regarding the recruitment and negotiation of access to the person with dementia. Once gained, an investment in time was required on behalf of the researcher to learn and understand more of the personal histories that may begin the development of effective research relationships. These increased understandings of the person, coupled with the support of those in a caring role, then enabled the researcher to establish a basis for gaining consent. It is important that researchers be skilled in their communication techniques and thoughtful in more practical considerations including accessible consent forms, possibly supported by visual props to aid the process of initial consent. This was achieved through demonstration of the technology (iPads) alongside potential participants to illustrate a) what exactly an iPad or tablet looked like and b) examples of activities to be enjoyed. Individuals could then make informed decisions regarding the appropriateness of the research topic and their potential involvement with it. Repeatedly assessing the persons’ choice to continue with the research requires ongoing consent monitoring. This was achieved through verbal articulation of the participant’s ongoing enthusiasm for the research or non-verbally by creating visual prompts in the form of images to aid recognition.

By showing an individual an image of their participation the previous week, an informed decision regarding their continuation in the research could then be reached. The researcher would show an image of the person interacting with the technology and follow this with ‘would you like to have another go today’? If the participants response was positive, then ongoing verbal consent had been achieved, equally if the person declined participation on that day, they chose not to continue. Using images taken from the video recordings of the previous week was considered an accessible aid memoir for participants. It was not possible to share the video recordings of participation without the proper AV equipment at each of the research sites. Finally, feedback and support are morally essential having built up trusting relationships with people with dementia that will ultimately end ([Hellström et al., 2007](#)). On each occasion an image of participation (taken as a still from the video recordings) was used in the dissemination of the research, irrespective of signed consent, the researcher

returned to all participants' and those in a supporting role to gain further verbal consent ensuring participants remained happy that their images would be used. If any participant voiced concern with a particular image the use of alternative images preferred by the individual and those in a supporting role were negotiated. This further verbal consent was for the use of images and in addition to the consent for participation in the research study.

Visual Methods for the Collection of Research Data

For the purposes of this research, data collection methods were video-based participant observations, deemed appropriate to unite the researcher and researched through mutual participation in a given context (Pink, 2012). Visual ethnographic techniques for collecting data, specifically the researcher as a 'participating observer' were appropriate because the researcher becomes immersed in the place and with the people and their behaviour rather than being separated from it (Pink, 2012). In practice, being a participating observer enabled the researcher to experience the setting from the perspective of people living with dementia, and the importance of establishing a rapport during the research relationship is paramount. Being a participant observer provided access to socially meaningful experiences that may otherwise be difficult to articulate in a semi structured interview or focus group. For example, non-verbal communication will include facial expression, direction of gaze, hand gestures and posture, all may provide the researcher with important insights regarding participant experiences 'in the moment'. Not only does this method form the foundations of ethnographic fieldwork, but it is also well established and effective in overcoming communication issues that can be encountered when undertaking research with people with dementia (Nygård, 2006).

Participant observations enable a deeper understanding of the social context and when video recorded, result in rich data that may act as representations providing insight to the ways participants express their own meanings and experiences of the research. Utilising video recorders specifically, can enhance the process of data collection (Margolis & Pauwels, 2011) as these methods allow the researcher to systematically document the behaviours, verbal and non-verbal, of all participants. Although photographic methods were considered as an alternative, it was considered that producing still images would not allow discreet data collection or enable the researchers' active participation and facilitation with people living with dementia.

Ritchie and Lewis (2003) describe observational data as the 'enactment' of social behaviour rather than the 'recounting' of experience from interviews. Furthermore, Bond & Corner (2001) argue that to focus solely on participants meanings from qualitative interviews has substantial shortcomings as they act only as representations of reality. Thus, video-recorded participant observation can be considered a

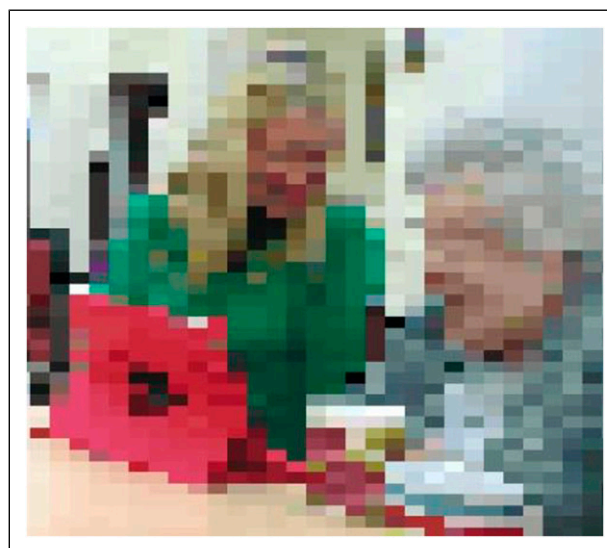


Image 1. Pixelated.



Image 2. Unpixelated.

method in its own right that documents the actual 'doing' of activities rather than 'saying', as they are played out in the social context (Pink, 2001). This is important and relevant when researching with people living with dementia as we attempt to access and understand their experiences. This method can capture data that 'provides a sense of the self and the other that is not easily put into words' (DeWalt & DeWalt, 2011, p. 10) and was found to be an appropriate and effective technique for collecting data in this qualitative dementia research project.

A key advantage of using video to collect data is that it can support an exploratory research design. At the core of this research was the creation of strategies for the inclusive participation of people living with dementia that are 'in the moment', practical, reliable, and sensitive, enabling expression and allowing the significance of the non-verbal to come to the fore. Visual methods enabled this and allowed the

researcher to facilitate the research sessions without the distraction of taking field notes and unwittingly concerning participants that they were being reported on.

Two small video recorders on small tripods (15 cm high) were used as the main form of data collection and were discreet enough to go unnoticed almost instantly. It was important to ensure the video recorders were as unobtrusive as possible, so each camera was positioned toward each end of a large table facing toward participants. The video data collected is shaped by decisions in the field such as the camera position and when and what is selected to be recorded (Jewitt, 2012) but most importantly, video recordings can capture things that the researcher might not have noticed at the time of being present. For example, despite the researcher being a participant observer, the size and length of the table dictated that interactions were missed when occurring at the opposite end of the table. Using the video recorders to collect the data united the researcher and the researched in the same activities, giving a sense of 'we're all in this together', resulting in more collaborative research. A reflexive research diary was maintained throughout the data collection phase enabling details of each session to be recorded after the event for the purposes of the data analysis process.

Visual Methods for the Analysis of Visual Data

Visual methods enable comprehensive data for analysis as the recordings may be repeatedly micro-analysed and subjected to detailed exploration of the phenomenon. This is significant as the opportunity to reflect, re-evaluate or even re-live a certain piece of footage is enabled through repeated examination of the video footage. The findings of a review highlighted that published articles reporting primary research including working with images, and the process of collecting, analysing, and describing results were limited (Smith et al., 2015). Researchers that have reported analytical techniques for visual data devised their own 'ad-hoc' solutions of analysis and reporting that was therefore unique to their project. Some techniques were developed for specific projects and others were adapted from existing methods to address different research questions. The review found that the most commonly described technique used for analysing video-based data was to transcribe talk and action into text. However, for the purposes of this research it was considered that the transcription of rich video into text would be an unsuccessful translation of the data and negatively impact the multifaceted significance of the participant's experience, thereby losing meaning.

The aim therefore was to develop a data analysis technique that may increase understandings and descriptions of the text, the images and the social action taking place. The challenge was to decide how the participant's behaviour, in particular the non-verbal dimension, could be represented in the analysis in a way that could do the data justice and without losing meaning.

Decisions had to be reached concerning what was represented and what was not, and which modes or episodes of social interaction were to be included in the analytic process. During the initial stages of data analysis, the video recordings were viewed with the volume turned off, providing a heightened sense of what was happening 'visually'. The video recordings were played again with the screen turned off which highlighted all that could be 'heard'. The video recordings were then transcribed verbatim.

Having transcribed the video recorded data into 'talk' (all that was heard) and action (all that was seen), it was decided to incorporate salient images taken from the video recorded data that could describe the gradual unfolding of a specific event that is characterised by multiple modes and when combined with text, transcripts become more meaningful. This enabled reinforced meaning and vital insight to the verbal and non-verbal behaviours that would be otherwise dependent on field notes and audio alone. It was important to represent the data in a way that enabled the reader to connect through a sense of 'being there or being with' the researcher (Jewitt, 2012). This form of multimodal transcription required a series of choices that influenced and shaped the data analysis in significant and meaningful ways.

The technique of data analysis for this research was influenced by the methodological framework referred to as 'multimodal interactional analysis' (Norris, 2004). 'Multimodality' characterises research data that is not primarily words or numbers. Modes may be audible, visual, or contextual but in any social situation they will definitely be multiple. Multimodality as a technique was appropriate for the purposes of this study as traditionally 'talk' has been considered the prominent meaning making mode of social interaction and everything non-verbal was relegated to context (Norris, 2004). As non-verbal behaviour can be particularly important as a means of communication by the person with dementia the significance of representing multiple modes came to the fore during analysis. Although not all people with a diagnosis of dementia are challenged when communicating, differences can emerge in the ways people express themselves as the condition progresses thus, an analytical technique was required that may translate these differences effectively. For example, [Image 1](#) illustrates an excerpt from a transcript involving interactions between Eva and Ann. Eva (on the left of the image) is very vocal as she navigates her way through the screens on an iPad and Ann (on the right of the image) is less so. A traditional transcript incorporating video into text would represent Ann's interactions differently, whereas the multimodal transcript enables insight into how engaged and deeply engrossed Ann was with the technology despite being less vocal. Further, when supported by additional modes including context and researcher reflexivity, knowledge is gained and understanding increases. Although the union between multimodality and visual methods is novel in dementia research, this combination has been successfully utilised in numerous other qualitative projects including children's learning of new

technologies (Dicks et al., 2011) and an ethnography of corridors in combination with authoring and reading practices (Hurdley & Dicks, 2011).

Example Transcription 1 illustrates the merging of multiple modes and can be seen below. Data analysis followed a qualitative process of familiarisation, data reduction and synthesis, merging multiple modes, illustrating the data thematically and meaning and explanation, comprehensive details of which can be found in a previously published article by the same authors (Smith et al., 2018).

Discussion

The aim of this paper was to highlight the ways that novel and innovative visual methods can communicate the continued participation and active engagement of people living with dementia in research. The approach highlights the appropriateness of visual methods in some projects and throughout the research process from ethical approval and consent procedures through to the collection, analysis, dissemination, and potential impact of the research data.

New ways of justifying the use of novel methods in the ethics review process are required that emphasise how it can be 'unethical' to not include images of people living with dementia actively engaging with technology should they choose. This paper has highlighted the potential value of using visual methods in consent procedures for all aspects of dementia research (Dewing, 2008) and may have wider application to other research areas. Often people living with dementia have no say regarding what information is presented about them, and the use of visual methods proved to be a real strength when involving individuals in research focused on their experiences. Having a choice as a participant regarding which images of you are used is empowering and collaborative and places the person living with dementia in control of their research data, where they should be. There is a need to continue exploring and developing novel dementia friendly research methods that can highlight the many ways people living with dementia can be enabled in the research process.

Visual methods in the process of data collection have also been advocated for in this paper. Although, acknowledging the impact of the researcher and the video equipment is an important consideration as the presence of both may be considered to influence the research participants as well as the context. Certainly, the two video cameras that were used were discreet enough to go completely unnoticed within the first few minutes of data collection; nevertheless, there is little empirical evidence that video recording research has such reactivity effects (Heath et al., 2010). The assumption that video data can replicate or distort reality is disregarded by visual ethnographers who focus primarily on how video recordings may be adopted to explore and understand the participants and the research context (Jewitt, 2012). In this project, video was utilised as a reflexive tool to preserve data and conduct analysis that enables re-representation from the

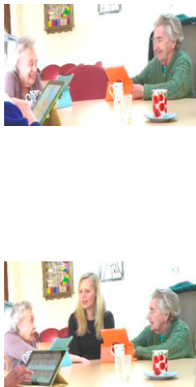
researchers' perspective so that '*things become visible because of how we see them rather than simply because they are observable*' (Pink, 2006, p. 36). This is important as the negative stereotypes of dementia persist creating a powerful barrier of socially constructed consequences which views people with dementia as 'other' or 'lesser' and not able to participate fully in society (Bartlett, 2021).

Visual methods enable comprehensive data for analysis as the recordings may be repeatedly micro-analysed and subjected to detailed exploration of the phenomenon. The stills from the video recordings may record, reveal, elicit, illustrate, demonstrate, or evoke meaning in a far more subtle way than purely text thus transforming the way transcripts may be understood (Felstead et al., 2001). '*Such reconstructions are inevitable and essential outcomes of any video analysis, and it is through reconfiguring video data that researchers and their audiences can see the observed interaction in the categories appropriate to their discipline(s) and position themselves in relation to that discipline(s)*' (Bezemer & Mavers, 2011, p. 203). Nevertheless, the use of video recordings in research can raise methodological questions around transcription and this should be acknowledged, for example, how to transcribe gesture, or gaze, and how to illustrate social interactions to readers. These aspects would be unique to a project, but multimodality provided an effective solution here as the technique does not prioritise research data as words or numbers but rather focuses on the representation of multiple modes, audio, visual and contextual (Norris, 2004).

Ongoing debate exists regarding the validity of video data and how it can be characterised depending upon a variation in researcher perspective. Critiques of visual methods have questioned researcher subjectivity, due to the ease which images may be manipulated or edited in order to depict an impression of events that may not necessarily be accurate, in other words, an ideological representation of events (Prosser, 1996). However, the choice of images and quotes incorporated is also subjective, but it is argued that in this research they are a faithful representation of the data collected. The images that were included were not meant to be persuasive in any way but rather a reflection of the engagement, achievement, and participation that each individual contributed to the research. All participants and care partners contributed to the selection of images to be incorporated within the multimodal analysis. This type of creative visual method gives rise to collaborative working between the researcher and the researched, providing opportunities for essential involvement and participation during analysis from the populations that the research is intended to enable.

Visual methods have aided the powerful documentation of events required to evoke meaning to each individual's participation that may not always be possible through text alone, giving expression that was both appropriate and necessary within this particular research. Yet it is the novel and creative ways that the data were analysed that provides a description and explanation supported by the visual that would not have been as

Example Transcription 1. Merging Multiple Modes into One Transcript.

Mode 1: Verbatim transcription	Mode 2: Description of non-verbal	Mode 3: Representation of non-verbal
<p>Eva: I think the heat from my hairdryer...I think it's that that's made my memory like it is. It might sound daft, but I also think that going to the hairdressers every week...I think its effecting my memory</p> <p>Researcher: No, it's what you feel.</p> <p>Ann: I think it could be that</p> <p>Eva: I noticed when I went to the hairdressers that they didn't turn it up hot, they kept it quite cool and I wondered, you know, if word had got round and they'd been instructed not to.</p> <p>Eva: So when they ask me what I do next time I come I shan't be able say 'I show people how to knit'.</p> <p>Researcher: No you won't, you'll have to say 'I've been exploring all the different apps in the apple store.</p> <p>Eva: Wait 'till my grandsons come.....err great-grandsons I should say</p> <p>Researcher: I'd be really interested to hear what they say about you playing on iPads.</p>	<p>The camera starts to film and is focussed on two female members of the group, Eva, and Ann. The seat between the two members is empty. The pair are seated at a large round table, and each have an iPad in front of them. Ann is laughing at something on the screen. Eva is focussed on her screen and navigating around a certain application with her finger. The two members are observed to be interacting independently with the devices.</p> <p>The researcher sits down between Eva and Ann. Ann has stopped interacting with the technology. The researchers' body language shows she has turned away from Ann towards Eva. Ann taps on the table to get the attention of the researcher and Eva. They both look up and all three begin to laugh at something on Ann's device. Eva begins to talk about something she has seen on her screen and the researcher and Ann both listen.</p>	

effective using alternative methods. Visual methods in dementia research are still in their infancy and certainly analysing video data in this way is so far unique to this research. Novel methods such as these would not be appropriate for all dementia research as they are labour intensive, interpretive, and subjective, highlighting the challenges when attempting to combine creative approaches with methodological rigour. Further research is required in the development of new ways to capture meaningful outcomes when researching with people with dementia which is underway (Smith et al., 2022). Many existing methods rely on self-report and raise questions regarding how certain domains may be measured when they may not be easily articulated, communicated, or indeed remembered. It has also been recommended elsewhere that future research should further consider the use of video analysis in order to capture nuanced and subtle behaviours that are not easily communicated in certain groups (Young et al., 2015).

This research has highlighted the necessity for capturing enjoyment through observation as well as expression 'in the moment' which was only achievable using visual methods. Visual data is impactful as it captures the actions, interactions and first-hand experiences of participation enabling other researchers, dementia practice and policy implementers to 'see' the potential of this research and future interventions, rather than purely 'reading' about it. The potential of utilising visual methods in research to positively affect social change is not a new approach. Knowledge Translation (KT) and Knowledge Dissemination (KD) activities have been bolstered by the use of visual methods, using Photovoice methods for example (Nykiforuk, 2021; Budig, K et al., 2018). Images of people living with dementia participating in research as active

collaborators, illustrating enthusiasm, engagement and enjoyment may go some way toward dispelling issues of stigma and marginalisation that persist. The potential of visual methods to communicate the strengths and abilities of people living with dementia are far reaching and can illustrate the impact of research participation in the real world. The challenge now is to adapt and develop these methods so that they may be less time intensive and more accessible to other researchers in the future. 'There are no unique methodological challenges in researching dementia....rather the complex nature of dementia and dementia care highlight the methodological challenges of investigating complex social phenomena' (Bond & Corner, 2001, p. 114). It is our responsibility as researchers to create and develop novel ways that enable people living with dementia to participate meaningfully in all aspects of the research process.

Conclusion

This novel approach describing the use of visual methods has enabled inclusive methods to be adopted, consulting people with dementia and care partners, whilst recognising the impairments associated with the condition. This research has highlighted the powerful nature of the visual in the capture, analysis, and dissemination of the continued participation of people living with dementia, but this is accompanied by the need for clear understandings of the ethical considerations this type of research involves. Visual methods will not be appropriate for all research projects and will always require a sound rationale and the support of the local ethical review committee. Visual methods should never be utilised to exploit people living with dementia or compromise

confidentiality or their anonymity. Rather, visual methods, if used appropriately, can give people with dementia ‘a voice’ and illustrate maintained abilities, strengths, and achievements as well as their ongoing active participation in research and society when provided with the opportunity should they choose it.

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