

Broadening and deepening the understanding of agency in dementia

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ABSTRACT

Agency has become an essential component of discussions concerning selfhood, well-being, and care in dementia studies but the concept itself is rarely clearly defined and the use of this term can be confusing and conflicting. This paper outlines some of the key ways in which agency has been conceptualised in relation to dementia, highlighting the complexities surrounding this concept and focusing on agency in a way that is tied to our ideas about citizenship, legal and human rights. Seven key dimensions of agency are examined: embodiment, emotions, sense of agency, intentional conscious action, the social context of agency, decision-making and moral responsibility. Using a critical realist approach, this paper brings together the diverse ways in which agency has been understood into an interdisciplinary, laminated understanding of agency. This model is then used in an applied example demonstrating that this model can be used to identify the ways in which an arts intervention can support the agency of people living with dementia. This paper proposes that agency is layered, multidimensional and exists on a continuum.

INTRODUCTION

The concept of ‘agency’ has received increasing attention over the last two decades in a variety of disciplines including philosophy (Schlosser 2015), psychology (Moore 2016, 2), neuroscience (David 2012), media studies (Eichner 2014), archaeology (Dobres and Robb (2000)) and sociology (Emirbayer and Mische 1998). But the uses and applications of this concept can be contradictory or overlapping, Marshall notes that the term ‘takes on many meanings in different disciplines, but also within the same discipline and indeed within the writings of the same author’. (Marshall 2005, 58). Agency can refer to a characteristic that is intricately tied to our sense of self, a neural process incurring a feeling of ownership over our actions, being morally responsible for the way we act, or the decisions we make. Nonetheless, most definitions of agency tend to privilege cognition, language and rationality, meaning that agency is frequently described in a way that excludes people with later-stage dementia (Boyle 2008). As a result, people with dementia are often assumed to ‘possess weak or even no agency’ (Boyle 2014, 1130). However, as is argued by Motta-Ochoa et al. (2021) ‘the complexities involved in defining agency can shed light on the capacity of persons with dementia to act’ (2021, 2). It has been argued that ‘nowhere is the need for genuine interdisciplinarity more evident than in research related to health and

well-being’ (Bhaskar, Danermark, and Price 2017, 3). However, the diverse understandings of agency can prevent useful conversations across disciplines. For example, some anthropologists argue that objects and entities including ‘spirits, machines, signs and collective entities (ancestors, corporations, social groups)’ possess agency (Hoskins 2006, 74). Yet this understanding would seem to counter work that views agency as a ‘necessary condition’ of possessing Human Rights (Griffin 2008, 258).

This paper addresses this by exploring the multitude of ways in which agency has been thought of in relation to dementia and proposes that these different conceptions can be seen to identify different dimensions of agency, and therefore can be taken together to form a laminated (or layered) interdisciplinary model of agency.

WHAT ARE PEOPLE TALKING ABOUT WHEN THEY ARE TALKING ABOUT AGENCY?

Despite the lack of unified accounts of agency, it can be established that agency refers in some way to our ability to act, to effect changes in the world and to be held responsible for our actions. Agency can refer to a characteristic of an action (an agential action) or as something we attribute to people (to call someone an agent). To say someone ‘has’ agency or is an agent means they have capacity to do agential acts. It is also seen as a positive attribute, and is therefore value laden. Some accounts look at the individual and look at what characteristics that individual has in order to make them agential (such as being rational, or having a certain amount of cognition) (eg, Boyle and Warren 2017). Whereas others look at the level of the actions and look at how we understand these actions to be agential (for example looking at whether an action was purposeful or intended) (eg, Anscombe 2000). This paper will look at agency by examining different ways in which we can understand actions and how disciplines and scholars have addressed queries about agency in dementia.

Despite various attempts within different disciplines to draw out a definition of agency there is still little critical engagement with the term within the interdisciplinary field of dementia studies. As a result of this there is no consensus on the meaning of agency as it relates to dementia, and agency is at risk of becoming ‘an ambiguous platitude meaning everything and nothing’ (Dobres and Robb (2000), 3).



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Patient and public involvement

Patients and members of the public were involved in the design of our research. Through work with people living with a diagnosis of dementia,¹ it emerged that most people only understood ‘agency’ as referring to ‘a business that represents one group of people when dealing with another group’ (Agency 2013). For example within a care setting people were familiar with the term ‘agency staff’. Once the term was discussed in more detail, members of the groups found that the idea of agency, as it relates to actions, resonated with some of their experiences of living with dementia. However, for the concept of agency to be useful, we need to critically reflect on the term and find a way to clearly communicate about this concept across disciplines.

Why agency? And why now?

Gerontological research has often focused on activity and freedom of choice as being a key component of ‘successful ageing’, and therefore being active has become closely tied to well-being (Pirhonen and Pietilä 2016, 19). For this reason, action and agency have come to be significant in our understanding of living well with dementia; for example, Kitwood and Bredin argued that having a sense of agency in one’s actions can be seen as an indicator of well-being (1992).

Dementia is a syndrome characterised by progressive cognitive impairment and is caused by a number of different diseases of the brain. Dementia is often treated as being synonymous with Alzheimer’s disease which, although it is the most common form of dementia, still only accounts for about two-thirds of all cases (Alzheimer’s Research UK 2020). Although a loss of memory is thought of as the predominant feature Alzheimer’s disease, dementia can also result in ‘impairment in other areas such as executive functions, attention, language, social cognition and judgement, psychomotor speed, visuoperceptual or visuospatial abilities’ (World Health Organization 2019). Therefore this paper will draw on research into other forms of dementia, such as frontotemporal dementia (FTD) and dementia with lewy bodies (DLB), in order to represent different experiences of dementia.

Dementia has a complex effect on agency (Bosco *et al.* 2019) and some scholars have argued that dementia strips an individual of their agency entirely (discussed in Boyle 2014). Agency has traditionally been considered to be rational, individualistic and reliant on language (Boyle 2008) and this conception of agency excludes people with dementia. Institutional care for people with dementia has also been argued to turn people from full adult members of society into the “have-nots” in terms of agency’ (Pirhonen and Pietilä 2016, 19). The assumption of a lack of agency for people with dementia is most clear in the still pervasive ‘zombie narrative’ (Aquilina and Hughes (2005) and Behuniak 2010). This narrative around dementia implies that people with dementia have no agency but also invokes a lack of personhood enforcing the idea of dementia as an ‘annihilation of self’ (Aquilina and Hughes (2005), 144). It is still not uncommon to see headlines such as ‘How to Keep Alzheimer’s From Bringing About the Zombie Apocalypse’ (Newton-Small 2019).

Within the field of dementia studies there has been a powerful resistance against this narrative of a lack of self and agency in dementia. Social scientists have aimed to provide proof that people with late-stage dementia still possess agency (eg, Boyle 2014, Kontos 2004) and philosophers have argued for different understandings of the self and agency (eg, Hughes 2011 and Nelson 2010). Julian Hughes has written informatively on the

agency of people with dementia and as such this work has been heavily influenced by his thinking (Hughes 2011; Hughes, Louw, and Sabat 2005). All these accounts reassert the agency of people with dementia, focussing on forms of agency that may be under-recognised or not represented in more traditional accounts of agency. However, a practical and useful concept of agency in dementia should also account for the fact that dementia can in some ways impair or interrupt someone’s agency. Such an account would therefore clarify the ways in which we can support and facilitate the agency of people living with dementia.

DIMENSIONS OF AGENCY

The next section of this paper will look at some of the different ways in which agency has been understood within different disciplines and in relation to dementia, focusing on agency in a way that is tied to our ideas about citizenship, legal and human rights. Frankfurt (1971) and Taylor (1985) have argued for the distinct nature of human agency as opposed to other agents (such as animals). This account is therefore limited to the agency that is possessed by human persons.

When we begin to explore a concept in more depth and draw out the different uses of the concept it can suddenly appear as if these uses of the concept bear no relation to another. For example if we take Wittgenstein’s famous example of the concept of ‘game’: when we begin to look at all the different types of games it is hard to see what they actually have in common and what does indeed make them a game (Wittgenstein 1968, #66). This could be the same when looking at the concept of agency, how can these complex and contradictory understandings of agency still all be understood as agency? Wittgenstein explains that we extend and explore a concept ‘as in spinning a thread we twist fibre on fibre. And the strength of the thread does not reside in the fact that some one fibre runs through its whole length, but in the overlapping of many fibres’ (1868 #67). So therefore, rather than viewing these understandings of agency as inconsistent disciplinary conceptions, this paper proposes that we should look at them as different fibres of the same thread, identifying different dimensions of agency. Moreover, we should not privilege one single understanding of agency and we argue these dimensions should instead be taken together to constitute a laminated model of agency in dementia. The dimensions of agency are ordered in a way that echoes the laminated ontology proposed by critical realism. As described in Shakespeare (2013, 74) these are: physical, biological, psychological, psychosocial and emotional, socioeconomic, cultural, and normative. The ordering of these understandings of agency is not related to the importance of each dimension of agency. However, bringing the dimensions together in a laminated model will help identify different areas of research and enable conversations across disciplines.

Embodiment

In recent years, the concept of embodiment has played an important role in discussions about selfhood and agency in dementia. In an effort to move away from solely cognitive models of agency, scholars have looked to the body as playing a far more important role in our agency than previously understood. The key proponent of embodiment and dementia is Kontos (2004), although writing from scholars such as Twigg (2006), Hughes (2011), Millett (2011), Boyle (2014), and others has also contributed to this understanding.

Pia Kontos has written extensively on this topic and her work and theory of embodiment has had a significant influence in the

field of dementia, having been widely referenced and pivotal in the burgeoning field of embodiment and dementia. Kontos has explored the idea of embodiment and more specifically embodied agency in a number of works (including Kontos 2004, 2005, Kontos and Grigorovich 2018). She argues that as a result of the dominant mind/body divide (epitomised by Descartes' *Meditations*), our concept of selfhood has become reliant on cognition (or the mind) (2004, 829). She states that we have placed too much emphasis on cognition and relegated the body to the passive instrument we use to navigate the world, whereas Kontos argues that our body also has agency independently of cognition (Kontos 2003, 167).

This is a complex idea that demands a clear theoretical grounding. Kontos draws on Merleau-Ponty's work on embodied consciousness and the way in which the body relates to the world without cognitive consciousness (Merleau-Ponty 2002). Kontos refers to this as the 'pre-reflective directedness towards the lived world' (Kontos 2004, 837). For Kontos the body is 'in and of itself intentional' (2004, 837), thereby challenging 'assumptions of loss of agency with dementia by treating the body as itself having creative and intentional capacity' (Kontos and Grigorovich 2018, 41). Kontos then looks to Bourdieu (1977) to inform her understanding of the sociocultural content of bodily movements. She uses his concept of 'habitus' to explain how our bodily practices that are below the threshold of cognition are shaped by social context (Kontos 2006). These sociocultural dispositions are non-conscious and embodied rather than consciously learnt rules (Kontos and Grigorovich 2018, 45). Taking these two theories together Kontos builds a new conception of embodied agency which is 'sustained at a pre-reflective level by the primordial as well as the socio-cultural significance of the body' (Kontos and Grigorovich 2018, 41).

Although Kontos claims that she is 'extending the meaning and usage' of Merleau-Ponty's terms such as 'non-representational intentionality' (2004, 847), her use of 'intention' tends to lack clarity. Intentionality is often the source of some confusion in connection with definitions of agency. This is because there are two distinct uses of the concept of intention in regard to agency. The first refers to intentional actions. An intentional action is seen as one that is 'done on purpose' (Agent, n.1 and Adj 2021), or deliberately. However, Merleau-Ponty uses 'intentional' in a second sense (Morris 2012, 16). This use of intentional (sometimes called a 'philosophers word' (Jacob 2019)) refers to 'the power of minds and mental states to be about, to represent, or to stand for, things, properties and states of affairs' (Jacob 2019). It describes a quality of 'aboutness' or 'being directed towards'. Merleau-Ponty wrote for the most part about intentionality in the sense of the *body* being directed towards the world, something he termed 'motor intentionality', but despite the fundamental nature of this concept in his work 'Merleau-Ponty wrote surprisingly little to explain this concept directly' (Jackson (2018), 2). The conceptual ambiguities complicate the idea of intentionality further and is not clearly addressed in Kontos' work.

One way in which Kontos illustrates her conception of embodied agency is by looking at the musicality of people living with dementia. Kontos discusses expressions of musicality in two individuals living with dementia who, despite their advanced cognitive impairment, are still able to sing old songs or co-create improvised songs with elder-clowns (Kontos and Grigorovich 2018). Kontos argues that their singing and playing is a 'coherent performance' but due to their impairment is 'produced without any conscious intention' (Kontos and Grigorovich 2018, 45). Instead, Kontos argues their musicality emanates from the body and it's learnt practices (*ibid*).

Dekkers is another scholar who has explored embodied agency, or 'bodily autonomy', he argues that when dementia has progressed to the stage in which a person may be unable to communicate using more traditional forms of language a 'patient's bodily reactions must be taken seriously' (Dekkers 2009, 259). He uses an example of a person with severe dementia reacting 'with facial expressions, vocalisations, muscle tension and bodily defensive movements following interventions such as physical restraints and other coercive measures' (*ibid*), this can be seen as the individual expressing their agency in communicating their wishes against this type of treatment. But Sabat draws our attention to the ways in which the body may obscure someone's agency, he looks at how dementia may 'compromise' one's ability to use the body as a vehicle to navigate the world (Sabat 2001, 229). As a result the movements of the person with dementia may be 'abnormal or difficult to comprehend', by taking these movements at face value it could obscure the intention (as it relates to goal-directed behaviour) that may be occurring beneath the surface (Sabat 2001, 230).

Emotions

Agency has principally been understood as something inherently rational, involving decision-making and forethought (Boyle 2014, 1131). However, in recent years agency has been thought about as also being tightly bound up with our emotions. The involvement of emotions in agency is a complex area, but looking at the emotional dimension of agency can begin to delineate the ways in which emotions can be both indicative of agency but also impair our agency.

Whereas Kontos responds to the overemphasis of the cognitive perspective in dementia by focussing on the body, Boyle looks to the emotional self. Boyle has argued that the dominant biomedical model places too much emphasis on rational, cognitive, language-based forms of agency, therefore people with dementia are considered to lack agency (Boyle 2014, 1131). As a result, the emotions and behaviours of people with dementia are not viewed as agential but rather as symptomatic of dementia (eg, the contended term Behavioural Psychological Symptoms of Dementia (Power 2019)). However, Boyle argues that even people with more advanced dementia 'use their emotions to exercise reflexivity and seek to influence their relationships' (Boyle and Warren 2017, 11). Therefore, we need a social model of dementia that 'acknowledges that behaviour and emotion may be indicative of agency' (Boyle 2014, 1141).

Another way in which emotions have been considered in relation to agency is put forward by Slaby, Paskaleva and Stephan. They argue for 'an approach to emotion that conceives of emotional processes as intimately tied up with agency' (Slaby, Paskaleva, and Stephan 2013, 34) but explore how this relationship can result in an 'impairment of agency' in conditions such as depression (*ibid*, 42). This understanding could inform discussions around agency in dementia as agency is seen as something that can fluctuate and be affected by emotional states as well as cognitive impairment^{2,3}

Perach *et al* have demonstrated how emotions and our ability to regulate them play an important role in decision-making (Perach *et al*. 2021). But, it has been found that 'emotion regulation resources and emotional experiences are affected in persons with DAT (Dementia of the Alzheimer's Type), bvFLD (Behavioural Variant Frontal Lobe Degeneration), PDD (Parkinson's Disease Dementia), DLB (Dementia with Lewy bodies), and vascular dementia' (Perach *et al*. 2021, 1836). If agency and emotion are seen as tightly bound together we can therefore assume that

Embodied agency	• Agency is not just cognitive, it also involves the body
Emotions & agency	• Agency involves our emotions: emotions can be indicative of agency but can also impair our agency
Sense of agency	• Agency involves a subjective feeling of control and ownership over our actions
Intentional conscious action	• Agency involves acting purposefully and for reasons.
Agency in a social context	• Agency is influenced by social context and the involvement of other people in our actions.
Decision making	• Agency involves making decisions
Moral responsibility	• Agency involves being appraisable for actions (praised or blamed)

Figure 1 Diagram listing the different dimensions of agency discussed in this paper.

these emotional changes in dementia may also affect agency. But the relationship is complex and further work is needed to understand how this is complicated by dementia. However, by broadening our concept of agency to include emotion we can already begin to interpret the actions of people with dementia in a different way, in some cases by acknowledging actions as being agential, and in others, being able to be more understanding of the way in which individuals may feel incapable of expressing themselves through their actions.

Sense of agency

This next dimension of agency relates to the ways in which agency has been understood in terms of specific brain functions. The concept of agency within neuroscience and psychology often refers to the experience of agency, or the ‘sense’ of agency, that an individual has while acting. The sense of agency is not just one kind of experience and the sense itself has been understood in different ways. An important distinction was made by Synofzik (a neuroscientist), Vosgerau and Newen (both philosophers) (2007) between a low-level feeling of agency, a conceptual judgement of agency and a sense of ownership. This distinction proves helpful in understanding the way neuroscientists and psychologists discuss agency and also how they purport to measure it. As both these disciplines are based in empirical research, the ways of understanding the sense of agency are heavily influenced by ways of measuring the sense of agency.

There has been some research into how the sense of agency can be effected in dementia, specifically for people with FTD. Balconi cites that ‘Some patients with frontal lesions automatically execute the action performed by someone else that they are observing, losing track of the distinction between their own intentions and the intentions of others’ (Balconi 2010, 132). This inability to identify one’s own actions against another’s signifies perhaps a lack of sense of ownership over one’s own actions, indicating that the sense of agency may be affected in certain types of dementia.

One important element of this understanding of agency is that it is measurable meaning that there has been more work on specific changes to this type of agency in people with dementia. Understanding how dementia can disrupt the sense of agency can help us understand the actions of people with dementia by looking at how we subjectively experience agency.

Intentional conscious action

One of the most common and influential ways in which agency has been understood comes from analytical philosopher GEM Anscombe (a student of Wittgenstein). Anscombe proposed the conception of agency as intentional (purposeful) action (2000). She argued that intention is fundamental to the way in which we understand actions. Anscombe examined the features of an intentional action and claimed that acting intentionally is closely related to acting for reasons (Schlosser 2015). Anscombe argued that an intentional action is one ‘to which a certain sense of the question “why?” is given application’ (Anscombe 2000, 1). There are particular situations in which the question of why would *not* be applicable. Namely: when someone replies (A) ‘I was not aware I was doing that’ or (B) ‘It was involuntary’⁴ (Anscombe 2000, 11–12). This account has been extended by philosophers such as Frankfurt (1971) and Taylor (1985) who examine our reasons and motivations for acting and the way in which we can evaluate and weigh up our motivations.

Intentionality is also one of the core features of agency in Bandura’s Social Cognitive Theory in Psychology, alongside forethought, self-reactiveness and self-reflectiveness. Bandura describes an intention as: ‘a representation of a future course of action to be performed. It is not simply an expectation or prediction of future actions but a proactive commitment to bringing them about’ (Bandura 2001, 6).

These understandings of agency as conscious intentional action contradict the earlier accounts of embodied agency put forward by Kontos where it is argued that actions can be agential without any ‘conscious intention’ (Kontos and Grigorovich 2018, 45). However, by drawing on the work of Aquilina and Hughes it is possible to make the distinction between actions in which there are conscious intentions, or as they term them ‘*explicit* intentions’ and actions which are intentional in virtue of the actions themselves aiming at something without conscious intentions (Aquilina and Hughes 2005, 156). Actions without explicit intentions can be explained causally, either biologically, psychologically or socially (*ibid*), however they are distinguished from the actions of an automaton due to their embedded ‘truly human’ context. Kontos’ understanding of embodiment focuses on actions as being meaningful, by virtue of the body and its relation to the world. But this is not to be conflated with Anscombe’s and Bandura’s conception of agential actions as being consciously purposeful and deliberate.

The intentionality of actions in dementia is a complex issue. Sometimes carers are actively encouraged to ‘understand the *lack* of intentionality of the behaviours’ (my emphasis) of someone with dementia, especially in relation to psychosis in dementia (Rayner *et al.* 2006, 648). It has been emphasised that ‘the challenging behaviour of the person with dementia is NOT on purpose’ (Suarez-Gonzalez 2021) and more generally Raetz advises family physicians to ‘Help caregivers understand that the disturbing behaviours of patients with dementia lack intentionality and are part of the normal progression of the disorder’ (Raetz 2013, 553). This advice runs counter to the work of many scholars who are trying to emphasise the agency of people with dementia and encourage us to see intentionality and meaning in their actions (such as the approaches articulated by Boyle and Kontos earlier in the paper). As Sabat argues, we risk labelling behaviours as “‘symptomatic of disease’”, which could be ‘quite easily seen as being just as reasonable, healthy, and worthy of respect as it would be in anyone not afflicted with AD’ (Sabat 2001, 304). By looking at different types of intention we can offer a different understanding of what can be termed ‘behaviour

Table 1 Table outlining the different dimensions of agency shown in the example and the ways in which we can recognise and support agency

Dimension of agency	Recognising and supporting agency
Embodied agency	We can understand how Alice's musicality and her agency is expressed through her body and is informed by her cultural upbringing. By doing this we can appreciate the significance of her gestures and non-verbal communication. Giving Alice opportunities to take part in these musical activities and supporting her embodied agency and musicality has been argued to 'promote human flourishing' (Kontos and Grigorovich, 46)
Emotional agency	We can recognise how Alice's gentle playing may communicate her feelings at this time of being content and happy. Music offers an important opportunity to express our emotions (Palo-Bengtsson and Ekman 2016). The musician can respond and reaffirm Alice's emotions in this context through their playing and their interactions. In this way they can help to support her emotional agency.
Sense of agency	We can consider Alice's subjective feeling of control over her actions while she plays in time with the other musicians. Music has been argued to facilitate a sense of agency (Saarikallio 2019). This feeling of control and ownership of her actions may be particularly important within a care home where many things may not be within Alice's control.
Intentional conscious action	Recognising Alice's playing as intentional and meaningful is important in understanding her creative agency in this context. Her intention is to make music with the group. By the musicians and carers interacting with Alice as a creative agent they can work with her creatively and artistically.
Social context	Considering the social context of Alice's actions is important in being able to recognise her agency and the meaning behind her actions. The care home is a unique setting with complex power relationships and these institutions have been found to create 'constraints on agency' (Pirhonen and Pietilä 2016, 21). Whereas creative activities can offer a space for people to exercise their agency (Zeilig et al. 2019). Being aware of this tension can alert us to changes and fluctuations in Alice's ability to exert her agency, but also the importance of supporting her agency in this context. We can also consider Alice's agency in relation to her choice to attend the creative session in the first place and how this may affect her interactions in the group. We should also be aware of Alice's relationship with the carer and how the carer has supported her agency by holding the drum for her. And how by creating music within the group, Alice is taking part in a collective activity thereby exercising group agency.
Decision-making	In this example the carer gave Alice the opportunity to make a decision by offering her the djembe drum and giving her plenty of time to decide if she would like to play or not. In this way the carer supported her in her ability to make a decision to be part of the group even though the effects of dementia may mean that it takes Alice more time and more support to make that decision.
Moral responsibility	Alice can be recognised as being responsible for her playing but also for her encouraging interaction with the musician. By seeing Alice as responsible her actions are also viewed as praiseworthy, and by acknowledging this the carers and musicians can interact with her as a responsible agent and support her agency.

that challenges' or more recently 'responsive behaviours'. This use of language emphasises 'that the person is not deliberately (or intentionally) being "difficult"' but it is also important that 'the behaviour will have meaning for the person with dementia' because of the human context of their actions (Alzheimer's Society 2021). A laminated model informed by the idea of intention can advise us about the agency of someone living with dementia in relation to these responses or behaviours: that the intention may be to communicate unmet needs, but the unintentional act may be upsetting their loved one.

Agency in a social context

Another fundamental way in which we can understand agency is in relation to other people. This section captures some of the approaches that describe how our actions are situated within a social context and affected by those around us.

Structure and agency

Sociology is primarily concerned with how human actions occur within and are shaped or affected by society. Therefore, within sociology, agency is tied to the interaction between structure (the idea that our actions and behaviours are determined and conditioned by society) and free will. Giddens criticises the philosophical approach to intention as 'extricating' action from its context (Giddens 1986, 3). For Giddens, agency is the capability of people to act in one way where there is a possibility that they could have acted another way, and for this reason agency is also tied to power (Giddens 1986, 9). Giddens argues that we operate within multiple overlapping and sometimes contradictory social systems. Agency then becomes a matter of an individuals' ability to both reproduce but also challenge and change the societal structures that govern our actions (Whittington 2015, 147).

A structure-agency framework has proved informative when examining agency for people with dementia within creative

activities. Motta-Ochoa et al. (2021) analysed a movement programme with people with dementia and looked at how the participants would recreate the movements prescribed by the programme but also how they would transform the structure of the movements, resist them and improvise movements collectively (Motta-Ochoa et al. 2021).

Feminist critiques of theories of agency and autonomy also criticise individualistic theories of agency in a number of ways, drawing our attention to the characteristics of the agent who is 'emotional, embodied, desiring, creative, and feeling', and also the 'complex social and historical contexts in which agents are embedded' (Mackenzie and Stoljar 2000, 21). Agents and their capacities are conceived relationally considering their social context (*ibid*, 22). This is important when looking at the agency of people living with dementia as Boyle reflects that people with dementia are often 'ungendered' within policy discourse as 'established identities are often rendered invisible, and a dementia identity is imposed' (Boyle 2017, 1792). Whereas feminist philosophical approaches can help inform our understanding of the way in which agency is shaped by an individual's social context and gendered identity in dementia (*ibid*).

Group/shared agency

Agency is also understood as something that can be shared or held in a group. Some philosophers argue that we can understand group collective agency and intention by taking together the individual intentions of members of the group with their beliefs about the group (Tuomela and Miller 1988). But Searle argues that group intention also requires the intention to cooperate (Searle 1990, 406).

Agency has also been considered to be shared or delegated by people living with dementia. Pirhonen and Pietila examined the experiences of older adults in assisted living and found that residents 'sometimes delegated execution of an action to other people while the decisional agency remained untouched' and

also used aids (such as walkers) to ‘extend one’s own agency’ (2018, 32)⁵. Bosco *et al* also explored shared decision-making, and found people with moderate dementia were ‘more likely to require substantial support from their carers and to express their wishes and preferences through shared decision-making’ (2018, 4).⁶

Work within arts and dementia that looks specifically at co-creativity and co-design may be informed by theories of group agency. For example, in looking at co-creativity in a group with people living with dementia and artists there was a move away from viewing agency as something individual and towards looking at leadership, creativity and agency as something shared within a group (Zeilig *et al.* 2019). Working in this way can give space for people with dementia to exert their agency (*ibid*).

Understanding agency in a social context and being aware of the involvement of other people in our agency highlights the importance of the social conditions and relationships of people living with dementia. Subsequently, there are many positive ways in which we are able to support the agency of people with dementia through these social interactions and relationships. However, this dimension of agency should also alert us to the possibility of malignant social psychology (Kitwood and Bredin 1992; Sabat 1994, 271) and how the experience of oppression can affect someone’s agency (McLeod and Sherwin 2000). It is essential to consider the lack of opportunities that people with dementia have had to be supported by others in their agency due to social isolation, especially throughout the pandemic.

Decision-making

Making choices and decisions is an important way in which we exercise our agency, and this has been the focus of much of the work on agency in dementia studies. This dimension of agency specifically refers to initiating social action through partaking in decision-making (Bosco *et al.* 2019, 2) (Boyle 2014, 1130). Bosco *et al* state that ‘agency and autonomy tend to be used interchangeably in the healthcare literature around decision-making’ (2018, 2). Although it is important to distinguish autonomy as agency combined with liberty to make choices free from ‘controlling influence’ (Beauchamp and Childress 2013, 102).

This dimension of agency is especially important with respect to the law. The capacity to make decisions is the key focus of Boyle (2009). Boyle has written informatively about how the Mental Capacity Act 2005 (MCA) enshrined the right to autonomy and right to exercise extant decision-making abilities (Boyle 2009). The MCA also defines the capacity to make decisions as ‘specific to the time when it needs to be taken (situational), rather than as a capacity that the individual either has or lacks’ (Bosco *et al.* 2019, 1). There is a general understanding that people in the very late stages of dementia are unable to make some decisions (eg, decisions relating to finances or healthcare). These issues are further complicated by advanced decisions or living wills. Some philosophers have explored this (eg, Jaworska 1999; Jennings 2010; Vogelstein 2016) and demonstrate how these cases demand a workable concept of agency in dementia. These cases also highlight questions around changes in personal values and ethical models of quality of life in dementia.

There is a further body of work that looks at everyday decision-making. In navigating our world, we are constantly making decisions, and understanding and supporting the agency of people with dementia in these decisions can be very important. Bosco *et al* undertook a helpful systematic review looking at research about agency as decision-making in dementia (2018). In contrast

to embodied understandings of agency, Bosco *et al* argue that cognition is an essential part of agency, stating that: ‘Decision-making and agency require a degree of cognition to influence social change’ (2018, 2). However, characterising agency as purely cognitive may mean that our understanding of agency is too narrow and excludes important dimensions of agency (such as the relationship between emotions and decision-making discussed in the section on Emotions). A laminated model of agency will enable us to look at how decision-making is not only cognitive but is also tied to our emotional and embodied agency.

Research into decision-making is one of the few areas where the voices of people living with dementia are included in the research. Featherstonhaugh *et al*, undertook a piece of research that explored the importance of being part of the decision-making process for people living with dementia and the type of ‘subtle support’ in decision-making ‘that enabled a feeling of worth’ (Featherstonhaugh, Tarzia, and Nay 2013, 149). They found that ‘Being and remaining central to decisions that affected them was a way to affirm: I am a person! I am still here!’ (Featherstonhaugh, Tarzia, and Nay (2013), 149). This demonstrates that supporting the agency of people with dementia can not only support their well-being but also support their sense of self and their place in the world.

Moral responsibility

Another dimension of agency relates to the idea of moral responsibility; being held accountable for your actions, or the question of whether actions are praiseworthy/blameworthy.⁷ Sabat notes that ‘responsibility for one’s actions’ is seen as a way in which ‘selfhood is manifested publically’ (2001, 276). In dementia studies, moral responsibility has not been discussed in any great detail. However, given the complexity that dementia poses to agency, it is important to reflect on whether certain actions should be worthy of praise or blame.

For people living with dementia whose agency may be affected, models of moral responsibility seem to leave two options. The first option is viewing the individual as not responsible for their actions, meaning at worst we are not interacting with the individual as an agent, just a victim of disease (Pickard 2017) and at best we simply pity the individual (Gorman 2020). In the case of dementia this is similar to the arguments around the lack of intentionality of actions and treating behaviours as simply the result of the disease rather than being meaningful. The second option would be to hold the individual as fully responsible and therefore in some cases see them as failing their moral responsibility and deserving blame. However, scholars within disability philosophy have begun to explore a third option.

August Gorman argues one way of finding a middle ground between these two options involves examining the environmental conditions of an action in more detail and understanding that this boundary between agency and environment can be different for different people (Gorman 2020).⁸ An agent’s environment constrains the options available to the agent; things in our physical environment may limit the actions available to us, but Gorman argues that there may also be psychological features that limit our actions and can count as environmental conditions. For example, for an individual with Tourette’s syndrome: the urge to say a slur, or for someone living with dementia: a problem with their memory. Gorman also highlights the importance of the social landscape in which the individual is acting and considering social justice in the way in which actions are appraised. By applying

a neurodiversity approach to agency, Gorman advocates for an approach to ‘agential differences’ as a difference in degree not kind (Gorman 2020). This approach could be valuable when applied to people living with dementia. A deeper understanding of the environmental barriers (both physical and psychological) in dementia that may affect that person’s ability to act agentially could facilitate a more nuanced approach to the actions that people with dementia should be held accountable for.

Another way of addressing this area is offered by the philosopher Hannah Pickard. Through her work with people with personality disorders, people living with addiction and people with eating disorders (mental conditions that can be broadly called ‘disorders of agency’) Pickard discovered that clinicians were employing a concept of responsibility without blame (Pickard and Ward 2013, 1134). She has developed and philosophically interrogated this concept by separating the notions of being responsible for something and being morally responsible for something. Responsibility is crucially linked to agency, but it does not have to be attached to blame however (Pickard and Ward 2013, 1136). In this way patients could be considered to be agents, and interacted with as such, but without blaming an individual for their actions.⁹ Understanding responsibility without blame may be helpful in understanding the so-called responsive behaviour in dementia as meaningful, or communicating an unmet need, without assigning blame. Pickard’s work also highlights the importance of interacting with individuals as agents.

Moral responsibility can be affected by dementia through changes to the ability to make moral judgements. Research has shown that in behavioural variant frontotemporal dementia (bvFTD) there are significant differences in how people make moral judgements (Baez *et al.* 2016). This is in part due to the way in which the understanding of intention can be affected by dementia. Baez reports that the participants with bvFTD ‘were not able to integrate intentions and outcomes as well as control subjects did’ (Baez *et al.* 2016, 213). If someone with dementia were to have their moral judgement affected in this way, their moral responsibility may be impacted. bvFTD can also result in a loss of empathy (Baez *et al.* 2014; Marshall *et al.* 2019) and this has been noted to have a complex effect on moral agency and responsibility when looking at other conditions that affect empathy (such as autism or psychopathy) (Aaltola 2013; Kennett 2002).

It is interesting that moral agency is the least written about and researched within dementia studies. This may be because it is arguably the most complex form of agency, involving cognition and also moral judgements. Nonetheless, it is important that we view people with dementia as moral agents. However, this must be accompanied by an understanding of the ways in which dementia and other environmental or contextual conditions affect someone living with dementia. Gorman and Pickard’s approaches demonstrate how it is possible to navigate these complexities when looking at agential differences.

DISCUSSION: A LAMINATED MODEL OF AGENCY

This paper has outlined the following dimensions of agency and their relevance in relation to dementia (figure 1).

These dimensions of agency have been brought together into one model by using a Critical Realist approach. According to Bhaskar *et al.*, ‘Critical realism is uniquely capable of providing a sound basis for interdisciplinary research’ (Bhaskar, Danermark, and Price 2017, 4), since it adopts a

stratified or laminated ontology, looking at different layers of reality and how they interact. Critical realism has also begun to be employed in disability studies (Shakespeare 2013) and nursing (Schiller 2016) and proves especially helpful in understanding complicated topics relating to health and well-being (Bhaskar, Danermark, and Price 2017). This is due to the fact that critical realism allows for complexity, at once accounting for the existence of an external measurable world, while also acknowledging the fact that our experience of this world is mediated by cultural and social factors (Shakespeare 2013, 73). For example, Tom Shakespeare’s critical realist approach to disability, draws on a plurality of theoretical approaches and disciplines in order to explain the phenomenon of disability as not something solely socially constructed, or biological, but rather an emergent phenomenon that we can only understand by examining mechanisms at play in different levels of reality (Shakespeare 2013, 74).

Taking inspiration from these critical realist approaches, this model of agency can be seen to outline some of the different dimensions of agency that operate at different layers of reality. This will facilitate scholars from different disciplines to identify the ways in which they are addressing agency, enabling conversation and learning across the diversity of disciplines addressing the field.

Some theories of agency in dementia can be seen to bring together several layers of agency, such as Julian Hughes’ SEA view—Situating Embodied Agent view—of people with dementia (Hughes 2011). This approach can be seen to incorporate embodied agency, intentionality and agency in a social context (Hughes 2011, 51–2). Emirbayer and Mische explored agency within sociology, and they found that accounts tended to be ‘one-sided’, rather than incorporating the different ways in which agency is understood within this discipline (1998, 963). They propose that if we conflate only one dimension with pertaining to agency itself ‘we lose a sense of the dynamic *interplay* among these dimensions and of how this interplay varies within different structural contexts of action’ (Emirbayer and Mische 1998, 963). This paper has addressed this criticism by including conceptions of agency across a number of disciplines and demonstrating that to understand the concept of agency in all its complexity, we must have an awareness of all these layers of agency. Only looking at or focussing on one of these layers is reductive and would fail to capture agency in its entirety.

By identifying these different dimensions of agency it is apparent that in dementia there is not a clear point or line that defines people having agency or not having agency. It is also evident that some dimensions of agency persist even into the very late stages of dementia. Therefore, it is most constructive to understand agency as existing on a continuum or a spectrum; the differences in agency that are a result of dementia are a difference in degree not kind (Gorman 2020).

Applying a laminated model

In Table 1 below, a fictional example of an interaction that will be familiar to many people working in care, or arts and dementia settings, is used to illustrate how this model of agency may help us understand and support the agency of someone with dementia.

Example

Alice is 82 years and living with middle-to-late stage Alzheimer’s disease, and is taking part in a music session in her care

home. She is seated next to a care worker, Raj, who has known her for 2 years and they have a good relationship. Raj offers Alice a djembe drum and although for a while she does not seem to react, after a minute or so she begins to tap a gentle rhythm in time with the other musicians in the room while Raj holds the drum for her. She looks at one of the musicians and smiles encouragingly. The musician follows her lead and plays along with her gently.

CONCLUDING THOUGHTS AND FUTURE DIRECTIONS

This paper has highlighted some of the key conceptual contradictions and confusions in the use of the concept of agency, such as the concept of intention. Examining agency in this way has shown how important it is that authors are clear about the way in which they are using agency, due to the diverse ways in which it can be understood. Areas for further research have also been identified; for example, our thinking around emotions and agency or moral responsibility and dementia.

This exploration has demonstrated that agency in dementia can best be understood as laminated, complex and involving multiple dimensions. Agency is embodied, emotional, intentional (both implicitly and explicitly) and socially situated. It encompasses the feeling of control we have over our actions, making decisions, and the sense of being responsible for our actions. Most importantly, agency is about actions being meaningful and expressing something about the individual.

Nonetheless, there is a key element missing in our understanding of agency and dementia: the voices, opinions and experiences of people living with dementia. There is still a gap in the literature concerning how the concept of agency is felt, used and employed in everyday life by people facing challenges to their agency. This is in part due to the challenges involved in getting ethical approval for studies involving people with dementia (Fletcher, Lee, and Snowden 2019), especially those in the late stages who may be experiencing more challenges to their agency. Although there has been some observational work which has looked at the agency of people with dementia (eg, Kontos 2004, Boyle 2014), there has yet to be any work looking to speak directly to people living with and alongside dementia about their experience and reflections on agency. This paper lays a foundation for further research in this important area.

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NOTES

1. Millie van der Byl Williams met with the Forget-me-nots (a Dementia Engagement and Empowerment Project (DEEP) group in East Kent) and the Voice of Independence and Positivity group at Rare Dementia Support.
2. In this context it may also be informative to think about apathy in dementia, which can be defined as a *lack* of emotion or motivation and how this may impair someone's agency. People with dementia are far more likely to experience apathy with about 50%–70% of people with dementia being affected by this and recent research indicates that apathy may be associated with a higher risk of dementia (Bock et al. 2020).
3. Anscombe also offers a specific definition as to what an involuntary action is by looking at non-observational knowledge. In the case of involuntary action we may still be aware (have knowledge) that we are acting. But Anscombe argues that we do not have non-observational knowledge about the causes of our action in cases of involuntary actions. So an involuntary act is therefore a movement of the body which may be known through non-observational knowledge but that the cause of which is only known through means of observation (Anscombe 2000, 15).
4. Although this research is not specifically on those living with dementia, the ideas within this paper can be extended to those living with dementia.
5. Another way in which scholars have considered the involvement of others in our agency in relation to dementia is through ideas around socially extended mentation: the idea that our minds extend beyond our bodies to objects and even to other people (Nelson 2010; Lyreskog 2021).
6. Kontos makes the assumption that these performances had no conscious intention behind them and this may be very difficult to concretely prove. The language of praise and blame may feel unfamiliar or even inappropriate in the context of dementia. However, moral responsibility is traditionally spoken about in these terms within philosophy and this offers a helpful way of understanding the way in which we assign actions and responsibility to others (Talbert 2019).
7. This presentation articulates some of their work which will form an upcoming book "*Altering the Fault Lines: How Neurodiversity Shapes Moral Responsibility*" (Gorman 2021).
8. Pickard has also developed an online e-learning module which aims to educate and inform people working with people with personality disorders or who are affected by these issues about the concept of responsibility without blame (Pickard 2021).
9. The thinking around 'impaired agency and the loss of experiential access' is particularly pertinent. Slaby *et al* discuss how the impairment of agency in depression can cause someone to feel incapable of doing things, that life becomes 'inaccessible' and that they feel like a 'burden' to others (44–45). These descriptions may resonate with some experiences of dementia. For example, in a survey in 2012, the Alzheimer's society found that 48% of people with dementia surveyed reported that they felt like a burden to their family (Lakey et al. 2012).

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