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Recognising the agency of people with dementia

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People with dementia have been assumed to possess weak or even no agency, so this paper provides a novel contribution to academic debate by examining their actual potential for agency. The author draws on findings from a qualitative study of everyday decision-making by people with dementia that aimed to identify the role of social factors (such as gender) in influencing their involvement in decisions. Whilst decision-making constitutes a form of deliberative agency, the research also identified when agency was alternatively habituated, embodied or emotional. The Economic and Social Research Council-funded research was undertaken in the North of England. Existing theoretical perspectives on agency are critiqued, particularly in relation to rationality, language and individualised agency. The study highlighted that people with dementia who lack deliberative capacity can nonetheless demonstrate creative capacity for agency. A more expansive concept of agency is needed in social science theory that is informed by the experiences of cognitively disabled people.

Keywords: dementia; cognitive disability; agency; decision-making capacity

Points of interest

- Current social science theory on agency is poorly informed by empirical research, particularly relating to the experiences of cognitively disabled people – this paper addresses that gap.
- People with dementia have been assumed to lack agency; that is, the ability to initiate social action or at least influence their own personal circumstances.
- This paper identifies that people with more advanced dementia who lack decision-making capacity can nonetheless exercise agency, often in quite creative ways.

Introduction

Ill-health, disability and agency

Whereas medical sociology has traditionally neglected the influence of social structure on health (Williams 2001, 2003), the social model of disability was instrumental in identifying how disability is systematically produced through the social and political processes that discriminate against disabled people (Oliver 1996). More

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specifically, the model has shown how individual and collective action can be used to initiate social, legal and political change (Evans 1996; Shakespeare and Watson 1997; Shah and Priestley 2011). Notably, the social model has also demonstrated when people can act to influence their own personal circumstances; that is, exercise agency (see Giddens 1991; Madhok, Phillips, and Wilson 2013). Accordingly, Williams (2003) identified the need for research to explore how both structure and agency influence health and illness within everyday life.

However, agency theory has been criticised for its concentration on rationality, language, intentional action and goal orientation (for example, Shilling 1999; Velleman 2000; Hemmings and Treacher Kabesh 2013). Since people with dementia may lack these abilities, they are therefore assumed to possess weak or even no agency. Yet empirical studies suggest that they can exercise agency, albeit in somewhat different forms than highlighted in current theory. However, an over-emphasis on rationality in agency theory excludes people with dementia who have erroneously been assumed to lack decision-making capacity, but also excludes those who do lack capacity but can nonetheless exercise agency (see Brock 1993). In addition, the relative neglect of emotion has led to a 'divided' concept of the self, whereby reason and emotion are viewed as superior and inferior selves (Burkitt 2008). This divided view of the self has influenced the biomedical model of dementia whereby the extant cognitive abilities of people with dementia are under-recognised and their emotions and behaviour are often viewed as symptomatic of the illness (see Finkel 2000). On the contrary, such behaviour and emotion may be indicative of agency, particularly in response to the structural constraints imposed by institutionalised care regimes, low societal expectations and a lack of opportunities for social participation.

As agency theory also privileges language (Madhok 2013), this makes it difficult to apply the concept to people with dementia who frequently have impaired speech. In addition, a bias towards intentional action has led to the neglect of habituated or embodied agency (Velleman 2000; Cleaver 2007). Fundamentally, the concept of agency is over-individualistic, such that relationality and interdependency are under-recognised (Hemmings and Treacher Kabesh 2013). Whilst the apparent threshold for agency is unachievable by many people with dementia, there is a need to identify whether they can nonetheless exercise agency.

Purposeful action and emotion

The capacity for agency in people with dementia has received little attention in the literature, partly because the dominance of psychological research has led to a focus on the negative impact of dementia on self-identity (see Robinson, Clare, and Evans 2005; Caddell and Clare 2010). Yet Kitwood and Bredin (1992) highlighted that both self-identity and agency are central to well-being in dementia. Since agency requires self-reflection (Burkitt 2008), and it was assumed that people with dementia lacked this ability (Kontos 2004), their capacity for agency has also been unrecognised. Although agency is the means by which the subjective self becomes a social self (Burkitt 2008), previous research has not systematically explored or theorised whether people with dementia can manifest a social self.

Whilst the potential for agency in people with early-stage dementia has also not been clearly theorised in the literature, research has highlighted how self-help groups can promote their empowerment (Clare, Rowlands, and Quin 2008; Orulv 2012). In

addition, a few studies have pointed to the potential for agency in people with advanced dementia. A study in the United States of conversations with a nurse showed that they demonstrated assertion of will – for example, a participant's comment indicated when he wanted to end an interview (Mayhew et al. 2001). Research in Sweden found that using background music led to increased 'co-operation' in care routines from residents with severe dementia who were ordinarily resistant (Gotell, Brown, and Ekman 2002). Whereas the same authors suggested that playing music during personal care led to a reduction in the instructions by staff and an increase in residents' participation, this suggested that the residents' apparent 'resistance' was indicative of their expressions of agency, rather than a lack of self-care ability. Their findings indicated that constraints on agency can prompt emotional and behavioural responses (e.g. aggression) in people with dementia (see also Ragneskog et al. 1998).

This paper will therefore examine the potential for at least basic agency in people with dementia. I draw on findings from a study of everyday decision-making by people with dementia living at home that aimed to identify the role of social factors in influencing their involvement in decisions. Whilst decision-making constitutes a form of deliberative agency, the research also identified when agency was alternatively habituated, embodied or emotional.

Methods

An intensive and facilitative qualitative methodology (for example, Denzin 1970) was used to examine decision-making in action and to enable people with dementia to use their extant decisional and communication abilities. The overall study identified whether people with dementia were given opportunities to make decisions when they retained capacity – either minor decisions such as what to wear or eat or major decisions such as moving house. However, the current paper explores whether people with more advanced dementia who experienced challenges with deliberation, communication and independent action could nonetheless manifest agency. Thus, the paper focuses on a subgroup of five people who usually had significantly impaired speech and lacked the capacity to make minor and more major decisions, including the capacity to consent to taking part in the research (as defined by the Mental Capacity Act [2005] in England and Wales). Nonetheless, the research explored when they retained capacity or subtle abilities in discrete areas; for example, when they could identify their food preferences even if they could not decide what to eat.

The research was undertaken in a local authority area in the north of England. Ethical approval was obtained from the national Social Care Research Ethics Committee. Ethnographic and creative methods were used, including participant observation and interviews. The fieldwork was undertaken over at least four home visits and each couple was observed going about their usual daily routines, in order to observe decision-making directly (to some extent). Prior attendance at Wellbeing Cafes or day centres was helpful in making the researchers familiar to the people with dementia and gaining their trust (see McKillop and Wilkinson 2004; Miesen and Jones 2004).

A person-centred approach was used to informally assess the capacity of people with dementia to decide to take part in the study (Mayo and Wallhagen 2009). The severity of dementia was also informally assessed – for example, based on abilities to undertake activities of daily living – except where more definitive information

was provided by a spouse (e.g. obtained via a memory assessment clinic). Although the study aimed to undertake individual interviews with each partner, the research process was adapted to the cognitive and communication skills of people with dementia. Brief, unstructured and conversational-type interviews were used with four of the five people in the subgroup who lacked capacity to consent to the research. As an open-ended approach was too challenging, these interviews instead incorporated closed questions or topics on key themes (such as their likes and dislikes), in order to explore their agreement or disagreement (see Acton et al. 2007).

Photographs of the couples (including social activities undertaken during observations) were used as visual and memory aids throughout the fieldwork to prompt recall and elicit conversation (for example, Harper 2002). Where they had speech difficulties, their non-verbal communication – such as facial expressions or gestures – was observed (see Mayhew et al. 2001). An ‘interaction’ method was employed to facilitate one woman’s communication and engagement when it was not possible to interview her (see also Grove et al. 1999). More specifically, the author spent time with her on a one-to-one basis; used sensory aids to stimulate her interaction; listened attentively to her speech; and observed her non-verbal expressions.

Recruitment

The couples were recruited via Wellbeing Cafes, support groups and day centres run by voluntary and statutory organisations. Theoretical sampling (Mason 1996) was used to recruit women and men with dementia with diverse cognitive and communication abilities. The couples were eligible to participate if they were co-resident; one spouse had been diagnosed with dementia and both spouses were willing to take part. Couples were excluded where the partner had only recently been diagnosed, to allow time for adjustment. Where the person with dementia did not have the capacity to consent, their spouses were consulted as to whether they would have wanted to participate and if they were happy for them to take part (as per the Mental Capacity Act). The researchers were mindful of when it may have been inappropriate for a spouse to act as consultee (e.g. if it was not in the best interests of the person with dementia). Throughout the fieldwork, the researchers were sensitive to any indicators of discomfort or undue anxiety from the people with dementia. The fieldwork was undertaken between June 2010 and May 2011. The interviews were digitally recorded and transcribed verbatim; fieldwork notes were recorded throughout.

Data analysis

A thematic approach was adopted to data analysis (Ryan and Russell Bernard 2003). The key themes were identified in each couple’s data in order to explore the couple’s perspective, but also to enable the views, experiences or feelings of the people with dementia to be discerned. Accordingly, an interpretative approach was useful in discerning the meanings of people with dementia (see Grove et al. 1999). The analysis was also informed by key concepts from agency theory, such as intentional action and reflexivity. The data from each person with dementia (interview, observation and non-verbal) were examined in an integrated way (see O’Cathain 2010). The observations focused on the dynamics of couples’ decision-making processes, whether people with dementia had the capacity to exercise deliberative agency and variations in their demonstrations of agency (such as when it was habituated rather

than clearly negotiated and articulated). Where the people with dementia lacked deliberative capacity, the observations explored their embodied, emotional and habituated expressions of agency (e.g. via body language, routines or rituals). As well as textual analysis, the audio-recordings were carefully listened to for evidence of speech patterns, tone of voice and utterances that might indicate agency.

The carer-spouses' perceptions of their partners' decision-making abilities and their rationales for including or excluding them from decision-making were examined. The levels and types of support given by the carer-spouses and its effects on the decisional capacity and agency of people with dementia were considered. The analysis primarily focused on the subgroup with more advanced dementia; otherwise, where the discussion relates to the full sample, reference is made to the 'overall study'. Whilst the subgroup was quite small, this allowed for their creative agency to be explored in-depth. The subsequent analysis sought to achieve theoretical saturation in relation to the key concepts of agency.

The various sources (such as observations or interviews) and types of evidence (speech and non-verbal data) were corroborated in order to verify the accuracy of interpretations. Whilst clearly 'knowing' the meanings of people with dementia can be a challenge, particularly when they have limited speech (see Nystrom and Lauritzen 2005), developing a more intimate knowledge of them over multiple visits, clarifying their views and feelings, contextualising their expressions and exploring congruence between their verbal and non-verbal communication facilitated more informed interpretations.

Sample characteristics

Twenty-one married couples took part in the study, including 12 women and nine men with dementia (mainly older than 65 years). The subgroup with more advanced dementia consisted of four women and one man, each of whom appeared to have moderate or moderate-to-severe dementia. Four people in the subgroup had significant speech impairment and one woman also had very limited ability for social interaction. As regards their abilities to undertake activities of daily living, four people needed help with personal care and even eating.

Revealing agency?

Doing or being?

The idealistic conception of agency as a deliberative process involving clear and intentional action is rarely achieved in practice (McDowell 1979; Reader 2007). Similarly, people with dementia can find it challenging to plan and undertake everyday tasks (for example, Cooper and Greene 2005). Accordingly, spouse-carers in the study often felt that their partners with dementia had lost their motivation. For example, Claire¹ said her husband, Gavin (who had dementia), had previously been a decisive man, but now when she asked his views (such as what to do for the day), he often responded 'I don't know'. However, whilst people with dementia lacked decisional capacity at times, other aspects of their daily lives showed that they could nonetheless view situations intersubjectively, engage relationally and subtly exercise influence within their relationships.

For example, Trevor said his wife Mary (who had dementia) had always been a smartly-dressed woman, although she needed help with personal care now. He said: 'over the years you see and she made all her own dresses ...'. Although Mary acknowledged that her husband helped her with dressing – 'yes, he does, yeah' – she retained pride in her appearance: 'I like to be nice'. The continued importance she attached to her sense of femininity, particularly within the context of her marital relationship, was highlighted when she said she sought her husband's views on how she looked: 'For his ... do ... do I look nice?'. Irrespective of her cognitive impairment, she was able to use humour habituated within her marital relationship to exert some influence over the research scenario, while at the same time exhibiting empathy with the researcher. More specifically, the couple shared a lot of banter during the observation visit, including jokes about 'beating' each other. However, because Mary said this while presenting a deadpan face, it was not always clear to the research assistant whether this was simply jesting. However, as Mary made a point of reassuring her – 'we're only joking you know' – this signified her observance of her visitor's disquiet and the abilities to imagine and empathise with her feelings.

Similarly, Grace had been a strong character prior to her dementia and could still use her determined nature to exercise some marital authority. Her husband Dennis said she was never 'one that likes to be told. If she feels that it's right, fine. But if she has a gut feeling it's wrong, she will argue'. Although Grace's speech was impaired, she could still indicate her preferences and dislikes, often non-verbally. For example, as she was unable to identify in advance where she wanted to spend the day, instead her husband discerned her wishes by taking her to a familiar place and if this was not her preferred destination she would remark: 'I didn't want to come here!'. Similarly, Dennis said Grace ate well in cafes but often did not eat the meals he cooked: 'when we go out ... she'll eat a lot but she just doesn't seem to want to eat at home'. Whilst Grace could not articulate that she disliked her husband's cooking, she could still convey where and whose food she liked to eat.

Setting goals or expressing values and aspirations?

Values and desires

Although goal-setting constitutes deliberative agency, imagining the future can also involve 'more ephemeral' expressions such as hopes, fears and aspirations (Emirbayer and Mische 1998, 984). Formulating goals may be challenging for people with dementia, such as planning for the future when the illness may progress (see Covinsky and Yaffe 2004). Although Gavin did not talk a lot (partly due to impaired speech), some of his responses were quite expansive, emphatic and insightful, indicating that he was more conscious of his environment and illness than initially appeared. At first, it was unclear whether Gavin was aware of his dementia, as he did not mention it or admit to having memory problems. When asked about his health, he simply said it was 'alright'. Nonetheless, it appeared that he had an implicit awareness of his condition but was reluctant to acknowledge it. More specifically, his wife had asked him about the illness: 'I just said to him, I said, "– [husband's name], if you could have anything, what would you like?" [and] he said, "I'd like to get better"'. So he is aware'. Similarly, as the overall study showed that men were more reluctant to acknowledge and 'accept' dementia than women, it appeared that masculine values associated with being strong and healthy partly accounted for his

efforts to distance himself from the illness (see also Verdonk, Seesing, and de Rijk 2010).

As Marion (who had dementia) often responded to the researchers with a brief and generic ‘yeah’, this suggested that she did not understand what was meant or could not find the words to articulate her thoughts. However, at other times, she said ‘yes’ emphatically and repeatedly or spoke short phrases and also smiled or laughed, indicating her comprehension and strength of feeling. Marion lacked the capacity to make financial decisions or handle money (e.g. she could not count or read or understand bills) and she acknowledged that her husband always paid for their shopping now: ‘well he ... he does really, yeah’ (see Boyle 2013a). Yet her husband explained that she had always been financially independent and, accordingly, would still ask him: ‘... she’ll say to me, “well, where is all my money?”’. Thus, she remained aware of her financial power and used this to exercise a degree of marital authority. Therefore, whilst people with dementia may be unable to formulate and pursue goals, they may still be able to identify their aspirations or use expressions of their established values to influence the direction of their lives.

Deliberative agency and equality

The Mental Capacity Act (2005) in England and Wales emphasises the importance of advance care planning to enable people with dementia to make decisions about their future in accordance with their beliefs and values, and while they still have capacity. However, the overall study showed that carer-spouses did not always involve their partners with dementia in major decision-making processes (such as whether to attend a day centre or designate financial authority). Whilst this lack of involvement seemed to be explained, in the main, by the presence of significant speech impairment that would have made decision-making more challenging, it was not necessarily appropriate in terms of capacity, as the people with dementia often retained the ability to make these decisions (Boyle 2013b). Indeed, the same Act states that decisions should only be made on someone’s behalf when they lack the capacity to make these decisions themselves. Accordingly, in some instances, it was evident that the people with dementia did not have the capacity to make such decisions themselves, although some could alternatively express their values or aspirations. For example, although Mary lacked the capacity to make financial decisions, she could identify the low priority she gave to wealth, in contrast to the emphasis she placed on her relationships: ‘You don’t need a lot of money, as long as you have your happiness and one another and friends’. In other cases, however, people with dementia were not given the opportunity to participate fully in decision-making processes relating to their present and future care.

For example, obtaining a Lasting Power of Attorney enables carers to make decisions on behalf of people with dementia (e.g. relating to welfare or financial affairs). However, although the Lasting Power of Attorney allows an authorised person to make decisions even when the person with dementia retains the necessary capacity, the latter must designate – when they still have capacity – the person to whom they want to give such authority; otherwise an application to the Court of Protection may be required (Department for Constitutional Affairs 2007). Yet some spouse-carers took over major decision-making without fully considering whether their spouses had extant capacity to make such decisions, such that people with dementia experienced unnecessary constraints on their agency. Consequently, it was not necessarily

the dementia (or a lack of ‘rationality’) that prevented them from influencing their lives. Instead, a lack of recognition or acknowledgement of their decision-making capacity partly explained why carers constrained their agency. Similarly, people with a learning disability may be marginalised in decision-making processes whereby they are consulted but not permitted to make the final decisions (Armstrong 2002). Whilst determining capacity may have been challenging for carers of people with dementia, at times their domination of the decision-making reflected a desire to maintain control over major decisions, particularly when spouses (notably husbands) had taken charge of such decision-making prior to the dementia (Boyle 2013b). Therefore, whilst the agency of people with dementia is often facilitated by their carers, it may also be constrained by them.

Indeed, gender inequality influenced whether women with dementia were given the opportunity to exercise deliberative agency in their everyday lives. Gendered assumptions resulted in women with dementia being more likely to be deemed to lack capacity, whereas men with dementia were more likely to have their capacity facilitated by their wives, at least for minor decisions (see also Stefan 1993). More specifically, wives who were carers were more likely to acknowledge and promote their partners’ capacity than husband-carers.

Body language and emotion

People with dementia often use non-verbal communication to clarify their speech or as alternative means of communication. Marion’s body language and mood were quite negative when we met her initially – for example, she made little eye contact. Correspondingly, her husband indicated that, whereas his wife had previously been quite sociable, following the onset of her dementia she no longer enjoyed having visitors. He said: ‘the strange thing about the illness is it’s caused us to not welcome visitors, mmm, she doesn’t even welcome people who she befriended ...’. Yet once a rapport had been established, Marion became more at ease with our presence. More specifically, she relaxed her body language, made good eye contact and often smiled or laughed. Although she did not have the capacity to consent to the research, she could articulate that she was happy to talk about her daily life – ‘yes, that’s okay’. However, it was her embodied and emotional expressions which gave the author confidence that she was comfortable with being interviewed. Similarly, whilst Marion appeared quite passive and ‘dependent’ at home, there were discernible differences in her communication and behaviour when she was engaged in a favourite outdoor activity. Although she needed assistance with activities of daily living from her husband and also required conversational support during her interview, Marion demonstrated initiative – verbally and hierarchically – when she and her husband took their dog for a walk during the observation visit. Notably, she guided the research assistant along their route by commenting and gesturing: ‘this way’ or ‘straight ahead’. Accordingly, her discursive and embodied agency demonstrated that she was not simply a passive care recipient but also someone who gave care (see also Davies 2011). Indeed, conversing, observing and interacting with Marion over time and in different social contexts enabled the researchers to develop a more informed understanding of her capability for agency, beyond deliberative agency.

It was not feasible to interview Emily because she had very limited speech and lacked the ability to interact. Although the author had met Emily a few times prior

to our one-to-one visit, she did not give any indication that she recognised me. Yet, because she had a habit of walking constantly from the living room to the kitchen but confined herself to the former on this occasion, this suggested that she was comfortable with my presence. Apparent shifts in Emily's mood were similarly conveyed through her embodied and verbal communication. For example, she seemed cheerful when she sang to herself 'la la la'; alternatively, she appeared down or cross when she made tearless cries or spoke negatively.

Despite Emily's lack of dialogical ability, she nonetheless often appeared to engage in conversation with one or more absent persons; that is, self-other dialogue (Sullivan 2012). The content of her dialogue suggested that she viewed herself relationally, particularly as she engaged in a key feminine role (as a daughter) and recognised other people's social roles, albeit her sense of self was somewhat outdated (see Caddell and Clare 2010). For example, she mentioned 'mam' twice as if she was talking to her own mother and also referred to a man at work: '... he goes to work and he comes, comes down ...'. In addition, she related to others in her dialogue according to accepted conventions; for example, by providing affirmations or reassurance: 'yeah, I know, I know love [inaudible]. Are you sure? ...'. She also took the lead at times, by giving instructions: '... what you, what you got? Have you got it? Yeah'. Moreover, she made social judgements, evident when she considered whether to reproach a man for a perceived injury: '... I could tell him off so, so'. As Emirbayer and Mische (1998) pointed out, imagination is an important conduit for envisaging social change, or at least social action.

Although Emily's internalised social reality may have substituted for a lack of ability to socially interact, nonetheless there were also instances when she engaged socio-emotionally. For example, during the observation visit, Emily's husband (Ken) guided her to sit beside him using a playful dynamic whereby he counted 'one, two, three' and she responded with a sound like a cheer. In addition, during the 'interaction' with the author, whereas Emily initially walked around the perimeter of the room, she later altered her route to walk diagonally through the centre whereby she had to pass directly by me. As she halted, made eye contact and smiled or laughed on each occasion, she evidenced curiosity and an interest in social relations. She also took a playful lead in the interaction at one point (she approached from behind, whereupon I jumped and she then laughed), suggesting some relational ability.

A social world, a social self

Whereas Giddens (1991) conceptualised reflexivity as an individualised, rational process, Burkitt (2012) suggested that it is relational, dialogical and emotionally driven. Joseph said his wife (Marion) did not accept her dementia. Correspondingly, when it was initially explained to her that the research involved talking to people with memory loss, she said she did not have a problem. This lack of acceptance or acknowledgement of dementia has been viewed as pathological (for example, Zanetti et al. 1999), indicative of an apparent lack of reflective ability. In contrast, however, such individuals can demonstrate that they do reflect on their illness and its possible implications. For example, Joseph said that Marion had recently got upset, revealing that she felt she was losing her mind and was afraid she was going to be taken away, which indicated that she had some awareness of her illness. He explained:

... she said something like ‘I think I’m losing it’ and she was crying ... and she’s realising that she’s not, mmm, you know fait accompli with everything ... Last week she said, ‘I think they’re coming to take me away’, mmm ...

Although Marion’s ability to participate in social relationships was reduced, as she revealed subtle relational abilities and an awareness of marital conventions, she nonetheless manifested a social self. For example, when asked who usually bought her clothes, she was quite clear that her husband did and also explained that he gave his opinion on what suited her, reflecting a gendered norm: ‘cos he says “oh, oh I don’t like that one”, you know, so ...’. She also evidenced an awareness that she needed help with dressing – that is, ongoing support: ‘... he’d have a look at it to see if it’s, er ... you know, the, the right thing ... Yeah, so that I don’t get, erm, the wrong sort of thing, you know?’ Despite the limitations imposed by her dementia and by gender norms, Marion still exercised some control over what she wore, as her husband said she did not wear the clothes he bought if she disliked them. Thus, Marion could exercise agency, including capacities for reflection and even reflexivity.

During the ‘interaction’ with Emily, her tone was initially a little negative, suggesting she was in a bad mood and was annoyed with another person. She said: ‘... I can’t be bothered ...’ and went on to say: ‘he’s done it, yeah’. As this was quickly followed by a comment: ‘... he will won’t he?, he come back ...’, she may have been aware that I was a relative stranger and therefore concerned that her husband had left her (even temporarily). She considered the possibility of reproaching someone, possibly her husband: ‘I could tell him off so, so ... this morning, when he comes home though ... I’ve got to say, say something ...’ (utterances omitted). Despite her apparent lack of social awareness, Emily may have been conscious that she was dependent on others, as she implied that she could not go out alone: ‘... I can’t, can’t get out there’. Paradoxically, her comment ‘... you’ve got to get your own life ...’ may have been an acknowledgement of her loss of independence and, subconsciously, an awareness of her ill-health.

Emily did not speak directly to the author in our ‘interaction’, except via limited utterances. Nonetheless, her dialogue was multi-voiced, such that she directed her commentary at others and addressed their perceived responses (see Sullivan 2012). For example, she appeared to advise another person that she should pose a request to a man they both knew: ‘no, you have to, have ask him ... Yeah. No, no, no, no. Yeah, I know, I know love ... Are you sure? ...’ As Emily’s ability to learn about or change her social world was very limited, she lacked the ability for complex reflexivity. Nonetheless, her communication – whether linguistic or embodied – was relational, dialogical and emotionally prompted (by love, joy, anger and anxiety). Accordingly, her nuanced communication revealed a degree of ‘reflective consciousness’ (Sullivan 2012, 178) and even a capacity for basic reflexivity.

Conclusions

Less talk, more communication

People with dementia demonstrated deliberative agency when they made decisions. Yet, because agency theory privileges language (Madhok 2013), and even conflates language and rationality, people with dementia who lack speech are then assumed to lack rationality. As a result, those who retain decisional capacity, but lack discursive abilities, are denied opportunities for exercising deliberative agency. Similarly,

professional discourse and interaction with people with learning difficulties often construct them as incompetent, particularly when disabling (rather than enabling) communication methods are used (Goodley and Rapley 2002). At the same time, an over-rationalised concept of agency disregards more pragmatic and creative forms of agency (see also Duncan 2011). Indeed, people with advanced dementia sometimes expressed their perceptions, feelings and desires in habituated, embodied or emotional forms. Such expressions often demonstrated continuity in their personal and social identities – for example, a feminine or masculine self, or marital and caring roles. Thus, even when their capabilities for language, deliberation and social (inter) action are extremely limited, people with dementia may still demonstrate imaginative agency (see Emirbayer and Mische 1998).

Acting and reflecting

Since conceptualising and undertaking action are often challenging for people with dementia, a ‘strongly purposive’ concept of agency is less relevant (Emirbayer and Mische 1998, 984). Nonetheless, the study showed that adequate provision of support can enable people with dementia to participate more fully in family life. Allardt (1993) referred to ‘having, loving and being’ as encapsulating the necessary conditions for human development, where ‘being’ relates to a person’s needs for meaningful involvement in society. Accordingly, as people with dementia find ‘doing’ more of a challenge than ‘being’ (or loving), their expressions of agency may be less distinctive from their identity, such that the latter may be a key means through which they seek to shape their social worlds.

Advance decision-making and care planning enabled people with dementia to make decisions about their future while they still retained decisional capacity. Alternatively, for some people with advanced dementia, basic expressions of their values or aspirations enabled them to have a say in their lives and project their hopes for the future (see Emirbayer and Mische 1998). Thus, whereas agency is theorised as highly reflexive or, alternatively, habituated and non-reflexive (Giddens 1991; Duncan 2011), some people with dementia may instead demonstrate imaginative projection (Emirbayer and Mische 1998).

Self-reflection is ‘the ordinary, everyday ways people reflect on themselves and their actions’, whereas reflexivity involves using knowledge about the social world to change social practices (Burkitt 2012, 459). It was evident that people with advanced dementia could demonstrate self-reflection – for example, in terms of acknowledging their illness, adhering to social conventions and negotiating marital dynamics. In addition, when reflexivity is defined as relational, dialogical and emotionally motivated (Burkitt 2012) – that is, as a socio-emotional rather than a cognitive process – then people with advanced dementia could be seen to be somewhat reflexive. Indeed, they used their emotions to form judgements about their interpersonal situations and to respond relationally. Therefore, it is suggested that they can exercise basic agency and even a social self (Burkitt 2008).

Agency and equality

However, whether people with dementia have a say in their current lives and can influence the direction of their future lives is often constrained by under-recognition of their agency, limitations in support, conflicts of needs and interests between them

and their carers, a lack of formal social care and wider social inequalities (see also Oliver and Barnes 2012). Whereas the dominant, cognitive model of dementia narrowly views (primarily negative) emotions and behaviour as symptomatic of the illness (Finkel 2000), in contrast a social model of dementia is needed which acknowledges that behaviour and emotion may be indicative of agency. Since people with dementia need practical support, they are dependent on others to enable their social participation. Thus, a concept of 'assisted autonomy' is relevant in dementia; that is, where support is required to enable the exercise of agency (see also Morris 2005). More generally, since agency is located within, and derived from, interdependent relations, it always requires the support of others (whether or not we have dementia). Similarly, whilst debate about caring for older people has traditionally focused on their 'dependency', Tronto emphasised the need to recognise our interdependency as 'throughout our lives, all of us go through varying degrees of dependence and interdependence' (1993, 135). However, whilst the relational basis of agency is portrayed as egalitarian, on the contrary, social resources are often unequally distributed (see also Duncan 2011). Indeed, some people with dementia lacked opportunities for exercising agency when their spouses did not acknowledge or facilitate their capacity for agency. Likewise, the support given to people with learning difficulties can either emancipate or oppress them (Goodley 2000). Of course, the limited provision of formal social care adds to the challenges carers experience when trying to support people with dementia (see National Audit Office 2007; Department of Health 2009).

In order for people with dementia to achieve equality, their potential agency needs to be recognised and facilitated. Fundamentally, a more expansive concept of agency is needed in social science theory that is informed by the experiences of cognitively disabled people. Such a concept would adopt a broader conception of capability (see Burchardt 2004), take account of communication other than language, recognise emotional forms of social 'action' and allow for imaginative agency even when the potential for social change is limited. Importantly, acknowledging the socio-emotional, rather than cognitive, basis of reflexivity would enable the agency of people with advanced dementia to be more readily recognised (see Burkitt 2012). However, as the study did not include people with severe dementia, further research is needed into whether they can also exercise agency. In addition, as research methods commonly used in advanced dementia are unable to recognise, or even disregard, agency (such as dementia care mapping; Brooker and Surr 2006), future research should prioritise the use of methods that engage directly with the individual's intersubjectivity (socio-emotionally and ethically) and are sensitive to her/his agency.

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Note

1. Pseudonyms are used throughout.

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