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Discovering deviance: The visibility mechanisms through which one becomes a person with dementia in interaction

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ABSTRACT

Objectives: This paper explores the emergence of dementia within interpersonal interactions as a matter of deviance and visibility. The sociology of deviance suggests that we rely on assumptions of normal behaviour to help us develop interpretations of other people when interacting with them. When a person acts within expectation, we deem them normal. When a person transgresses expectation, we deem them deviant. In this way, dementia is revealed.
Methods: Semi-structured interviews were conducted with seven community-dwelling people with dementia and 26 carers living in the East Midlands, United Kingdom. Carers were selected for inclusion by participating people with dementia. Interview data was analysed using thematic analysis informed by symbolic interactionism.
Results: Four ways in which audiences may interpret a person as having a dementia are outlined: speech, temporality, conflict and novelty. These four mechanisms of visibility represent key moments in which dementia emerges in interaction.
Discussion: Examining dementia in terms of deviance and visibility positions dementia within social processes. This externalisation of dementia, relocating it within a combination of action, situation and audience, may suggest new possibilities for mediating its negative repercussions.

Introduction

In this paper, I chart the ways in which dementia emerges within interpersonal interaction. Using a deviance approach, grounded in symbolic interactionism (SI), I present a typology of visibility, denoting several mechanisms through which dementia can be perceived as a deviance in interaction. The major methodological ramification of this interactionist account is that the apparently internal and personal can be relocated within a relational space emerging between interactors. This suggests the potential for therapeutic interpersonal responses to dementia because relationships are understood to be an important feature of the experience of dementia. Such an account sits within wider psychosocial work exploring the actions of people with dementia in social contexts (Herron & Wrathall, 2018) and is attuned with appeals for recognition of relationality as a means of improving wellbeing (Kontos, Miller, & Kontos, 2017). I begin with an outline of deviance as an issue of visibility.

Interacting dementia

Historically, dementia was conceptualised as a problem of the afflicted individual, contained within the brains and cognitions of the people who were diagnosed. Over recent decades, this approach has been challenged through SI-informed explorations of dementia within relationships (Bartlett & O'Conner, 2010). Interpersonal experiences of dementia have received substantial sociological attention within an interpretivist tradition, characterised by Bartlett and O'Conner (2010: 18) as the “third moment” in dementia research. Kitwood's (1997) influential work on personhood and malignant social psychology spearheaded a social scientific movement that has produced such notable works as Sabat (2001) on selfhood, Kontos (2004) on embodiment and Twigg (2010) on dress. While diverse in scope, this body of work is united by the intellectual influence of SI and the positioning of dementia as an issue of meaning-making processes within interpersonal interactions.

More recently, Beard's (2016) work on identity has explored dementia diagnosis as a label that is negotiated in everyday life. Beard notes the various ways in which people's perceptions of people with dementia affect their lives. For example, Beard (2016: 145) writes of her participants with dementia: “perceptions of being deemed compromised led many respondents to express feelings of aggravation”. The experience of dementia in relation to others can thus become a painful

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one, encompassing the potential for roles to be lost and identity to be challenged (Beard, 2016). This interacted self-erosion is reminiscent of Kitwood's (1997) famous exploration of the ways in which malignant social psychology stripped away the personhood of people with dementia. He argued that because personhood is a conditional status granted to people within relationships, it can therefore equally be removed within relationships. The importance of interpersonal encounters in shaping experiences and wellbeing can be considered the key thread of continuity within the third moment interactionist tradition of dementia research. This paper contributes to that tradition, suggesting a range of mechanisms of visibility through which dementia emerges in interaction as deviance. To enable me to do so, I will first outline my theoretical approach.

Deviance and visibility

In this paper, I conceptualise dementia as a deviance that is ascribed to people based on moments of visibility in interaction. Two issues are of central importance to this understanding: deviance and visibility. The first is grounded in an interactionist understanding of shared situational expectations. Within the interactionist tradition, awareness of the shared meanings of a situation guides people to act appropriately within a given interaction (Becker, 1963). The importance of these meanings in denoting appropriate action means that ‘we lean on these anticipations that we have, transforming them into normative expectations, into righteously presented demands’ (Goffman, 1963: 12). If an actor satisfies these expectations and acts in the anticipated fashion, we are likely to consider them normal. Should an actor breech our demands, we may deem them abnormal. In deviating from expectation, the action, and hence the performer of that act, are interpreted as being deviant (Becker, 1963).

The situation and its associated expectations are important means of differentiating deviance. For example, crashing a car, getting lost or insulting a stranger, when enacted by an older person, may readily be deemed indicative of dementia or age-related cognitive decline. These same indications would likely be interpreted differently if enacted by a teenager following a night in the pub. Two different types of deviance are denoted, not by the actions, which are identical, but rather by implicit situational meanings. Such varying types deviance emerge in the interpretation of interaction, implying two important qualities. First, deviance is related to expectation; every deviant needs something to deviate from (Becker, 1963). Second, deviance is perceptual; every deviant needs their deviance to be perceived and attributed meaning by an interpretative agent (Becker, 1963). This latter requirement of audience is where our second important concept – visibility – becomes pertinent, because it means that deviance depends on whether it is perceived by an audience (Goffman, 1963). In this sense, visibility is the vehicle of deviance, because it is the process through which an underlying trait, such as dementia, is perceptually transformed into a deviance. Deviance is hence the outcome of the visibility process.

In this paper, I suggest that the emergence of dementia as a deviance, through interpersonal interaction, can be understood in terms of visibility. Dementia represents an underlying trait that has the potential to be a deviance and is made so via a process of visibility in interaction. Specifically, I present a typology of visibility, identifying four situational and relational mechanisms through which dementia becomes visible in interaction. These mechanisms are speech, temporality, conflict and novelty.

Methods

The data presented in this paper derive from in-depth semi-structured interviews conducted with people diagnosed with a dementia, their family members and formal carers in the East Midlands region of the United Kingdom, as part of a research project exploring the experiences of people affected by dementia. The study was theoretically grounded in SI due to the theory's previous use in similar third moment dementia research (Fletcher, 2018a,b; Beard, 2016; Kitwood, 1997; Sabat, 2001), as discussed. It sought to address the following research questions:

Table 1
Participants.

People with dementia	Network members
Henry 79, retired optician, Derbyshire, Alzheimer's disease, diagnosed 4 years	■ Julie, wife ■ Michael, son ■ Claudia, daughter
April 82, retired teacher, Leicestershire, Alzheimer's disease, diagnosed 4 years	■ Lauren, daughter ■ Caroline, daughter ■ 5 adult grandsons (Cameron, Joe, Jacob, Matt, David)
Paul 74, retired lorry driver, Derbyshire, fronto-temporal dementia, diagnosed 10 years	■ Janice, wife ■ Pauline, community mental health nurse ■ Ian, son
Melvin 92, retired electrical engineer, Leicestershire, vascular dementia, diagnosed ½ year	■ Mary, wife ■ Michelle, daughter
Brian 85, retired electrical engineer, Leicestershire, mixed Alzheimer's disease and vascular dementia, diagnosed 3 years	■ Mavis, wife ■ Jacob, son ■ Ellie, hired carer ■ Carl, son
Bill 80, retired labourer, Nottinghamshire, vascular dementia, diagnosed 2 ½ years	■ Beth, wife ■ Meadowview Day Centre (Katherine) ■ Memory Café (Lisa)
Peter 82, retired accountant, Nottinghamshire, Alzheimer's disease, diagnosed 2 years	■ Marylyn, wife ■ Malcolm, son ■ Dr. Taylor, GP ■ Reverend Houghton, vicar

- How do people affected by dementia perceive interaction within care?
- How is the experience of dementia influenced by interaction within care?

A qualitative design was pursued, seeking to explore the processes of interpretation and role negotiation within interpersonal interactions (Gibson & Brown, 2009). Recruitment comprised two stages. First, people with dementia were recruited. Second, people important in their care were recruited. Recruitment was initiated by emailing community organisations and churches in the East Midlands to identify people diagnosed with dementia living in local communities. Dementia-related organisations were not contacted to avoid over-representing high service users. A total of 782 organisations were contacted resulting in the recruitment of seven people living in non-institutional settings across the region. Table 1 displays participant characteristics. Preliminary meetings were arranged with each person at their homes. Consent procedures were followed in line with Mental Capacity Act (2005) provisions.

The second recruitment stage was enacted through ecomapping, a method of visually recording a care network from an individual's perspective (Rempel, Neufeld, & Kushner, 2007). Ecomapping aided inclusivity by involving people with dementia in study design, enabling them to decide the sample, and provided a naturalistic definition of the difficult concept of ‘care’ (Phillips, 2007). Participants were provided with a blank ecomap incorporating six blank spaces for network members and were asked to include the people who were important in helping them in their everyday lives. Some ecomaps were completed by the person with dementia without external input, while others stimulated discussion between carers and the person with dementia regarding who to include. This contrast introduced third party opinions but was valuable for exploring the co-construction of meaning. In most discussions, the person with dementia exerted obvious preferences, but

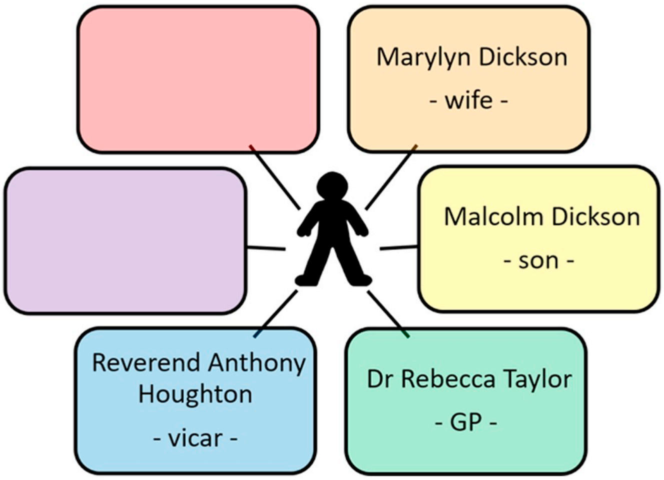

Fig. 1. Example ecomap.

on two occasions people were included in ecomaps who would likely have not been without carer input. Ecomapping was engaging for participants. Conversations during the process inspired questions for subsequent interviews and provided useful contextual insights. Another unanticipated benefit was that having the page in front of them allowed participants with impaired memory to remind themselves of who they had identified and to avoid repetition. For an example ecomap see Fig. 1. Each completed ecomap denoted the person's network members. These people were recruited into the study. A combined sample was generated of seven people with dementia and 26 network members, though three network members who worked for the National Health Service could not be interviewed due to procedural ethics limitations. Table 1 displays participant characteristics.

Data was collected via semi-structured in-depth interviews. Participating network members were interviewed in order of importance, as specified during ecomapping, leading up to the main carer. People with dementia were interviewed last so that the interviewer had maximum contextual knowledge to aid interviewing. Most participants were interviewed individually, though one couple was interviewed jointly at their request. Interviews covered experiences of dementia from initial suspicions to the present day, and focused on changes in people and relationships over this period. Interviews lasted between 40 and 105 min and were audio recorded.

Interview recordings were personally transcribed, and transcripts were analysed using NVivo during the interview period. This iterative approach enabled interview refinement as the study progressed. Thematic analysis was used because the study's strong theoretical framework and intended inclusivity required a mixed inductive and deductive approach, combining both theoretical and organic coding (Fereday & Muir-Cochrane, 2006). Analysis began with minute coding. Descriptive words were attributed to small sections of text, denoting the meaning of that section. Each transcript was minutely coded twice, after which no new codes were evident, resulting in 135 distinct minute codes. Analysis then progressed to categorical coding. Codes were grouped into seven overarching categories, a process of data organisation that revealed patterns and stimulated deeper interpretation. These categories were subsequently regrouped into four themes, synthesising findings into an overarching theoretical scheme situating dementia within relationships and interactions. The phenomenon of deviance visibility, presented in this paper, is the main manifestation of dementia within interactions.

Ethical considerations and limitations

People with dementia were included in the research as both participants and designers in response to historic exclusion and disenfranchisement in dementia research (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). People with dementia can provide theoretically and practically useful insights into experiences of dementia that are unavailable to others (Knauss & Moyer, 2006; McKeown, Clarke, Ingleton, & Repper, 2010). Studies demonstrate the abilities of people with dementia to participate in qualitative research if conducted conscientiously (Murphy et al., 2015). Participants in this study were interviewed when most functional, as denoted by a main carer. People with dementia often have a specific time of each day when their ability to converse appears highest, and this is usually the best time to interview them. Interviewing participants at preferred times enabled all to contribute meaningfully. Participants were informed that intra-network confidentiality could not be assured due to the close relationships between participants and the likelihood of quotes being attributed to individuals by family members. Participants consented to the interviewing of network members, and all participants were aware of the person's diagnosis. Only extra-network confidentiality could be provided. To this end, all names used in this paper are pseudonyms. The study fell under the remit of the MCA, and all relevant provisions were followed to enable the lawful inclusion of three participants who lacked legal decision-making capacity (see Fletcher, 2019). Capacity to consent was formally assessed by the researcher, in line with the MCA. Three of the four people with dementia who did have capacity to consent did so through signing a consent form, while the fourth person provided recorded verbal consent due to dexterity issues. A personal consultee advised on the participation of the three people who lacked capacity to consent, each of whom assented to their own participation. The study was approved by the Social Care Research Ethics Committee and subsequently by the Health Research Authority (project reference: 16/IEC08/0007).

Though dementia-related organisations were avoided, sampling via churches and community organisations introduced formal organisations into the study, deselecting the most disengaged people. An unintended consequence of this recruitment through community organisations was the involvement of locally active women as gatekeepers. This resulted in a sample mostly consisting of men with dementia due to the predominance of spousal care in dementia. Email sampling was another issue as it deselected organisations without web-infrastructures and made recruitment reliant on accurate internet records. Only one female with dementia participated, and no ethic minority or early-onset participants were recruited, potentially leading the study to overlook important perspectives. Recruitment emails to 782 organisations resulted in a small sample of seven people with dementia and 26 network members. The sampling strategy was successful in generating a sample of hard-to-access service-disengaged participants, but was a laborious approach relative to the resulting sample size. Study findings must be metered against this trade-off between the quality and quantity of participants. Recruitment via email likely hampered sample size because it was based on questionable online records and required potential gatekeepers to have digital access. Similar future recruitment might be better enacted via local newspaper or radio advertisements to achieve greater reach.

Results

Having outlined the study's methodology, I will now discuss its findings. Specifically, I present a typology of visibility, charting four mechanisms through which dementia emerges within interpersonal interaction. When considering cognitive impairment, the issue of visibility is especially pertinent because neurodegeneration is often concealed initially. Dying brain cells are not immediately visible to the external observer. There is little likelihood of one spotting a person with dementia in everyday life simply by looking at them as they pass by. Instead, deviance can only be ascribed to the person with dementia through the interpretation of their action as being indicative of the hidden pathophysiology within their brain. In this manner, a person with dementia's deviance must emerge from a starting position of invisibility. The process of visibility, whereby the person with dementia transitions from invisibility to deviance, can occur in several ways. During the study, four major conduits of visibility were repeatedly evident: speech, temporality conflict and routine.

Speech visibility

Though dementia is widely characterised as a short-term memory problem, there are other common symptoms, one of which is aphasia. Aphasia denotes difficulties with various elements of speech, such as word finding or pronunciation. Many people with dementia experience this symptom. While several participants had aphasia, Brian, diagnosed with mixed Alzheimer's disease and vascular dementia 3 years previously, experienced the most acute symptoms. He considered his speech difficulties to be the worst aspect of his condition. As a result, discussion of speech and conversation dominated our interview.

Brian's aphasia caused him great embarrassment when he interacted with others. Wherever possible, he would avoid interacting with people. He also suffered considerable apprehension preceding unavoidable interactions. In his interpretation, he was judged unfavourably by others when they became aware of his impairments upon hearing him speak. To the unwitting observer, Brian was a normal 85-year-old man. His abnormality was hidden beneath skull and skin. Engaging in conversation risked undermining this concealment and exposing his dementia. While he could sometimes maintain a normal conversation, at other times his deviation from situational expectations of speech became perceptible to his audiences. His wife Mavis noted:

> He can hold quite a good conversation. I mean, this week I've had at least three people who've said that, "I was talking to Brian the other day and he seemed quite normal." But then it goes, then he loses it and people realise.

Audience was a salient topic for Brian. His negative experiences of dementia were heavily related to social others. He recognised that the specific nature of his audience had a notable effect upon his experience of the interaction. On the one hand, interacting with people who were accustomed to his aphasia put him at ease. The risk of a sudden surprising revelation of his deviance was lessened when interacting with those who already expected a degree of conversational difficulty. On the other hand, when interacting with people who were unaware of his impairment, Brian felt that his insight into his own embarrassment exacerbated his symptoms, creating a vicious cycle:

> That's probably one of the reasons that I find it difficult to carry on a conversation, because I know it's embarrassing... I talk to people, but with difficulty. And I suppose I expect that to happen every time, so it makes me even worse

Brian's anticipation, and indeed expectation, of his probable forthcoming deficiency created a self-fulfilling prophecy. His anxiety over being exposed increased the likelihood of it happening. This level of reflection indicates the importance of the looking-glass self in Brian's experiences. In these scenarios, deviance was not only a consequence of audience, but also an implication of the actor's interpretation of the audience's interpretations of his action. Brian's fears regarding the potential riskiness within an interaction caused him as much distress as the actual experience of interacting. He collated negative experiences as evidence of the validity of his anxieties, while he discounted positive experiences as anomalies. It is notable that Brian was pleasantly surprised by his completion of the interview, a sentiment he expressed emotionally as our discussion ended. His wife and sons each suggested that his capabilities exceeded his personal estimations, and my conversations with Brian confirmed these assessments. While his impairments were often apparent, they were not insurmountable. As such, the threat of visibility appeared to cause Brian as much distress as the experience of visibility itself.

In words that seem to speak pertinently to Brian's experiences, Goffman (1963) argued that a person 'with a speech impediment, who in many ways is much less handicapped than someone in a wheelchair, can hardly open his mouth without destroying any unconcern that may have arisen concerning his failing, and he will continue to introduce uneasiness each time thereafter that he speaks. The very mechanics of spoken encounters constantly redirect attention to the defect'. In social interactions, the person with aphasia finds themselves in an impossible situation; damned if they do and damned if they don't. Interaction risks a display of deviance to one's audience, and the resulting ascription of deviance will likely remove one from normal human interactions. Yet the remedy to this problem, removing oneself from interaction so as to maintain invisibility, has the same effect. We see in this problem a tension noted by Laing (1959), that both visibility and invisibility are potentially detrimental to the person in different but equally harmful ways. The person with aphasia is stuck in this conundrum. For this reason, speech is perhaps the most tyrannical of the methods of visibility discussed in this paper.

Temporal visibility

While difficulties with the specific activity of speech are the most overt form of revelation, other subtler forms of visibility were observed. These visibility types also expose themselves during spoken interactions, but the deviance is not the speech difficulty itself. Rather, the situation reveals a failure to satisfy other interactional expectations, such as temporality. Situations often encompass expectations relating to time specifically. 'Temporal visibility' occurs when a person's action fails to satisfy such situational expectations.

People with dementia can often find the concept of time challenging. For example, Bill, an 80-year-old retired labourer diagnosed with vascular dementia for 3 years, told me that "time [had] become elastic" for him. He struggled to get a purchase on time as his dementia rendered it increasingly mutable and elusive. People with dementia often have complex relationships with time. This complexity is especially perceptible in the difficulties that short-term memory impairment causes people when they transition between discussion of the distant and recent past. People with dementia can often interact with ease when discussing the distant past, yet struggle when conversation turns to recent events. The perceptible difference in their abilities between these two temporal sites can render previously unseen deviance visible.

My interviews with Bill and Henry both contained instances of this 'temporal visibility'. Both were able to converse naturally when our discussions centred on experiences in their earlier lives. Indeed, both spoke fluently and at length about the importance of sport in their lives. Due to the broad chronological trajectories of the interviews, I gradually guided our conversations forward in time to cover more recent events. At certain temporal junctures, both men's communicative abilities noticeably lessened. They appeared to experience something akin to aphasia, with increases in stuttering, pauses and repetition. This was combined with difficulties recalling and articulating recent events. Having discussed his time as a lorry driver fluently and at length, Bill was unable to answer my subsequent question as to why he had stopped. He stuttered, paused, and then laughed, noting, "I can't remember. It's called dementia you know". For Henry, temporal visibility occurred when we progressed from a coherent conversation about his wife's past career, onto her current occupation. At this point, Henry struggled for the first time in our interaction, "Err, what does she do? I'm just trying to work out" – before abruptly redirecting my attention – "have you seen my railway?"

The transition from fluent to uneasy conversation represented a perceptible juncture in the interaction. Expectations moved from being satisfied to not being satisfied. As expectations stopped being met, deviance via temporal visibility was revealed. Bill was aware of this transition and the distinction between his abilities to conceptualise and discuss distant and recent events. In response, he recalled an old Johnny

Cash song and observed:

> Now why can I remember the words to a pop song that was on possibly before your mother was born? But there we are, memory's a strange thing.

Seltzer (1983) has considered older people in contemporary society as akin to temporal immigrants. The concept is revealing when applied to people with dementia and the experience of cognitive impairment. Not only can people with dementia be considered "temporal refugees", acclimatised to a context far removed from that in which they now reside, they are also less able to assimilate than other older people because of their impairment (Seltzer, 1983: 122). The temporal immigrant metaphor suggests that if we engage with people with dementia on their own grounds, within their own temporal context, they are functional. If we attempt to force our own context upon them, without regard for their temporality, they are dysfunctional and deviance is made visible.

Conflict visibility

The third type of visibility, 'conflict visibility', is rooted in shared meaning. As discussed in the introduction, the interpretative interaction of everyday life relies on shared meanings to loosely guide social action (Blumer, 1969). The process is reliant on a "reciprocity of perspectives", enabling one actor to share the other's interpretations to whatever extent is necessary to facilitate joint action (Gerhardt, 1973: 230). Sometimes, this reciprocity is found wanting. It is not uncommon for a situation's expectations and demands to vary from the perspectives of different actors (Stryker & Macke, 1978). While commonly negotiated in everyday life, interpretational discrepancies can arise that are so substantial as to be difficult to reconcile within interaction. Such an occurrence may be considered a "situational conflict" (Gerhardt, 1973: 234–235), and can be interpreted as indicating the deviance of an other in interaction (Stryker & Macke, 1978), a process that I term 'conflict visibility', borrowing 'conflict' from Gerhardt.

My most significant experience of this conflict visibility came when interviewing April, an 82-year-old former teacher who had been diagnosed with Alzheimer's disease for 4 years. During the first 10 min of our interview, April spoke eloquently and at length about her early life and the teaching profession. Were one to interact with her solely regarding these topics, one might be unaware of her dementia. Her deviance remained invisible throughout her various recollections and observations. April's apparent abilities to satisfy expectations of normal cognition in interaction were undermined when the interview turned to her current residence. At this point, I perceived a developing rupture between April's interpretation of the situation and my own. Consider the following exchange regarding the location of our interview:

> April: I'm here for a couple of days, no, a couple of weeks I think, before I go off again home.
> Interviewer: Are you enjoying it here?
> April: Oh yes, yes, yes, I enjoy the teaching, I enjoy the teaching.

April had been living with her daughter's family for several years. The interview took place in the lounge of their house. Such was my interpretation of the situation, having spoken to family members and visited previously. However, April suggested that she was briefly staying in the property while she was teaching. The sudden interpretative disparity between April and I made her deviance visible. My own conviction in the validity of my interpretation of her setting, a long-term family home, stood in opposition to April's indication of our situation as temporary accommodation.

Later in the interview, a similar situational conflict arose when I questioned April about her professional life as a teacher. After a brief conversation about her motivations for becoming a teacher, she asked me:

> April: How long have you wanted to be a teacher?
> Interviewer: Not very long actually, it was sort of thrust upon me.
> April: You enjoy it? That's the main thing, you enjoy it. And presumably, how many weeks have you been working with the children in the school?

It took me a moment to grasp what was happening in this exchange. Indeed, as a university-based researcher, I do sometimes teach students. As such, I initially responded to April's questioning under the assumption that she was referring to my occasional university lecturing. Only as she progressed did I begin to perceive that that she understood me to be a trainee primary school teacher seeking her advice. At this juncture, our shared interpretation of the situation ruptured.

I avoid making claims as to the validity of either party's interpretations. It is the conflict rather than the validity of interpretations that drives visibility. I was simply convinced by my interpretation, and therefore unconvinced by April's different interpretation. What is important is the emergence of a discrepancy between the two realities, and the resulting effect of this discrepancy in rendering a deviance visible. Of course, my actions may have revealed some deviance of my own to April. It is plausible that such interpretational discrepancies may be bi-directional. If situational conflict arises unexpectedly in interaction and is interpreted by an actor as indicating the deviance of the other, then it may similarly indicate that actor's deviance to the other. For both, conflict makes their deviance visible.

Novelty visibility

The importance of maintaining routine and familiarity is often attested as a means of enabling people with dementia to continue to lead normal lives for as long as possible (Porock, Clissett, Harwood, & Gladman, 2015). Several participants in the study used this strategy, observing that they were relatively functional in daily life so long as they were able to act within established routines. The importance of routine and familiarity in facilitating the continuation of normal action imbues novelty with the potential to become a further means of visibility. Just as familiarity aids function, so novelty can drive dysfunction.

Having dementia can impede a person's capability to stray from routine action and their adaptability in response to new situations. People may become progressively vulnerable to change, and therefore become more reliant on established routines. Within familiar situations, expectations can be met through routine actions, thus dementia remains invisible. Novel situations likely call for spontaneous action to satisfy expectations. Witnessing a person with such vulnerabilities negotiating novel situations with varying degrees of success can lead audiences to interpret the person's unexpected actions as indicative of dementia. One example of this came from Peter's breakfasting habits. Peter had discovered and developed a fondness for breakfast cereals in his earlier life, and as a result, he had established a complicated breakfasting routine in which he ate a different cereal on each day of the week. Each morning, Peter would go into the kitchen and prepare his own breakfast. However, his wife Marylyn recounted the following story of Peter's confusion regarding the location of cereals when asked to retrieve them outside of his routine:

> On one occasion I was making some all-bran loaf cake, and he was near the food cupboard. And I said, "Could you get the all-bran out while you're there please?" And I saw him stand and look, "All-bran?" I said, "The all-bran that we have. The breakfast cereal." He started to open the cupboard doors, even the fridge, until I suddenly saw him. I said, "Bend down and they're in that, the bottom of that cupboard." Now the next day he would have got them out and had them automatically because that was part of breakfast, but because I'd asked him for something, he couldn't connect it to where it was.

When enacted on the typical day at the usual time, Peter's long-established routine breakfasting enabled him to carry out an expected line of action that satisfied the situation and therefore did not indicate any deviance. He maintained this ability despite the relatively complex nature of the routine itself, involving a weeklong process of alternating cereals. The uninformed audience member, witnessing Peter's action, would have scant cause to interpret anything as indicating a dementia. However, despite the apparent effortlessness with which Peter commonly negotiated his morning routine, the introduction of a novel element destabilised his abilities completely. Similar actions had the potential to be either simple or impossible depending on the presence of novelty.

This dichotomy between the simplicity of familiarity and the impossibility of novelty furnishes a means of invisibility and visibility respectively. When routinised, Peter's daily retrieval of the appropriate cereal not only provided no indication of deviance, but actively served to attest his cognitive functionality. When an element of novelty was introduced into his usual procedures, failure to act as the situation required served as a stark indication of his dementia in Marylyn's interpretation, and would likely have done so for other observers. Thus, novelty is a further conduit through which deviance may become visible in dementia.

Discussion

The negotiation of speech, temporality, conflict and novelty presents a challenge for people with dementia because of the cognitive finesse that is needed. Rather than detailing these primary difficulties, in this paper I have explored a secondary challenge that stems from the first – the process of visibility through which people become deviant. Visibility occurs when the person with dementia experiences some difficulty in conducting a certain action. This difficulty is perceived by an audience as a failure to satisfy the situation's expectations, and is interpreted as indicating a deviance, in this case dementia. While I have described four means of visibility, I do not suggest that this list is comprehensive. Speech, temporality, conflict and novelty solely represent four means of visibility that I witnessed on various occasions during the study and that I can present here with confidence. It seems likely that are further means of visibility.

Likewise, the use of typology reveals that these means of visibility are not universal. The process of visibility relies on an intersection of factors, namely the situation, the audience and the person's unique impairments. The latter are vital in constraining the eventual manifestation of visibility. Though April was susceptible to conflict visibility, she spoke fluidly and at length about her early life and was therefore invulnerable to speech visibility. Alternatively, while Brian's life was greatly affected by his fears and experiences of speech visibility, he was able to discuss the recent and distant past with equal readiness. Where speech visibility was ever present, temporal visibility made no mark on his concealment. There is hence a deeply personal facet of visibility. The advantage of theorising dementia as a matter of visibility and deviance is therefore its recognition of the power of the situation and the audience in designating dementia.

The situation and the audience become the difference between being a ‘person’ or a ‘person with dementia’. One would presume that any underlying neurodegenerative pathologies and resulting cognitive impairments remain roughly equivalent both pre- and post-revelation. It is unlikely that some aspect of invisibility is itself curative of neurodegeneration. Yet despite these foundational similarities, the manifestation of dementia in the actor's lines of action and the audience's interpretations differs substantially before and after visibility. The actor, their action, the situation and the audience must be considered together. The delicate oscillation between visibility and invisibility is not attributable to one factor exclusively, but rather to all in combination.

Though this paper draws on examples of visibility to construct an account of dementia as a deviance, it must be acknowledged that the examples that occurred within interviews cannot be considered naturalistic. The interview is an inherently artificial situation. There was also no true invisibility to begin with because each of the interactions described here was predicated upon my prior awareness of the participants' diagnoses. In this sense, these actors' deviances were already visible to their audience (me). The given accounts still have some utility in evidencing the broader experience of deviance and visibility. I do not think that it is unrealistic to envisage the same visibility mechanisms occurring in everyday life. The intended focus is on the ways in which deviance becomes visible within interpersonal interaction generally. The process is the same, though the outcome differs slightly in that deviance was never entirely unanticipated.

Beyond the parameters of a research project, one may easily envisage more natural everyday interactions in which the same processes of visibility occur. In these situations, unaware audiences, such as those feared by Brian, are likely to interpret failures to meet situational expectations as indicative of deviance in a manner that does abruptly shift the person's dementia from invisibility to deviance. In such scenarios, speech, temporal, conflict and novelty visibility may be the difference between whether that person is a ‘person’ or a ‘person with dementia’. Given the qualitative differences between these two categories, understanding the social processes that distinguish them is vital.

These findings elucidate the specific mechanisms at play within the interactive processes of meaning-making in dementia that have been described by various authors in the “third moment” interactionist dementia research tradition (e.g. Beard, 2016; Kitwood, 1997). These mechanisms represent important “junctures” within “the process of becoming an Alzheimer's patient” (Beard, 2016: 164). These junctures are important stepping stones within the long-term careers of people with dementia (Fletcher, 2018a, b; Beard, 2016). A typology of the ways through which dementia is realised as deviance is useful in denoting specific mechanisms within the condition's broader trajectory. This focusses our analytic upon a certain scale, and reveals component micro instances within the patterned careers that are evident at a more macro scale. Broad accounts are hence deconstructed and expanded to incorporate greater detail. In doing so, a typology of visibility opens up possibilities for targeting specific processes within dementia. It is important to understand that the process of becoming a person with dementia is not simply a consequence of the immediate instance of diagnosis, but instead emerges gradually over long periods of time. This paper has detailed several ways in which that gradual emergence progresses in the everyday lives of people with dementia. Understanding these mechanisms is vital to improving wellbeing because such interactional moments represent important instances of “loss” within dementia (Beard, 2004: 418).

While speaking to issues of wellbeing, in presenting dementia as a matter of visibility and deviance, this paper has sought to explain rather than judge. The goodness or badness of visibility is fodder for a different discussion, but the issue does require brief acknowledgement here. There certainly appears to be scope for debate regarding whether being visible as a person with dementia is beneficial (for example through explaining failures to meet expectations), or harmful (for example through stigmatisation). Within such a debate, I would suggest that the most appropriate approach may be to respect the personal wishes of the individual in question. Some participants in this study dreaded visibility, while others accepted it openly, and most found it variably positive and negative. It is challenging to postulate the rights and wrongs of such a personal issue, but it is hoped that the understandings presented in this paper may at least alert minds to potential harmful and beneficial implications of visibility.

These implications are not solely applicable to people who have been diagnosed with a dementia. That dementia is inextricably entangled with ageing more generally (Lock, 2013) means that many older people are at some risk of being perceived to have a dementia. For example, AD is characterised clinically by cognitive decline and physiologically by beta-amyloid protein aggregation in the brain (Lock, 2013). However, from early adulthood, cognition typically declines with age in all people (Salthouse, 2009) and beta-amyloid aggregates in the brains of many older people (Aizenstein et al., 2008). As a result, a large group of older people exhibit clinical and physiological characteristics that might readily be deemed to indicate a dementia. Visibility can therefore be considered in relation to a much broader invisible population than solely those people who have been diagnosed with a dementia but are not commonly interpreted as having dementia by audiences in everyday interactions. A deviance approach is unique in extending analysis beyond the strictly medicalized population and onto those who are potentially medicalizable. This is especially pertinent to dementia due to the contemporary promotion of increasing diagnosis rates and early diagnosis (NHS, 2017). Such promotion could be interpreted as an institutional process of encouraging visibility, potentially sensitising audiences to indications of deviance. Analysis of dementia in terms in deviance should therefore facilitate reflection on the specific ways in which the promotion of diagnosis is enacted, as well as the medicalization of older people more generally.

In externalising and questioning manifestations of dementia in this way, we may reveal avenues for moderating some of its interpersonal implications within everyday interactions. To this end, I have had several conversations with care professionals and family carers concerning these findings. All have considered the possibility that dementia may partially be an artefact of audience interpretation and situational expectation; that dementia does not merely spring into existence in a vacuum. The apparent arbitrariness of the visibility process has provoked reflection regarding practice towards people with dementia. In particular, people have questioned whether they sometimes attribute behaviours to dementia too readily, without considering other potential motivations. Goffman (1963: 15) notes that the discredited individual is permanently mindful of the need to act carefully because “incidental impropriety may... be interpreted as a direct expression of his stigmatized differentness”. People with dementia could be partially freed from such concerns if audiences were more reflective. Analysing dementia in terms of deviance encourages recognition that people with dementia's actions might be grounded in more than cognitive impairment alone. Such recognition could facilitate relationships with people with dementia in which their actions are not always automatically attributed to dementia and therefore somewhat delegitimised. It is hoped that the publication of this account of dementia as a matter of the visibility and deviance acts to further stimulate such reflections in a wider audience. As Sabat (2001: 340) noted almost two decades ago, dementia can be looked upon as a mirror - “our treatment of people with Alzheimer's disease speaks of who and what we are.”

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