

**Title: 'All the world's a stage': Accounting for the dementia experience - insights from the IDEAL programme.**

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## **‘All the world’s a stage’: Accounting for the dementia experience - insights from the Improving the Experience of Dementia and Enhancing Active Life (IDEAL) study.**

### **Abstract**

Qualitative dementia research emphasises the importance of recognising the voice of the person with dementia. However, research imbued with a politics of selfhood, whereby individuals are called upon to give coherence to experience and emotion, jars with representations of dementia as a gradual decline in capacity. Moreover, it reinforces an assumption that there is an essential experience that can be accessed through different methods. Drawing on Atkinson and Silverman (1997), we view the interview not as confessional but rather as an outcome of social interaction. This paper draws on qualitative interviews from the IDEAL study (Clare et al 2014), to focus specifically on the forms of accounting and storytelling of people living with dementia and how these are produced through the course of the interview encounter. Extracts from our interviews highlight key aspects of this interactional process: (i) social conventions and temporality, (ii) self presentation and identity work, (iii) accounts and wider cultural meanings. To conclude, we suggest that qualitative research with people with dementia requires a reframing of both the interview encounter and interpretive practices.

**Keywords: Qualitative interviews; dementia; identity; representation**

### **Introduction**

- Researcher: Yeah, what kinds of things do you tend to do around the house?  
John: Oh as little as possible, what do you mean?  
Researcher: The things ... you know do you tend to read, watch TV, listen to music, sit in the garden?  
John: Just really, if I try to analyse what I do it’s very ... it’s sort of non-descript. I don’t say that I am going to sit there for four hours a day, and always listen to only classical music. I quite like the idea of that, but that’s not what I do, erm ...  
Researcher: So there is no ... you don’t have a set kind of pattern or routine to your days?  
John: No, hmm are you going to be talking to that one later? [gestures towards his wife]  
Researcher: I am, yes.  
John: Yeah, I could well believe that she said ... she will say, well what he will say about listening to music or whatever that’s not true. So that’s all of the things you have to bear in mind don’t you?  
Researcher: Uh-huh, well I am interested in your perspective as well.  
John: Hmm, hmm.  
Researcher: Because it’s what’s important to you, what you feel is important.  
John: Hmm.  
Researcher: And what you enjoy doing.  
John: But suppose I am just a real rogue and a liar and all that, and I will tell you anything, I will tell you what I think you want to hear and ...  
Researcher: That’s the nature of interviews. I am well versed in that.

This extract is taken from an interview with John who is living with Alzheimer's disease. We begin with this conversation as a helpful starting point through which to set out the aims of our article. This interaction explicitly challenges the common assumptions that frame concerns regarding authenticity and reliability in the interview accounts of people living with dementia. More broadly, it also highlights implicit assumptions which inform some approaches to qualitative interview research (particularly those which define the interview as a tool for expressing voice or accessing experience); such assumptions can prevent meaningful engagement with forms of identity work, relations of power and the wider social and cultural contexts that shape the interview encounter.

During this interaction, John sets out the difficulty of reflecting upon, describing and quantifying his daily activities. He describes the difference between what he might like to do or think of himself as doing and what he actually does. The assumption, that can frame some approaches to the qualitative interview, is that interview participants (with or without a cognitive impairment) are capable of detached analysis of their daily lives and can connect their actions to some underlying source of motivation or emotion and that the researcher, through the interview, is able to access these. John directly questions this assumption and in doing so also challenges the role and position of the interviewer as an interpreter of his account. Furthermore, he makes explicit the distinction between his account of his experience and the experience itself.

John asks if his wife will take part in an interview, concerned that she may contradict his own account. In response, John positions himself as potentially unreliable, as a 'liar and a rogue' who will tell you what he thinks you want to hear. By doing this, John is able to construct his identity in important ways: it detracts from the effects and symptoms of the condition itself – as something that can render him unreliable – and, instead, regains him a degree of power and control, as someone who is able to strategize, manipulate and make choices about how he represents himself and his experience.

What we go on to show through this paper is that people living with dementia are engaged in practices of narrative construction and identity work<sup>1</sup>. Recognising this helps to overcome some of the concerns regarding reliability or authenticity in the responses of those living with dementia and instead focusses on an engagement with the ways they account for their experience. This shift in approach has two major consequences: firstly, it makes explicit the different conceptions of selfhood which inform both the qualitative interview encounter and its interpretation; and, secondly, it enables connections to be made between participants' stories and the wider social and cultural meanings associated with ageing, disease and personhood which shape them.

It is important at the outset to distinguish our sociological focus from approaches to observing breaches in social convention as a diagnostic tool (see for example Cicourel 2012; Jones et al., 2016; Mendex et al., 2014). Our focus is not to deploy this analysis as a tool to identify people who 'fail' to meet criteria for social behaviour, but rather as an approach which takes account of the socially mediated ways in which people with dementia perform and enact their lives and experiences.

## Background

### *The turn to personhood*

The turn to personhood in qualitative research with people with dementia (Kitwood, 1997) has led to a proliferation of participatory qualitative research (e.g. Brown and Durrheim, 2009; Dewing 2007; Keady et al. 2007), including various forms of the qualitative interview (for example, McKeown et al. 2010; 2013). This development occurred in recognition of the lack of inclusion of people living with dementia in research (Cottrell and Schultz, 1993) and subsequent calls to give voice and access the experience of those living with the condition (Harris, 2002; Moore and Hollett, 2003). While this fostered a culture of inclusion in dementia research, it also generated methodological difficulties for the qualitative interview- notably how to access and represent the experience of your participants when recalling events and reflecting on their meaning poses them significant challenges.

To a large extent, this crisis of representation has been approached through practical strategies to manage and adapt the qualitative interview to accommodate the difficulties experienced by those living with dementia such as memory loss, fatigue and language difficulties (Beuscher and Grando, 2009; Heggstad et al., 2012; Lloyds et al., 2006; Nygard, 2006; Wilkinson, 2002). These methodological innovations have sat alongside calls to develop research ethics beyond a one-off, contractual style consent procedure and to instead situate ethical practice within ongoing qualitative research relationships that attend to the differences and challenges of people living with dementia, including for example the fluctuations in capacity that can form part of the dementia experience (Bartlett and Martin, 2002; Clare et al., 2016; Pesonen et al., 2011; Quinn et al., 2018). This work has, undoubtedly, provided important practical and ethical contributions to the development of dementia research; however, questions over the role of the qualitative interview in accessing the experience of the person living with dementia- and the assumptions regarding selfhood which underpin it - require further interrogation. It is the purpose of this paper therefore to explore the role of the qualitative interview in the context of interviewing people living with dementia and to interrogate the meanings attached to selfhood and identity that shape both the interview itself and interpretations of interview encounters.

### *Accessing the dementia experience: From a confessional to a social process*

There have been some contributions which have asked questions about the socio-cultural and political grounding of methodological choices and approaches and their implications for qualitative interviews with people living with dementia. For example, Bond and Corner (2001) and Sabat (2003) have asked whether the challenges of doing research with people with dementia are new or simply reflective of ongoing problems for the qualitative interview method. Moriera, O'Donovan and Howlett (2014) go further in challenging what they describe as a politics of selfhood that underpins many approaches to the qualitative interview, with particular assumptions about identity and personhood. They suggest these assumptions jar with the forms of communication, story telling and self-presentation used by people living with dementia.

To explore the qualitative interview in the specific context of doing research with people with dementia, we begin with Atkinson and Silverman's (1997) seminal paper on the interview society. Their paper, along with subsequent work which has continued their critique (Back, 2012; Blakely and Moles, 2017; Gubrium and Holstein, 2012), argues that conceptualising the interview as a method that allows for an authentic gaze into the soul of another, as some kind of confessional of the self, is deeply problematic. Instead, they seek to make explicit the biographical work of both the interviewer and interviewee that occurs through the course of an interview, in which both are engaged in practical efforts to construct themselves and their lives. They suggest that some approaches to qualitative interview research have held 'an implicit appeal to the authenticity of narrative experience in the dialogic revelation of selves' (Atkinson and Silverman, 1997: 305) to the detriment of interview data analysis (Silverman, 2017). In the field of dementia research, this implicit appeal can manifest as representations of the qualitative interview as a tool to express voice (Moore and Hollett, 2003) or a means of revealing or accessing experience (Nygard, 2006). Central to this critique is a recognition that the work of both interviewer and interviewee occurs in social and cultural contexts, shaped by both the interview itself, and the meanings attached to it, but also to wider socio-cultural and political framings.

Silverman (2017) contends (building on Potter and Hepburn, 2012; Holstein and Gubrium, 2016), that seeking to access perceptions or experiences will always be flawed as such aims assume extraordinary capacities on the part of the interviewee (Potter and Hepburn, 2012), attributing to them a 'special epistemic position' including 'cognitive judgements and feats of memory and analysis' (p.567). Treating interview talk as a way of referring to some inner psychological object, or neglecting the socially produced nature of the conversations that ensue, is particularly problematic for those living with dementia, for whom the mind and memory is a central source of social concern. Framing the qualitative research interview in a way that desists from attributing interviewees with this 'special epistemic position' is therefore beneficial not just for including those with cognitive impairment in research, but also for interpreting their talk. A shift of focus away from inner states of mind and towards social processes in the qualitative interview would also help strengthen research that seeks to show how dementia and its symptoms are experienced in and through the contexts of social relationships, environments and everyday practices.

In building upon this approach, we suggest that the so-called challenges of representation in dementia research require us to engage in not just the practicalities of researching with people with cognitive impairments, but also to ask questions of our method and methodology, including: what are our expectations of the research encounter; what constitutes the 'products' of our research; and how do we interpret data produced through the qualitative interview? This paper draws on qualitative interviews from the IDEAL study (Clare et al 2014), to focus specifically on the forms of accounting and storytelling of people living with dementia and how these are produced through the course of the interview encounter. This focus also enables us to ascertain whether and how it is possible to attend to differences in social and temporal frames, rather than seeking to eliminate these as unreliable. By drawing out these considerations through our data, we engage more explicitly with existing politics of selfhood which inform research practices and consider what they mean for representing the experiences of those living with dementia.

## Stories about living with dementia

We have organised our interview extracts into three categories: (i) social conventions and temporality, (ii) self-presentation and identity work and (iii) accounts and wider cultural meanings. Many of the extracts chosen could be considered inconsistent, unreliable or inaccurate in some way – including, for example, shifts in spatial and temporal frameworks. By situating these within the wider social and cultural contexts of the interview encounter, the paper attends to the behaviours and practices of people living with dementia, employed to present and account for themselves and their experiences.

### *Social conventions and temporality*

Our first extract comes from Julie, who is living with Alzheimer's disease and is described by her husband as a 'time-traveller'. She is increasingly bringing the past into the present and her husband describes how she is much more 'at home' in the past. This extract is not an act of time travel, but instead illustrates how she purposefully shifts the conversation to talk about events of the past. In order to accomplish this, she draws on the everyday, common-sense social conventions of storytelling, to re-frame the question that is posed to her:

Researcher:       What's life like for you day to day at the moment, do you have a routine?

Julie:               Well, it's a bit (laughs) ... up and down, depending on what's going on. So it's probably better to start at the beginning, because I went to school, now I'm trying to remember which schools I went to (laughs)..... so the main, the main school when I was young was a High School for Girls.

The context of this interaction is important in Julie's response, this context includes: the qualitative interview about Julie's life; the expectations of storytelling that it produces; the interviewer as the audience who has a specific interest in her life. Her telling of her story is therefore framed by this context; as she says, it is best to 'start at the beginning'. The extract also illustrates the performativity of narrative that enables those telling their story to show certain aspects of themselves (Mishler, 1986). Most importantly, this framing of the question as a story of her life enables Julie to talk about the past rather than engaging with the present; the past being a time and place that is more accessible and comprehensible to her. Social conventions, such as rules of storytelling, can be seen in this instance to offer Julie a mechanism through which to manage this particular aspect of her dementia. In a similar way to John, with whom we began our paper; Julie redefines her engagement with the past, not as a symptom of her condition, but instead as a logical starting point to responding to questions about her life.

In the following extract, Julie embarks on a time-travelling moment. The researcher asks about spending time at her church, which she had previously described as being of central importance to her life:

Julie:               Em, but we don't usually go during the week. Em, because there really isn't much, you know, I mean, if, if there's a, if there's a, you know, er, er, there's, em, er, er, a big service for something, well, then we go. But, but not otherwise.

Researcher: Yeah.  
Julie: ... and besides when you've got children, you've got to make sure that you're around so they can go to bed and have their tea and all that.  
Researcher: Mm.  
Julie: (Laughs). The good stuff.

Julie describes being at home with her young children and the responsibilities that come with this caring role. In the present time, Julie's children are living independently with children of their own. In reflecting on and interpreting these moments of time travel, questions arise as to whether these moments are dismissed as manifestations of a person's illness, or whether something can be learned from their consideration. During Julie's interview, she repeats and returns to two key narratives in constructing her life and identity, her commitment to church and faith and her caring roles, either for her five children, her husband or her sick mother when she was growing up. Her account of these roles formed a central part of her self-presentation. In responding to questions about her daily activities, Julie travels to an earlier point in her life when she had a greater degree of order, structure and routine, based upon the caring responsibilities she describes throughout her interview, a routine and structure which is largely absent in her present.

We propose that qualitative interviews with people with dementia should carefully consider and interpret stories in which time is not linear and space is not fixed. This has often been considered a barrier to doing qualitative research with people with dementia, particularly at the later stages of their condition. If we consider interview accounts as being situated within practices of storytelling and identity work, it is possible that such 'broken narratives' or responses deemed to be 'out of time' cease to be read as flawed or incomplete, but can instead be made meaningful, when read within the broader context of the social encounter. To undertake this interpretative work, we must consider some of the assumptions that underpin the problem of reliability or authenticity in interview accounts in the first place, particularly with regard to selfhood and identity. There is a presumption that personal identity is bound to the temporal trajectory of one's autobiographical past, present and future. Brockmeier (2014) describes this as a biologically anchored sense of time, or remembered time, which enables us to localise our experiences and thus ourselves as beings that are continuous in time. This perception of time and its connection to identity also has relevance beyond dementia; as Klein and Nichols' (2012) work with patients with amnesia shows, episodic memory is not necessarily fundamental to personal identity. Hyden et al (2014) suggest that this conception of identity, that is tied to 'biologically anchored time', excludes conceiving of personhood, identity and autobiographical time in a contextualised way. In other words, it creates barriers for recognising both identity and memory as being localised processes, embedded in social practices. For example, Julie's conflation of time is in part a reflection of the kinds of questions being asked of her, the wider context of the interview itself and the kinds of social conventions which shape conversation and storytelling. In this sense, identity or sense of self is conceived to be grounded in forms of action and interaction, including the qualitative interview.

#### *Self-presentation and identity work*

Telling stories about ourselves also involves a considerable amount of self-presentation and identity work. Understanding the requirements of identity work in everyday interactions is something that the people living with dementia we spoke to were sensitive to and, in some



cases, explicitly described. This is one example in which Jack, a man living with young onset Alzheimer's disease, describes the challenges of accounting for oneself:

Jack: And I'm very conscious of the fact that what you see isn't what you get so to speak, I am, I am, I am honestly and openly and sincerely talking with you as I do with everybody but there is an element of front. Because, because I am constantly trying to be the old Jack Donovan and the old Jack Donovan isn't quite the same anymore you know. I'm still trying to present as the old bank manager and the friend and the father and the grandfather and the husband and the friend and okay he's still there and he's still, the essence of that person and to an extent what you see of that person is still there. But I know it's not the same because of the effect the dementia is having upon me. It's exhausting.

Any illness can challenge a person's sense of identity (Sacks, 1991) including maintaining a sense of coherence and continuity of identity over time (Bury, 1982). This is particularly true of dementia, a condition that can be represented as a gradual diminishing of identity and personhood (Behuniak, 2011). Narrative and storytelling, particularly about one's own life or life events, therefore takes on a performative force for people living with dementia that enables them to maintain a sense of self (Hillman et al 2018). Stories provide a means with which people living with dementia are able to present, account for and construct their identity in ways that can counter identities that may be attributed to them as a consequence of their diagnosis. An important part of Jack's story is the extent to which he sees himself as the same person or not, reflecting the challenge dementia poses in holding on to a sense of continuity in the experience of self (Caddell & Clare, 2011; Harman & Clare, 2006). This account also feeds in to a cultural preoccupation with the idea of an inner, truer self that exists beyond social roles or relationships. Like much of the public representations of dementia (Basting 2009; Peel 2014), it is this past or inner self which Jack presents as being gradually eroded by the condition. The significance of this aspect of Jack's self-presentation is to acknowledge the politics of selfhood which shape understandings of dementia and what it means to live with it. It is therefore essential that we make explicit and critically engage with the constructions of selfhood and identity which inform our own research practices, including the ways in which we interpret the responses of those living with dementia in qualitative interviews.

John, in the extract provided at the start of our article, utilises questions over his own reliability as an interviewee. Doing this had the potential to reduce him to aspects of his dementia diagnosis. Instead, he used it as a means with which to regain a sense of power and control over the construction of his identity by shifting the interactive frame (Goffman 1974) from one of deficit- resulting from the symptomatic expression of disease- to one of agency and choice – resulting from a 'roguishness' of character. The next extract is taken from a conversation between Fred, who is living with vascular dementia, his wife Lucinda and the researcher. During this joint interview, Fred engages in a similar strategy of self-presentation as John by switching frames to focus on humour and his ability to make his wife laugh:

Lucinda (Wife): I think the funniest thing, I mean we laugh about it afterwards, but the funniest thing is I've got in, and I've laid all his clothes out, um and I've said right now, I'm going to quickly have a shower and get dressed, and you get shaved and dressed. And I will come back and I'll just burst out

- laughing because he's standing there with his sweater for instance up his legs. His um pants over his head, and he looks so lovely. And I say well I think you'd better take all those off.
- Fred: You see I make her smile.
- Researcher: I was going to say yeah, making her laugh.
- Fred: I'm absolutely.
- Researcher: Never a dull moment.
- Fred: Absolutely, actually I.
- Lucinda (wife): So I think you've got too many, you know, pathways in the brain now crossing.
- Fred: Yeah, but I will say seriously I have done it accidentally if I thought it, not that I've missed a thing, it made you, make you smile or something like that.
- Lucinda (wife): Okay sweetheart.
- Fred: Well it's easier to make her laugh.
- Lucinda (wife): Yes, it's good to make me laugh.

Rather than allowing this interaction to become framed by 'pathways in the brain' that could result from his wife's explanation, Fred instead persists on framing this incident according to his ability and desire to make his wife laugh, a long standing aspect of their relationship. The extent to which Fred is claiming to have purposefully dressed incorrectly to make his wife laugh is unclear. It is however clear that Fred's focus is not on the 'failure' itself, or what may have caused it, but on his continued ability to make his wife laugh. Here we see again how potential threats to a person's sense of self, which arise as a consequence of the effects of dementia, are managed and adapted to (Clare, 2003) through switches in interactional frames (Goffman, 1974). These help situate aspects of behaviour not as a symptom but instead as resulting from aspects of character: in Fred's case as a source of humour and laughter and in John's case, as a kind of mischief or roguishness. These framing devices help to maintain both a sense of narrative coherence and a continuity of self.

The following extract illustrates a common scenario in qualitative interview research with people living with dementia and their family carers: the different stories told by those living with dementia compared to those of their relatives. There are many ways in which differences in accounts between those living with dementia and their carers have been framed within qualitative dementia research that move beyond a simple concern over reliability or authenticity, including for example taking a relational approach to the constructing of the dementia experience, as something created through social relationships (Merrick et al., 2016). We suggest that focussing on practices of self-presentation and identity work in people's accounts may help provide greater insight into these differences. The extract below is taken from an interview with Jim, who is living with vascular dementia. He describes the ways in which his wife is getting 'knackered' and how he is doing 'okay', which, as he explains, is precisely the opposite scenario to the story his wife would present:

- Researcher: And have you noticed any changes over the last year or so in terms of your memory, things like that?
- Jim: Well, what I keep saying now is that my wife is getting knackered, getting older you know what I mean, because she's just been ill herself just lately, myself I think I'm alright but my wife will tell you otherwise,

the other way [laughing], yeah I seem to be okay, I go to the pub every Sunday and I play five and threes Dominoes, it's a game, have you ever heard of it?

Researcher: Oh yeah, yeah.

Jim: Yeah I play that, every Sunday, so you know, so I'm not going doolally, I can play very well at five and three, so no problem that way.

Researcher: Yeah.

Jim: And I back horses and I don't do so badly you know, I look at form and think, so I'm not going daft yet you know what I mean love, yeah I seem to be, well literally, I seem to be alright in that respect you know. So I've think I've not got any worse, you know, come some way, the way it happened, when I had it a while back, but that's it you know, otherwise I'm healthy, just my knees I'm not, just this knee.

Jim's responses are illustrative of the self-presentation and identity work that shapes people's stories about living with dementia. Telling stories about ourselves requires a degree of creative capacity to execute different performances of ourselves for various audiences (Goffman, 1959). In Jim's case, he presents his ongoing abilities to play dominos and to understand the form and bet on the horses as ways of showing how he is not 'doolally'. The differences in Jim's presentation of himself to that of his wife's are less illustrative of the realities of their everyday lives, and are instead examples of the different presentations of self, the multiple personae (Sabat and Harre, 1992) created according to different audiences and specific interactional encounters. This is particularly the case when being called upon to reflect on ones' life and identity for the purposes of a research interview.

Taking account of self-presentation, its purposes and what it means in relation to the stories we tell about ourselves offers greater potential for interpreting the differences in the accounts of people living with dementia and their relatives or carers. The first extract below is from an interview undertaken with Tony, the husband of Janet who is living with Alzheimer's disease, and the second extract is from Janet herself:

We had a disaster yesterday. She made a Christmas cake, which is something she's done for yonks. But it didn't work. It didn't rise....Er, it's something she hasn't' done, so she's never had that happen in all the years

I still bake a lot you know I do home baking...I always do my own Christmas cake and I'll do um various cakes and pastry...That's no problem, things like that are no problem.

In the early work of Sabat and Harre (1992), in which they propose a social constructivist approach to understanding the self in relation to living with Alzheimer's disease, their participant Henry corrects the way he is introduced to claim that he *is* a lawyer, rather than he *was* a lawyer. Similarly, for Janet, the significance of her response is not whether or not she undertakes the activities of baking or whether her recent attempt was a 'disaster', but rather that she considers herself a baker and, in making this a part of her self-presentation, she calls upon others to identify her as such. This is a conception of selfhood, as something accomplished and maintained through social interaction, which shifts the focus of the interpretation of Janet's response, and recognises the role others play in helping to maintain

identity. Such a shift in interpretative focus also critically challenges a view of selfhood as something which can be irrevocably lost or eroded through the effects of dementia or that episodic memory is an essential component of identity (Klein and Nichols, 2012). Instead, presentations of the self are shown to be produced and reproduced over time.

The sense in which the lives of people living with dementia are acted out is a reflection of the specific requirements of those living with a disabling condition. Those living with dementia engage in aspects of self-presentation which are akin to Garfinkel's (1967) concept of 'passing', whereby they must continuously work at gaining entry into a category of self which is socially recognised as 'normal', in part by finding ways to 'normalise' dementia and its effects (Buse and Twigg, 2018). While, at the same time, they must always provide for the possibility of detection or recognition as different. This precarious position leaves those living with dementia always on the cusp of potential failure, of breaching social norms. This position can create a greater awareness of the performative aspects of everyday life, as this extract from John who is living with Alzheimer's disease describes:

I'm just going through a little bit of Shakespeare that seems to be my mantra almost, do you know 'all the world's a stage and all the men and women merely players'? Well I mean that's life and I learned that at a very impressionable time in my school life and it's somehow bubbles up surprisingly frequently

This Shakespearian 'mantra' is not only illustrative of the performative aspects of everyday life for those living with dementia, but also represents a view of life: as the roles we play, as essentially finite, comprised of various entrances and exits, including our final role of 'second childishness'. This recurrent metaphor, which 'bubbles up frequently' for John, is thus an illustration of the ways in which entrenched cultural narratives regarding ageing and dementia are invoked to present and account for experience.

#### *Accounts and wider cultural meanings*

Rather than seeing interviewees as providing a passive account of their experience, interviews are also a site for the production and resistance of cultural narratives (Miller and Glassner 2016). Cultural narratives of dementia – as well as ageing and disease - form a significant part of our participants' accounts. We have seen in Jack's story, for example, the production of a narrative of dementia as an eroding of the self (Zeilig, 2013), while for John and Fred, the cultural narrative of dementia as failings – either the failure of accomplishing everyday tasks or the failure to accurately recount activities – is resisted. For others, it is the label itself that is resisted:

Betty: Must admit this sort of dementia aphasia as my doctor calls it, he says I don't call it dementia, it is aphasia, erm I suppose because dementia sounds like you're going nuts. He says no, no you're not going (laughs) it doesn't alter your intelligence, just alters your ability to speak to people.

Betty prefers to account for her difficulties through the term aphasia that relates specifically to the difficulties she has in finding words, rather than presenting herself as a person living with dementia. Cultural narratives of dementia remain to a large extent connected to the word's Latin roots meaning loss of mind (Lock, 2013) with accompanying synonyms including insanity, lunacy and madness (Trachtenberg and Trojanowski, 2008). Betty's description of

dementia, as sounding like ‘you’re going nuts’, is therefore grounded in dementia’s wider cultural associations, despite increasing efforts to shift the public discourse and combat stigma (Beard et al. 2009; Sabat, 2017).

For others, dementia’s negative associations are directly challenged on the basis of an alternative cultural narrative of the illness experience and what it means to live well with dementia:

Ron: But not everybody’s like me, I’m unique [chuckling], um and you’ve got to look after yourself, because there’s so many people out there, when they get that message, they decline from that day onwards, because they’re already put it in their mind and they can’t change the, the outcome, they’re going to die, they’re going to die of dementia, not of a heart attack no more, it’s going to be dementia, oh God when am I going to go? And the more they think about it, the more they go into themselves, and the worse they get, and people who do that are very sad.

Ron’s story about how others respond to being given a dementia diagnosis in comparison to his own response is reflective of two competing cultural narratives, one which he resists - that of dementia as a life sentence (Zimmermann, 2017) – and the other which he calls upon in constructing his own story, which relates to practices of self-management (Moore et al., 2015) in living well with dementia, a discourse which suggests a degree of personal responsibility and control over the condition (Hillman et al 2018). Often there are multiple cultural narratives which compete or sit alongside each other in people’s accounts of their lives and experiences. Attending to discourse and wider socio-cultural meanings in the talk of interviewees is therefore an essential part of recognising the socially mediated nature of the dementia experience and how these shape and inform participants’ accounts.

## **Discussion**

Our examples illustrate the interpretive benefits of engaging with interviewee’s talk as accounts, which require a sustained analysis, rather than being treated as an unmediated version of personal experience. We have shown how these interviews are products of social convention, narrative structures and other aspects of the interaction order (Goffman, 1983). Such an approach makes it possible to identify the production of and resistance to wider cultural narratives about dementia, aging and what it means to live with the condition *and* attends to the power relations that mediate the production of accounts.

It has been proposed that qualitative research produces a partial perspective, rather than a complete or ‘true’ account, of the experiences of the person with dementia. This viewpoint helps to avoid discrediting the views of the person with dementia on the basis of dependability or accuracy (Bond and Corner, 2001). Our paper directly addresses issues of reliability and authenticity in qualitative interviews with people with dementia by engaging with the wider assumptions that frame the interview method, the politics of selfhood embedded in these assumptions and how and why these might be particularly problematic for doing research with people with dementia. At the heart of these critiques lie particular views regarding selfhood and identity which can be especially problematic for those living with dementia.

If we return to our starting point in this paper and consider Atkinson and Silverman's (1997) work, they contend that the interview society is predicated on a concept of the person with a 'deep interior' which can be accessed and revealed through the techniques of interviewing. Hartman (2015) suggests that such assumptions are based on a view of the self as unified and self-contained, standing apart from its relationships to people and culture, so that so-called inconsistencies in interviewee accounts are understood in terms of being muddled, confused or as a result of pathology. Our interview extracts illustrate how people's accounts and stories are rarely uniform and often include contradictions as well as shifts in roles that align to different aspects of a person's personal or social identity. Our work suggests that the difficulties arising from questions of reliability in the accounts of those living with dementia may therefore be more usefully interpreted if we are to understand their responses as productive, biographical accounts that involve self-presentation and identity work that is shaped by their social contexts. Instead of focussing on accessing *the* voice of the person living with dementia, or to seek to reveal their experience, we suggest it is more fruitful to pay attention to processes of narrative production and the role these processes play in creating the meanings that are assigned to individual experiences (Holstein and Gubrium, 2016).

Through engaging with our interview accounts, we describe ways in which this shift in approach can provide strategies for interpreting so-called inconsistencies or inaccuracies in people's accounts, including moments of time travel. We have shown how this can be accomplished through the analysis of people's biographical accounts, paying attention to the interactional contexts of their stories, including both the interview itself but also the role of wider cultural narratives, and finally by considering the performativity of the interview and the ways in which people with dementia are engaged in framing practices and self-presentation. Our interviews show that when identity is threatened, by existing representations of what it means to live with dementia (Behuniak, 2011), as in the case of John and Fred, framing practices, self-presentation and identity work provide useful resources through which to maintain the appearance of narrative coherence and a sense of self. Indeed, our analysis suggests a degree of adroitness in our participants' accounts which would run counter to perspectives which highlight narrative and discursive deficit (Ehrlich, 1994) for people living with dementia. For some of our participants, like Jack, there is an explicit awareness of the very nature of the interview society and the kinds of stories and identity work it elicits. Perhaps the threat to identity that can result from living with dementia, can create for people living with the condition an increased awareness of processes that would otherwise remain taken-for-granted aspects of social interaction. For those living with dementia, these forms of interaction become a point of focus and attention, requiring them to develop strategies to manage and adapt their responses in order to 'pass' into a category of 'normalcy'.

Not only is turning our attention to these practices an important mechanism through which to understand and represent qualitative interview data with people with dementia, but it is also an important means through which those living with and working with people living with dementia may listen, in a different way, to what they say and recognise enduring aspects of personhood. To attend to the interview and its products as accounts, directly challenges a view of personhood as residing in the inner workings of individual minds. Instead, this approach recognises the inherent sociality of the interview and builds upon the significant contributions of qualitative research with people with dementia by foregrounding the study

of biographical work, self-presentation and storytelling as a fruitful, robust and insightful endeavour for the future.

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<sup>i</sup> Identity work refers to the 'the range of activities individuals engage in to create, present and sustain personal identities' (Snow and Anderson, 1987: p.1348).