



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

Creating Vignettes of Early Onset Dementia

Citation for published version:

Jenkins, N, Keyes, S & Strange, L 2015, 'Creating Vignettes of Early Onset Dementia: An Exercise in Public Sociology.' *Sociology*. DOI: 10.1177/0038038514560262

Digital Object Identifier (DOI):

[10.1177/0038038514560262](https://doi.org/10.1177/0038038514560262)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Sociology

Publisher Rights Statement:

© Jenkins, N., Keyes, S., & Strange, L. (2015). Creating Vignettes of Early Onset Dementia: An Exercise in Public Sociology. *Sociology*. 10.1177/0038038514560262

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Creating Vignettes of Early Onset Dementia: An Exercise in Public Sociology

Abstract

Drawing on core principles of public sociology, this paper discusses the creation of four theatrical vignettes about living with early onset dementia (symptoms of dementia pre-65). The vignettes were developed through an Image Theatre workshop, involving families living with early onset dementia. They were designed to capture key themes, issues and experiences that emerged from the group's collective experience. Whilst the *content* of the vignettes speaks to a range of key sociological debates (especially in relation to the lived experience of time, risk, social exclusion and stigma in dementia) the *process* of creating and using the vignettes represents the first empirical application of a (public) sociological approach to 'person-centredness' in dementia; which views persons as 'dividual' and selves as transactive. We conclude by advocating for a rich and diverse public sociology of dementia in the 21st century.

Keywords: Dementia; Early Onset; Image Theatre; Individualism; Public Sociology; Vignettes

Introduction

What is public sociology?

Public sociology seeks to take the sociologist and their work outside of the academic arena and into the public domains, where a dialogical exchange of knowledge and ideas can occur. Whilst the notion of public sociology has been in circulation since the 1980s (e.g. Gans, 1989) Burawoy's (2005a, 2005b) call to arms has brought the concept firmly back to the sociological centre-stage. In essence, Burawoy's notion of public sociology seeks to reclaim some of the vigour for social progress characteristic of previous sociological epochs and which, for Burawoy, has become increasingly diluted by the institutional frameworks within which much of sociology is practised.

Central to public sociology is the production of sociological outputs that are engaged with and debated beyond the academy, and by sociologists and non-sociologists alike. Such outputs should not only serve to advance sociological theory but should also serve to 'bolster the organs of civil society' (Burawoy, 2005a: 319) and, in so doing, contribute to the greater good. This understanding of public sociology is not without its vehement critics (see, for example, Charles, 2004). For those sociologists whose focus lies in critiquing the evolution of social movements and in revealing the complexities and moral ambiguities that underpin them, Burawoy's approach not only over-estimates the degree of consensus which exists within the sociological community but risks prioritising the advancement of left-leaning goals over rigorous academic practice (e.g. McLaughlin et al., 2005).

In this paper, we discuss the creation of outputs designed to contribute to a public sociology of dementia in the 21st century; namely, four professionally recorded theatrical vignettes representing everyday life with early onset dementia (EOD). In discussing the vignettes, we argue that the advancement of public sociology does not, *ipso facto*, come at the cost of rigorous academic practice, neither does it seek to impose the sociologist's sense of morality onto others. Instead, and at its best, it involves the bringing together of disparate methodologies in order to produce high quality outputs that advance our sociological understanding as well as problematize the ways in which issues in civil society are framed.

Researching early onset dementia: organic public sociology

Early onset dementia (EOD) is an umbrella term used to refer to a variety of neurological disorders experienced by people under the age of 65; including Alzheimer's disease (AD), Huntington's disease (HD), vascular dementia (VscD), frontotemporal dementia (FTD), alcohol related brain disease (ARBD) and HIV-related neurological disorders, amongst others. Official figures suggest there are approximately 17,000 people with EOD in the UK. However, as only those with a formal diagnosis appear in official statistics, these numbers have been criticised strongly by the Alzheimer's Society for dramatically underestimating true prevalence, which the organisation claims may be up to three times higher than the official figure (Alzheimer's Society, 2012).

Since the 1990s there has been a growing consensus that families affected by EOD face a *unique*, or *special*, set of challenges. The National Institute for Health and Clinical Excellence (NICE), for example, argues that:

‘Younger people with dementia have special requirements, and specialist multidisciplinary services should be developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care.’

(NICE, 2006: 14)

Examples of such ‘special requirements’ typically include: difficulties and delays in obtaining an accurate diagnosis; the loss of employment and resulting financial hardship; the impact on younger family members and the loss of physical intimacy between the person with EOD and their spouse/partner (Allen *et al.*, 2009, Harris and Keady, 2004, Harris and Keady, 2009, Svanberg *et al.*, 2011, Svanberg *et al.*, 2010, Van Vliet *et al.*, 2011).

Beattie *et al.*, (2002) however, argue that the construction of *uniqueness* in EOD is based largely on the assumptions of healthcare professionals, as opposed to empirical evidence, and that emphasising the uniqueness of EOD has unintended consequences for older people with dementia .

‘An unfortunate side effect of arguing for the “special case” of younger people is the unspoken ageist assumptions that are seemingly made about older people in the process. Are we to assume that older people aren’t physically fit, that they have no sexuality, that their carers do not work during the day, that

they don't live with their children, and that they are satisfied with services that provide little in the way of activities and opportunities for physical exercise?’

(Beattie *et al.*, 2002: 210)

In the autumn of 2012, NJ established a long term research and knowledge exchange relationship with a specialist EOD service based in Scotland UK. Established during the mid-1990s, the service is one of the longest running of its kind in the UK and provides a range of support to families living with EOD; including day care, family outreach, social and community-based activities. The aim of the relationship is to explore, together, the social organisation of EOD (Prior, 1993). This project, following Burawoy's typology, we describe as a form of *organic public sociology*; whereby 'the sociologist works in close connection with a visible, thick, active, local and often counter-public' and where 'between the organic public sociologist and a public is a dialogue, a process of mutual education' (Burawoy 2005b: 7-8). As part of this process of mutual education, we sought to create a series of theatrical vignettes highlighting the everyday experiences of living with EOD. The methodology we used to do this, and what the vignettes helped to reveal about everyday life with EOD, are discussed in detail in the following sections.

The (dual) use of vignettes in interpretive social science

Vignettes have been defined as short hypothetical scenarios involving fictitious protagonists and situations (e.g. Bloor and Wood, 2006). As a technique for data collection, vignettes have (since the 1980s) found a home amongst a small and predominantly British-based group of sociologists, whose use of the method dates back to the work of family sociologist Janet Finch (1987). Whilst vignettes have a

longer history in quantitative survey research, their use within interpretive sociology is driven by a desire to gain insight into the lived experiences (e.g. Barter and Renold, 2000, Hughes, 1998) and interpretive processes (e.g. Jenkins *et al.*, 2010; O'Dell *et al.*, 2012) of participants. There is, however, a lesser-known approach to vignettes in qualitative research that has its origins in the literary and anthropological traditions. This approach seeks to use the vignette technique as a means of *representing* (rather than *eliciting*) qualitative data. There, vignettes have been defined as:

‘Compact sketches that can be used to introduce characters, foreshadow events and analyses to come, highlight particular findings, or summarize a particular theme or issue in analysis and interpretation. Vignettes are composites that encapsulate what the researcher finds through the fieldwork.’

(Ely *et al.*, 1997: 70)

Vignettes of this nature serve two primary functions: First, they seek to give voice to individuals and social groups whose knowledge and experience has hitherto been marginalised. This is achieved by the researcher using the vignette technique as a means of engaging in acts of vicarious introspection, as if they were the research participant (Ely *et al.*, 1997, Spalding and Phillips, 2007). Second, vignettes may be used to provide snapshots that represent an entire issue or series of phenomena under investigation. This requires the characters or events depicted in the vignette to be intentionally symbolic, speaking to the over-arching themes in the same way that ‘writers often use, for example, a wave to stand for the ocean or the North star to stand for a galaxy’ (Ely *et al.*, 1997: 74).

As a research methodology, vignettes are a relatively new addition to the qualitative paradigm. Thus, whilst both approaches to utilising the vignette technique have been used successfully within interpretive inquiry (e.g. Jenkins et al., 2010; Spalding and Phillips, 2007), how best to combine these approaches within a single methodological and epistemological framework is a question yet to be fully explored.

Methodology & Method

The data used to create our vignettes were collected during a creative workshop involving people with a diagnosis of EOD, their spouses, offspring and parents (see Table 1). The workshop drew substantially on techniques from participatory theatre (i.e. theatre in which audience members and performers inter-act). This was led by a performing arts company (name), which specialises in health and social care issues. In particular, we used Image Theatre - an established methodology created by Augusto Boal (1979) as part of his Theatre of The Oppressed (TO) and influenced by theories of power from his contemporary Paulo Freire (1970, 2000). Image Theatre employs a range of dramaturgical techniques in order to facilitate marginalised groups finding a collective power to challenge oppressions. This begins by first bringing oppression to light and comprehending its dynamics, then exploring possibilities for change and rehearsing tactics for challenging oppression. Using the games and exercises in TO, Image Theatre seeks to create an environment where a social group can act as both artists and activists, exploring the oppressions they collectively experience (Boal, 1992). Games are designed to build solidarity and to create a 'safe space' where situations can be mapped and the structures of oppression revealed. As personal experiences of oppression can be traumatic,

creating fictional characters and situations through images enables participants to divulge personal experience at a safe distance, and for the group to explore them dispassionately. The method therefore refrains from exploring personal problems, which are more appropriately addressed through drama therapy, focusing instead on societal problems and oppressions common to a group. As a methodology, then, Image Theatre is rooted firmly within an emancipatory approach to participatory theatre. Engaging this approach within interpretive vignette-based sociology is an issue we now explore.

Ethical considerations

Participatory arts are being increasingly promoted as a means of working with people who have a diagnosis of dementia (e.g. Mental Health Foundation, 2011). Lepp *et al.*, (2003) for example, identified a range of positive effects from a series of drama workshops involving people with dementia and their care-givers in a care home setting, including enhanced relationships between staff and residents, and improved communication skills, self-confidence and re-gained memories for the person with dementia. Indeed, drama is used widely in dementia care, both as a means of therapy (e.g. Bolmsjö *et al.*, 2012, Kontos *et al.*, 2010, Wilkinson *et al.*, 1998) and as a tool for stimulating creativity, resilience and cognitive functioning (e.g. Roush *et al.*, 2011, Rylatt, 2012). Whilst theatre has been used as a medium for disseminating research in dementia (e.g. Mitchell *et al.*, 2011a, Mitchell *et al.*, 2011b), there is little evidence that sociologists have sought to utilise participatory theatre in data collection.

Using theatre in data collection, however, raises important ethical issues. Of critical importance is ensuring that the procedures employed are consistent with established frameworks for ethical research; in particular the importance of seeking informed consent to participate in data collection. Seeking informed consent to participate in Image Theatre for the purposes of research (as opposed to therapy, political expression or personal development) does require careful management. This is particularly the case in dementia, where seeking informed consent can be a highly complex and challenging process, requiring a level of consideration and vigilance which exceeds that usually stipulated by ethics committees (Black *et al.*, 2013, Heggstadd *et al.*, 2013). Whilst ethical review and approval was obtained from Edinburgh University *Interdisciplinary Social Science in Health Research Ethics Committee* (Ref: ISSH/REC/13-01) this was considered but the first step in the process of ensuring ethical conduct.

In accordance with relational and process-based models of consent-seeking (e.g. Nuffield Council on Bioethics, 2009, O'Connor and Purves, 2009) the project team adopted a stepped-approach. In the first instance, family representatives who had expressed interest in taking part in the research during a knowledge exchange event (facilitated by the authors) were contacted via phone by NJ (a sociologist) to arrange a face-to-face conversation. He suggested during this phone call that all family members interested in participating in the workshop be present at the meeting, including the person with a diagnosis of dementia. One purpose of these consent conversations was to get to know the family and to discuss the specifics of the research. During discussion, the capacity of the person with dementia to give or withhold their consent was explored overtly. Of primary consideration was the ability

of the person with dementia to understand the nature of the research, how the workshop contributed to the overall aims of the project, as well as the person's ability to retain information long enough to make an informed decision. Wherever possible, consent conversations were conducted with two researchers (NJ & SK) present. If family members were willing to participate and able to give their informed consent each participant was asked to complete a consent form. In cases where participants were willing to participate but, in the opinion of the researchers, may not have capacity to give informed consent, proxy consent was sought in accordance with the (title of national legislation). The use of proxy consent is an established practice in dementia research and in the two instances where proxy consent was sought, this was done in addition to (as opposed to instead of) seeking the views and permission of the person with dementia. Thus, regardless of proxy consent, the main indicator of consent was taken to be the participant's behaviour and interactions during the workshop itself. If any participant showed any signs of discomfort or distress, their participation would cease until such time as the issue was addressed.

The workshop

Once participants gave informed consent (or proxy consent) they were invited to a creative workshop which was held in May 2013. The workshop was divided into two one-hour sessions interspersed with a 45 minute lunch break, which provided an opportunity for relaxation and discussion. *Session One* entailed a series of exercises designed to build rapport between participants and begin to introduce the use of images within the group. Following these warm-up activities, and to introduce participants to Image Theatre, participants were asked to divide into their respective families and to each develop a visual representation of how they travelled to the workshop. Participants then divided into two groups and each group was asked to create a visual representation of any mode of transport and to present this to the other group. These were shown as static images then movement was added and finally sound. When performing the images, the facilitator (LS) would ask the observing group, 'What could this be an image of, if it was *not* a mode of transport?' and 'What could this be an image of, if it was about early onset?' These questions enabled the group to begin to think about the nature of the oppression they experience. For example, one groups' attempt to represent a hot air balloon was transformed, through these questions, into a representation of social exclusion; as the people who had joined hands to represent the basket of the hot air balloon (and who were facing away from the traveller inside) were re-interpreted as symbolising society turning its back on the person with dementia.

In *Session Two* of the workshop, participants were invited to construct a hypothetical family living with EOD. During this session, professional actors (who are members of Strange Theatre) were asked to improvise suggestions from participants as they

co-constructed scenarios from everyday life. For this part of the workshop, participants were in the roles of director and audience and were able to dictate what they wanted to see. Participants were informed that they did not have to share examples from their own experience unless they wished to do so. Out of this process, a hypothetical couple (Paul and Irene) were created. Paul and Irene are both in their mid-fifties and have been married for 35 years, having first met at a dance. Paul, a former railway worker, had to leave work shortly following his diagnosis, whereas Irene, a secondary school language teacher, continues to work as well as care for Paul. Paul and Irene have an adult daughter and two young grandchildren.

In the latter part of the workshop, participants were again invited to form two groups and for each group to develop an image highlighting a challenging situation in EOD. As per *Session One*, each group was asked to create a still image of their scenario and to perform it to the other group. The observing group saw the still image first and were able to put their own interpretation onto what they saw. This both confirmed the collective experience of the difficulty that the group had presented and revealed further insights and examples of everyday challenges. Images were then brought to life with movement and sound. With participants' consent, photographs were taken of the images and *Session Two* of the workshop was audio-recorded.

Analysing the 'data'

Questions as to what constituted our data were central throughout the process, as data collection and analysis intersected frequently. To begin with, we took as data the comments, reflections, images and actions produced by workshop participants.

Analysis of these data was informed by the principles of inductive, thematic analysis (e.g. Glaser and Strauss, 1967). Immediately following the workshop, NJ, LS and the actors Strange Theatre met to discuss the sessions and agree emergent themes. Observational notes, pictures and audio-recordings that were made during the workshop were reviewed and areas of agreement and divergence identified. Through this process, data were organised into four primary themes. These themes were developed, two days later through improvised dialogue and stage direction, led by LS with input from NJ, into four theatrical vignettes. Care was taken at this point to ensure that the perspectives, experiences, practices, embodied gestures and sayings of participants were reflected throughout the scenarios. Once these scenes were finalised, they were acted and filmed at the (name of centre) using a black box stage. The recordings were then professionally edited and produced. The vignettes are available to view via Strange Theatre's YouTube Channel (<https://www.youtube.com/watch?v=ctDU7iAPGg8>).

Once completed, we took the vignettes themselves as data, providing insights into how we, as sociologists and performing artists, sought to make sense of families' lived experience. In line with the principles of co-operative inquiry (e.g. Reason and Bradbury, 2001) and in order to develop greater richness in our data collection, NJ led an analytical focus group with members of the support service's *Carer Support Group* (see Table 1). The purpose of the focus group was to analyse, in turn, each of the four theatrical vignettes. The focus group was audio-recorded, and recorded discussion lasted for 59 minutes. Discussion focused on the plausibility of the scenarios, the nature of experience re-presented, and the extent to which the vignettes connected with carers' everyday lives. Members of the *Carer Support*

Group were informed about the focus group beforehand, both in person and via letter, and had the option to either participate in the focus group or hold a separate meeting alongside the focus group. All members of the *Carers Support Group* elected to participate in the focus group. With participants' consent, the audio-recording of the focus group was transcribed. This transcript was treated as data, providing insights into how carers sought to make sense of the vignettes and relate them to their own lives. As such, the transcript was analysed by NJ using thematic analysis techniques.

[Table 1 to go about here]

The vignettes

Here we present a thematic description of each of the four vignettes. In particular, we discuss the relevance of the vignette content to contemporary debates surrounding the lived experience of time, risk, social exclusion and stigma in dementia.

Out of sync: experiencing de-synchronicity in dementia

Difficulties in the perception of time are consistent features in dementia, especially in relation to Alzheimer's disease. Hence, it was not surprising that workshop participants described challenges in managing time and memory. Indeed, participants tended to describe a variety of techniques for keeping track of day-to-day-life, such as recording daily activities in a planner or checking the dishwasher to see whether the person with dementia had eaten breakfast. A particular tension in managing time in EOD, however, related to the different time zones in which the

person with EOD and their family members operated in; especially if the latter were in employment. *Out of Synch* was developed in order to highlight these tensions.

In this vignette, Irene is hurriedly preparing to go to work whilst also getting Paul ready to go to the Day Club. Freeze-frame photography was used in the editing phase in order to contrast the different time zones in which Paul and Irene are experiencing. As the scene develops, Irene is increasingly trying to move Paul into her faster paced time zone, resulting in Paul experiencing confusion and disorientation; a phenomenon described by Kitwood (1999) as *outpacing*. This culminates in conflict, with Paul resisting Irene's efforts and asserting the importance of time management to his own sense of self (*'I used to keep the trains running on time!'*). This quote was adapted from one of our workshop participants who described a similar experience. Thus, the vignette is intended to highlight the tensions that arise in everyday life when the timescapes of late-modernity (see, for example, Adams, 1998) clash with those of dementia lived experience.

When members of the *Carers Support Group* came to analyse this scene, it was interesting to observe how adopting the perspective of the independent observer enabled participants to move out of their own perspective in order to enter, through a process of vicarious introspection, the subjective position of the person with dementia:

'I recognised myself in that! What that did for me though was give me a better understanding, actually, of my husband's perception; because I could be a bit

objective sitting here. When you're embroiled in it all it's very hard to be [pause]. It just made me realise what it must be like for him.'

Claire

Flammable - handle with care: managing risk in everyday life

With the emergence of *Risk Enablement* approaches to dementia care (see for example, Moriarty and Manthorpe 2010) attempts to eliminate risk in all its forms are being increasingly viewed as dis-empowering for people with dementia, by taking away autonomy and the ability to manage uncertainty (Bailey *et al.*, 2013, Clarke, 2000, Clarke *et al.*, 2011b). Managing risk was a cross-cutting theme within the creative workshop and examples of risk in everyday life were commonly highlighted (e.g. forgetting to ignite or turn off the gas when cooking, to eat, or to take medications). However, what also emerged were some of the *silent harms* (Clarke, *et al.*, 2011a) that couples living with EOD encountered.

Flammable – Handle with Care was designed to highlight the multi-faceted nature of living with risk in EOD. In this scene, Paul is preparing a roast dinner for the family and, in order to remember how to do so, he relies on a strict sense of routine. Following one of the workshop participants, he describes this as '*My own way of doing things*'. During this process, Paul forgets to ignite the gas in the oven, which is discovered by Paul's daughter as she checks on the food. The daughter's fear at this discovery quickly translates into anger at Irene for allowing Paul to continue to cook. Paul's grandchildren, who are sleeping in the next room, are awoken by the commotion. When Paul offers to help settle them, he is prevented from doing so by his (now irate) daughter. The scene is designed to underscore how fears over

physical safety can, if not handled carefully, lead to a denying of agency for the person with dementia, which has deleterious implications for self-worth.

When analysing the scenario, the relationship between risk and blame (Douglas, 1985) which the vignette was designed to speak to was a strong, and spontaneous, focus for discussion within the Carers Focus Group:

‘Well, the wife got the blame for it actually, from the children... When things go wrong it’s our fault.’

Mary

‘My daughter she blames me because I married him. I say “well he wasn’t like that when I married him, you know”. She says, “He should be in a home, he should be in a home”. She actually works in the care system, right, looks after the elderly. I say “No, not yet”; a long time before that happens.’

Sandra

In this context, disclosing EOD to offspring was described as a difficult process, which can result in attempts to conceal the diagnosis:

‘It can be difficult with early onset, particularly when it’s very early onset. In our case, we didn’t even tell our sons who were at university for a couple of years. There’s no need. Life was pretty much as normal, given extra complications.’

Gordon

Others, however, contrasted their experiences with those displayed in the vignette, highlighting how their children and grandchildren have learnt to adapt to dementia:

‘I’ve had an entirely different experience. *Chloe* gets on extremely well with the grandchildren and they go to her. I mean they know what’s wrong with her because they have grown up knowing the problem...’

Colm

The phone (never) stops ringing: the impact of EOD on social networks

Previous studies have highlighted the loss of friends, colleagues and extended family members that often characterise the psycho-social sequelae of EOD (see, for example, Svanberg et al., 2011). Such experience was echoed in the creative workshop. ‘*The Phone (Never) Stops Ringing*’ seeks to highlight the rapid and dramatic ways in which social networks can decline in EOD. In this scene, Irene is preparing to leave for work and reminds Paul not to answer the phone unless it is her. When Paul interjects by asking what would happen if his friend Tom calls and wants to go for a drink, Irene replies by saying ‘*Tom won’t call*’. This aspect of the scene was designed to highlight the resigned acceptance families often appeared to display when talking about the loss of friends and other members of their pre-diagnosis social network. Irene goes on to remind Paul of their phone code: she will ring once and then hang-up before calling back, so that Paul knows it is her. Having a phone code was suggested by one couple during the workshop, who reported using a similar method to protect against the threat of cold callers wishing to take advantage of the person’s memory difficulties. In the editing phase, telephone

sounds and extracts of remembered conversations were layered over this scene, as fond memories are progressively replaced with loud and intimidating ringing sounds. This was designed to emphasise the shifting symbolism of the telephone, from a source of community connectedness to a potential source of danger.

When carers came to analyse this scene, there was an extended discussion around the reactions of friends, colleagues and family members to EOD. Some carers, for example, noted how friends and family members had disappeared from their lives following diagnosis:

‘My wife, her brother, in what, four years, has only seen her once at her sister’s funeral. Never phones ... Sends a Christmas card believe it or not.’

Paul

Furthermore, whilst some emphasised the emotional difficulties that friends and former colleagues encountered in seeing the impact of EOD, others argued that a diagnosis of EOD proved to be the litmus test for the strength of pre-existing social bonds:

‘You really find out who your true friends are in a situation like that...the way they act, you know. You’d think my wife was dead.’

Henry

We won’t be invited back: facework and the management of *faux pas*

Goffman (1967: 5) defined facework as ‘the positive social value a person effectively claims for himself by the line others assume he has taken during a particular

contact'. During the creative workshop, managing the risk of faux pas (and other events that may impact negatively on the facework of people with EOD) was highlighted as a consistent source of anxiety. This appeared to be linked to the belief that, in contrast to late-onset dementia, EOD is a more invisible form of illness. Hence, whilst forgetful, erratic or anti-social behaviour may be attributed to dementia amongst those in the fourth age of life, fewer people are aware that younger adults may be living with dementia-related impairments and, as such, they may not respond accordingly. In this context, we noticed how one workshop participant with early onset AD would repeatedly use the phrase 'I won't be invited back' as a joke and, fundamentally, as a means of defusing feelings of awkwardness and embarrassment that came about by not being able to remember certain names, faces or events. We adopted this saying as the title of our final vignette.

In it, Paul and Irene are sitting in a restaurant. Paul appears distressed by the fact that he recognises, and wishes to talk to, another diner in the restaurant who appears to be ignoring him. When the manager comes over, she recognises Paul and Irene as regular visitors to the restaurant. After Irene explains that Paul's approach to the other diner was a genuine mistake, the manager offers to intervene, reassuring Irene that Paul's behaviour was simply the result of a male lack of tact ('It's a man thing'). This phrase was introduced following insights from one couple at the workshop, who reported feeling highly frustrated that the presence of dementia was ignored by those both within and outside of, their nuclear family.

According to Goffman (1967), one of the most widespread ways in which people seek to manage the risk of social faux pas is avoidance. During the Carers' Focus

Group, managing the risk of embarrassment and the potential loss of face was emphasised as a heavy burden, which could easily lead to avoidance behaviour:

‘There can be issues, even things like socially because what happens is a glass will get knocked over, water or wine, or a party if you drop it, red wine on carpet, you know, all these things happen and have happened and again that’s a reason to not bother going, because it’s a risky situation ...’

Gordon

With the rise of dementia activism in the UK (see, for example, , Bartlett, 2014, Bartlett and O’Connor, 2007) the experience of stigma and social embarrassment are increasingly becoming re-cast as political (as opposed to private) issues. This emerging orientation towards resisting the disabling pressures of society-at-large found resonance within the Carers’ Focus Group, when analysing this vignette .

‘I used to think, you know, going in a restaurant was a bit of a struggle, that it’s me, but now I just cut *Gladys*’ food up and if she uses her hands and fingers to eat, fine; if people get upset with that, tough.’

Paul

[Table 2 to go about here]

Discussion: Using the vignettes within a public sociology of dementia

In the pre-ceeding section, we described how the content of the vignettes speak to a range of sociological issues and debates surrounding dementia. In this section,

however, we focus on how, as research outputs, the vignettes can contribute towards a public sociology of dementia in the 21st century. As research outputs, our vignettes (like many outputs from sociology) serve a dual role, communicating our findings in ways that further sociological understandings whilst also contributing to broader debates within civil society about the ways in which members of that society are treated. It is for this reason that we view our project as an *organic* form of public sociology (Burawoy, 2005a); a process formed in mutual education that extends both within and beyond the circle of people who participated in data collection. What then, do our vignettes contribute to a public sociology of dementia? Drawing on the first author's previous work (Jenkins, 2014), we view their main contribution as helping to challenge the increasing emphasis, within minority world cultures and their formal care systems, on the promotion of *individualism* in dementia. Originally advocated by writers such as Kitwood (1999), recognising the essential *uniqueness* of the person with dementia has since been used to justify a raft of neoliberal approaches to the organisation of health and social care. The *Personalisation Agenda* (Department of Health, 2007) for example, arguably stands as a prime example within the UK policy context, with its championing of personal budgets and self-directed support. This contemporary facet of what Durkheim (1933/1997) first referred to as the *cult of the individual* has served to re-enforce unhelpful distinctions between those positioned as *caring* and those positioned as *cared-for* (Jenkins, 2014) whilst also facilitating the social and psychological alienation of carers who feel they no longer recognise the *inherent individuality* of the person they once knew (Davis, 2004). In contrast, we seek to advance an *inter-embodied* approach to person-centredness in dementia (see Jenkins, 2014). Whilst individualistic person-centred praxis seeks to revive, reminisce-over or otherwise re-claim a pre-morbid,

previously unified self, our (sociologically-informed) model of person-centredness is based on the core ontological belief that the self is transactive and multi-faceted, as opposed to discrete and unified. As such, the goal of an inter-embodied approach is not to *re-unify* the *individual* with dementia, but to help enable a rich and polyphonic *montage of selves* to emerge. Symbolising this, our vignettes do not reflect any one *individual's* perspective on dementia but are, instead, the product of our workshop group's collective insight. Furthermore, through the use of professional actors and their skills in intercorporeal expression, we were able to enfold the sayings, expressions, embodied gestures and routinized practices of participants within the vignette protagonists (Paul & Irene). These protagonists are best conceptualised, then, not as *indivisible individuals* but, rather, as polyphonic montages of selves housed (temporarily) within material bodies (Jenkins, 2014). Is this not what we all are, regardless of whether or not we have a diagnosis of dementia? Is it not the case that our selves are constantly being shaped and re-shaped through our interactions with others? Do we not enfold the perspectives and practices of others within our selves and do we not transmit our own in return? In short, are we not *dividual* (Marriott, 1976) as much as we are *in-dividual*? What might be possible in dementia if we, at the very least, temper our deep appreciation for individuality with an equal respect for our ability to transact and inter-embodiment our selves (Jenkins et al., 2013; Jenkins, 2014)? This is the key question we would like to offer a public sociology of dementia.

By disseminating these vignettes as widely as possible, and to audiences both inside and outside of academia, we hope in the coming months and years to engage a range of publics in discussions about the nature of oppression in early onset

dementia, as well as the value of intercorporeality, collective voice and shared expression in dementia more generally. Copies of the vignettes have already been disseminated to people with dementia, senior health and social care professionals and post-graduate students across the globe. We are working with partners outside of academia to present the vignettes at an exhibition within the (name of government building) in December 2014, and to host a series of public workshops aimed at re-imagining dementia in the 21st century.

By reporting upon the process by which we arrived at these (public) sociological outputs, we hope, in this paper, to encourage others within the academy to consider what public sociology has to offer in terms of addressing the challenges, and maximising the opportunities, surrounding dementia in the 21st century.

Acknowledgements

We are extremely grateful to the families and practitioners who participated in the research; and without whose honesty, wisdom and insight this study would not have been possible. Thanks are also due to Dr Martyn Pickersgill, in particular, for his detailed reading and comments on earlier drafts, as well as Dr Neheh Rowar-Dewar, Dr Catriona Rooke and Dr Amy Chandler for their helpful comments and suggestions.

Funding

This study was funded by the Alzheimer Scotland Dementia Research Centre and the University of Edinburgh.

References

- Adams B. (1998) *Timescapes of Modernity: The Environment and Invisible Hazards*. London: Routledge.
- Allen J, Oyebode J, and Allen J (2009) Having a father with young onset dementia: The impact on well-being of young people. *Dementia* 8 (4): 455-480.
- Alzheimer's Association (2006) *Early Onset Dementia: A National Challenge, a Future Crisis*. Chicargo, IL: Alzheimer's Association.
- Alzheimer's Society (2012) *Factsheet 400: What is Dementia*. London: Alzheimer's Society.
- Bailey C, Clarke CL, Gibb C, Haining S, Wilkinson H, and Tiplady S (2013) Risky and resilient life with dementia: Review of and reflections on the literature. *Health Risk & Society* 15 (5): 390-401.
- Barter C, Renold E (2000) I wanna tell you a story: The application of vignettes in qualitative research with young people. *Social Research Methodology, Theory & Practice* 34 (4): 307-323.
- Bartlett R (2014) The emergent modes of dementia activism. *Ageing & Society* 34 (4): 623-644.
- Bartlett R, O'Connor D (2007) From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies* 21 (2): 107-118.
- Beattie A, Daker-White G, Gilliard J, and Means R (2002) Younger people in dementia care: A review of service needs, service provision and models of good practice. *Aging & Mental Health* 6 (3): 205-212.
- Black B, Wechsler M, and Fogarty L (2013) Decision making for participation in dementia research. *American Journal of Geriatric Psychiatry* 21 (4): 355-363.

- Bloor M, Wood F (2006) *Keywords in Qualitative Methods: A Vocabulary of Research Concepts*. London: Sage.
- Boal A (1979) *Theatre of the Oppressed*. New York, NY: Theatre Communications Group.
- Boal A (1992) *Games for Actors and Non-actors*. London: Routledge.
- Bolmsjö I, Edberg A, and Andersson P (2012) The use of drama to support reflection and understanding of the residents' situation in dementia care: A pilot study. *International Journal of Older People Nursing* 00: 1-9 (accessed 28 November 2013).
- British Sociological Association [BSA] (2002) *Statement of Ethical Practice for the British Sociological Association*. Durham: British Sociological Association.
- Burawoy M (2005a) The critical turn to public sociology. *Critical Sociology* 31 (3): 313-326.
- Burawoy M (2005b) For public sociology. *American Sociological Review* 70 (1): 4-28.
- Charles R (2004) The arrogance of public sociology. *Social Forces* 82(4): 1639-1643.
- Chaston D (2011) Between a rock and a hard place: Exploring the service needs of younger people with dementia. *Contemporary Nurse* 39 (2): 130-139.
- Clarke C, Wilkinson H, Keady J, and Gibb C (2011a) *Risk Assessment and Management for Living Well with Dementia*. London: Jessica Kingsley.
- Clarke C (2000) Risk: Constructing care and care environments in dementia. *Health Risk & Society* 2 (1): 83-93.
- Clarke C, Wilcockson J, Gibb C, Keady J, Wilkinson H, and Luce A (2011b) Reframing risk management in dementia care through collaborative learning. *Health & Social Care in the Community* 19 (1): 23-32.

Davis D (2004) Dementia: sociological and philosophical constructions. *Social Science & Medicine* 58(2): 369-378.

Department of Health (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*. London: Department of Health.

Douglas M (1985) *Risk Acceptability According to the Social Sciences*. New York, NY: Russell Sage Foundation.

Durkheim E (1912/1995) *The Elementary Forms of Religious Life*. New York, NY: The Free Press.

Durkheim E (1933/1977) *The Division of Labor in Society*. New York: Free Press.

Elliott E, Williams G (2008). Developing public sociology through health impact assessment. *Sociology of Health & Illness* 30(7): 1101-1116.

Ely M, Vinz R, Anzul M, and Downing M (1997) *On Writing Qualitative Research: Living by Words*. London: RoutledgeFalmer.

Finch J (1987) The vignette technique in survey research. *Sociology* 21 (1): 105-114.

Freire P (1970) *Pedagogy of the Oppressed*. New York, NY: Continuum.

Freire P (2000) *Cultural Action for Freedom 2000 Edition*. Cambridge, MA: Harvard Education Press.

Gans H (1989) Sociology in America: The discipline and the public. *American Sociological Review* 54(1): 1-16.

Glaser B, Strauss A (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine Publishing Company.

Goffman E (1967) *Interaction Ritual*. New York: Doubleday.

Harris P, Keady J (2004) Living with early onset dementia: Exploring the experience and developing evidence-based guidelines for practice. *Alzheimer's Care Quarterly* 5 (2): 111-122.

Harris P, Keady J (2009) Selfhood in younger onset dementia: Transitions and testimonies. *Aging & Mental Health* 13 (3): 437-444.

Hermans H, (2001) The dialogical self: Toward a theory of personal and cultural positioning. *Culture & Psychology* 7 (3): 243-281.

Heggestadd A, Nortvedt P, and Slettebø A (2013) The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics* 20 (1): 30-40.

Hughes R (1998) Considering the vignette technique and its application to a study of drug injecting and HIV risk and safer behaviour. *Sociology of Health & Illness* 20 (3): 381-400.

Hughes R, Huby M (2002) The application of vignettes in social and nursing research. *Journal of Advanced Nursing* 37 (4): 382-386.

Hughes R, Huby M (2004) The construction and interpretation of vignettes in social research. *Social Work & Social Sciences Review* 11 (1): 36-51.

Jenkins N, Lawton J, Douglas M, Hallowell N (2013) Inter-embodiment and the experience of genetic testing for familial hypercholesterolemia. *Sociology of Health & Illness* 35(4): 529-43.

Jenkins N (2014) Dementia and the inter-embodied self. *Social Theory & Health* 12(2): 125-137.

Kitwood T (1999) *Dementia Reconsidered: The Person Comes First*. Beckingham: Open University Press.

Kontos P, Mitchell G, Mistry B, and Ballon B (2010) Using drama to improve person-centred dementia care. *International Journal of Older People Nursing* 5 (2): 159-168.

Lepp M, Ringsberg K, Holm A, and Sellersjö G (2003) Dementia - involving patients and their caregivers in a drama programme: The caregivers' experiences. *Journal of Clinical Nursing* 12 (6): 873-881.

Manthorpe J, Moriarty J (2010) *Nothing Ventured, Nothing Gained: Risk Guidance for People with Dementia* London: Department of Health

Marriott K, (1976) Hindu transactions: diversity without dualism. In: Kapferer B (ed) *Transaction & Meaning: Directions in the Anthropology of Exchange and Symbolic Behaviour*. Philadelphia: Institute for the Study of Human Issues, 109-142.

McLaughlin N, Kowalchuk L, and Turcotte K (2005) Why does sociology need to be saved: Analytic reflections on public sociologies. *The American Sociologist* 36(3-4): 133-151.

Mental Health Foundation (2011) *An Evidence Review of the Impact of Participatory Arts on Older People*. London: Mental Health Foundation

Merleau-Ponty M (1968) *The Visible and the Invisible: Followed by Working Notes*. Evanston: Northwestern University Press.

Mitchell G, Dupuis S, and Jonas-Simpson C (2011a) Countering stigma with understanding: The role of theatre in social change and transformation. *Canadian Theatre Review* 146 22-27.

Mitchell G, Dupuis S, Jonas-Simpson C, Whyte C, Carson J, and Gillis J (2011b) The experience of engaging with research-based drama: Evaluation and explication of synergy and transformation. *Qualitative Inquiry* 17 (4): 379-392.

Moscovici S (1984) The phenomenon of social representations. In: Farr R, Moscovici S (eds) *Social representations*. Cambridge: Cambridge University Press, 3-69.

National Institute of Clinical Excellence (2006) *Dementia: Supporting People with Dementia and their Carers in Health and Social Care* London: NICE.

- Nolan M, Davies S, Brown J, Keady J, and Nolan J (2004) Beyond 'person-centred' care: A new vision for gerontological nursing. *International Journal of Older People Nursing* 13 (3a): 45-53.
- Nuffield Council on Bioethics (2009) *Dementia: Ethical Issues* London: Nuffield Council on Bioethics.
- O'Connor D, Purves B (2009) *Decision-Making, Personhood and Dementia: Exploring the Interface*. London: Jessica Kingsley.
- O'Dell L, Crafter S, de Abreu G, and Cline T (2012) The problem of interpretation in vignette methodology in research with young people. *Qualitative Research* 12 (6): 702-714.
- Prior L (1993) *The Social Organisation of Mental Illness*. London: Sage.
- Reason P and Bradbury H (2001) *Handbook of Action Research: Participatory Inquiry and Practice*. London: Sage.
- Roush, R., Braun, M., Basting, A., Winakur, J., Rosenberg, F. and McFadden, S. (2011) Using the arts to promote resiliency amongst persons with dementia and their caregivers. In: Resnick B, Gwyther C, and Roberto K (eds) *Resilience in Aging: Concepts, Research, and Outcomes*. New York, NY: Springer, 105- 120.
- Royal College of Psychiatrists (2006) *Services for Younger People with Alzheimer's Disease and Other Dementias*. London: Royal College of Psychiatrists.
- Rylatt P (2012) The benefits of creative therapy for people with dementia. *Nursing Standard* 26 (33): 42-47.
- Spalding N, Phillips T (2007) Exploring the use of vignettes: From validity to trustworthiness. *Qualitative Health Research* 17 (7): 954-962.
- Svanberg E, Spector A, and Stott J (2011) The impact of young onset dementia on the family: A literature review. *International Psychogeriatrics* 23 (3): 356-371.

Svanberg E, Stott J, and Spector A (2010) 'Just helping': Children living with a parent with young onset dementia. *Aging & Mental Health* 14 (6): 740-751.

van Vliet D, de Vugt M, Bakker C, Koopmans R, Pijnenburg Y, Vernooij-Dassen M, et al. (2011) Caregivers' perspectives on the pre-diagnostic period in early onset dementia: A long and winding road. *International Psychogeriatrics* 23 (9): 1393-1404.

Wilkinson N, Srikumar S, Shaw K, and Orrell M (1998) Drama and movement therapy in dementia: A pilot study. *Arts in Psychotherapy* 25 (3): 195-201.

Nicholas Jenkins is a Chancellor's Fellow at the University of Edinburgh. Since obtaining his PhD in 2006, he has worked on a variety of research projects exploring the lived experience of health, risk and illness. In 2012, he was awarded a prestigious 5-year Chancellor's Fellowship at Edinburgh University, to develop an inter-disciplinary programme of work into the social organisation of dementia. He has already published in this area and his current focus includes the role of Web 2.0 technologies in re-imagining dementia in the 21st century.

Tables and figures

Table 1: Research Participants

Participants	Drama Workshop	Focus Group	TOTAL (n=)
<i>Persons with a diagnosis of EOD (pwd)</i>	4	0	4
<i>Spouses of pwd</i>	3	8	9
<i>Parents of pwd</i>	1	1	1
<i>Children of pwd</i>	2	1	3
<i>EOD practitioners</i>	1	2	3
<i>Workshop facilitators</i>	2	0	2
<i>Workshop actors</i>	2	0	2
<i>Academic researchers</i>	1	1	1
TOTAL (n=)	16	13	25

Table 2: Focus Group Participants Quoted

Pseudonym	Relationship to the person with dementia	Attended the creative workshop?
<i>Claire</i>	Wife	No
<i>Mary</i>	Wife	Yes
<i>Sandra</i>	Wife	Yes
<i>Gordon</i>	Husband	No
<i>Colm</i>	Husband	No
<i>Paul</i>	Husband	No
<i>Henry</i>	Husband	No

<i>Simon</i>	Son	No
--------------	-----	----