
DANIELLE PETHERBRIDGE
University College Dublin
danielle.petherbridge@ucd.ie

SELF, PERSONHOOD AND SELF-AWARENESS: A PHENOMENOLOGICAL ANALYSIS OF DEMENTIA

abstract

This paper takes a phenomenological approach to understanding self and personhood in dementia. The paper challenges the view that subjects with dementia can simply be understood in terms of diminished cognitive capacities or that they have lost all vestiges of self and personhood or the capacity for meaningful interaction. Instead, drawing on phenomenology, an alternative view is offered that can more adequately account for self and personhood, as well as self-awareness and self-experience in dementia. The view offered here is of a body-orientated and relational view of personhood and selfhood. It not only assumes that cognition is always already embodied but significantly that embodiment and embodied memory are central to personhood. It also highlights the ways in which persons are constituted and affirmed through relation with others and considers the way in which surrounding worlds or care environments might be more or less enabling in contexts of dementia and aging by attending to personhood in care.

keywords

self, personhood, self-awareness, dementia, phenomenology, Merleau-Ponty, Husserl

1. Introduction There are several common assumptions that dominate the general understanding of dementia, which pivot around the loss of self and personhood. Commonly held views about dementia include assumptions about the loss of memory, an inability for meaningful interaction and loss of linguistic communication, a turning inwards, disconnection from the world, and most notably, a complete loss of self and personhood. The latter is particularly vexing for the family and loved ones of those with dementia, but is especially stigmatizing for persons with dementia. A further consequence of the assumption about loss of self or personhood is the impact it has on the vulnerability of aging with dementia but particularly on modes of care.¹ The impact on care is particularly noteworthy since the pioneering move to person-centred care in dementia studies facilitated by those such as Thomas Kitwood (1997b). However, there is often a disconnect between the claim to attend to the ‘person’ in person-centred care and (mis)understandings about what the ‘person’ in person-centred care actually refers to both philosophically and practically. Such views are evident in philosophical assumptions about the connection between self or personhood and dementia. For example, according to Singer’s and McMahan’s respective criteria for personhood, people with severe dementia would no longer be deemed persons as such, but would be considered ‘quasi-persons’ or ‘non-persons’ because they fall below the threshold required for personhood (McMahan, 2002; Singer, 2021; Fuchs, 2020). Likewise, certain predominant philosophical theories of the self that are based on criteria of selfhood restricted to memory, language and narrative, are proven inadequate when so-called ‘pathological’ cases such as dementia are taken as a starting point.²

In this paper, I examine problems associated with conventional approaches to self and personhood in the context of dementia, especially those accounts based on narrowly conceived views about narrative, cognitive and linguistic capacities.³ I seek to challenge conventional accounts of self and personhood that offer rigid views of basic and higher levels of self, including some theories of minimal self and narrative self. Against these approaches I develop an alternative phenomenological approach that considers basic and higher levels of self and personhood, including self- and personal- identity as well as the capacity for self-

1 The issues discussed here also have ethical and ‘juridical’ ramifications but there is not the scope to discuss them in detail in this paper. For work related to some of the ideas explored in this paper, also see Petherbridge (2019).

2 In this sense, a consideration of persons with dementia also provides insights for a more generalizable understanding of self and personhood.

3 I specifically focus on Alzheimer’s disease when discussing dementia in this paper.

awareness. The paper also highlights the ways in which persons are fostered through relation with others and concludes by considering the ramifications of an appropriate account of self and personhood in the context of aged care and care settings.

In order to consider the problems associated with many conventional understandings of self and personhood in dementia, it is necessary to examine some of the most prevalent philosophical accounts. In many theories, to be a self or person in the full sense of these terms, is defined by functions such as rationality, memory, linguistic skills and cognition. There are different views about what constitutes the self, and different aspects are said to comprise what a self is. There are also distinctions made between concepts of 'self' and 'person', or self-identity and personal-identity (see Čapek & Loidolt, 2021; Drummond, 2021).

In certain accounts, the self or personal-identity, is defined in terms of persistence across time. John Locke (1975), for example, whose concept of personal-identity has largely set the terms of the debate, ascribes to a diachronic account of personal-identity, which defines it in relation to its persistence across time in contrast to a synchronic focus on personal identity, which privileges "what makes for personal identity at a time" (Lowe, 2013, 100-101). According to Locke, a person is defined as a "thinking intelligent Being, that has reason and reflection, and can consider it self as it self, the same thinking thing in different times and places; which it does only by that consciousness, which is inseparable from thinking ... and essential to it" (Locke, 1975, 2.27.9; Lowe, 2013, p. 102). The defining features of personhood for Locke are then rationality, consciousness and notably self-consciousness. The notion of self-consciousness is therefore central to the understanding of what it is to be a person, and moreover, for Locke personhood obtains only so far as "this consciousness can be extended backwards to any past Action or Thought, so far reaches the Identity of that Person" (Locke, 1975, 1.27.9; Lowe 2013, p. 103). In this sense, Locke is dedicated to a psychological view of personal-identity that "consists in same consciousness" over time (Boeker, 2021). Essentially, Locke seems to maintain that "I am identical with myself of a week, or of ten years ago, by virtue of the fact that I still remember thoughts I had and actions I performed at those times" (Lowe, 2013, p. 103). Locke emphasises the connection between memory and self-consciousness, or conscious remembering (Fuchs, 2020, p. 666). One's personal-identity persists over time, then, only as long as one's memory "remains intact" and I must be able to "recall my previous states and accredit them to myself" (Fuchs, 2020, p. 666).⁴ Personal-identity is therefore determined by self-consciousness over time in a manner that assumes a certain account of memory (what now might be termed declarative or explicit memory) and the ability to connect one's identity across thoughts and actions.

Significant, for our purposes here, is that one of the assumptions central to Locke's account is that "no particular bodily form is crucial to personhood" (Lowe, 2013, p. 103). Famously, Locke's ruminations lead him to conclude that a person is not determined by nor identified with a particular body (even though some bodily form is necessary), and that in fact a person could continue to exist in principle despite assuming a different body (Lowe, 2013, pp. 103-4). In other words, he accepts the premise that "a person's consciousness may be transferred from one body to another, without loss of identity", as exemplified for him by the thought experiment of the body swap between prince and cobbler (Lowe, 2013, p. 116). As will be discussed below, this overlooks many of the insights of phenomenology in relation

2. Re-examining Notions of Self and Personhood in the Context of Dementia

⁴ As Fuchs suggests, the consequence of this claim is that we also cannot strictly ascribe to ourselves states of sleep or infancy because these are not states we can strictly remember and this would also result in a discontinuity (Fuchs, 2020, p. 666).

to the intrinsic interrelation between mind and body, but also the importance of embodied habit and memory, which are particularly important for an understanding of dementia. As Fuchs suggests, Locke's approach not only represents a dualistic and rationalistic account of the person but because he makes no distinction between "reflexive and pre-reflective self-experience", he overlooks the manner in which "the lived body conveys a continuity of selfhood" (Fuchs, 2020, p. 667).

Moreover, Locke's theory seems to suggest that to be a person, one also requires "a 'unified' consciousness, in the sense that one is 'jointly' conscious or aware of all the things of which they are currently conscious" (Lowe, 2013, p. 107). Locke's view then relies on memory, specifically first-person memory such that I remember experiences in a first-person (internal) sense, and not a third-person one; they are remembered as experiences that are undergone by *me* (Lowe, 2013, p. 108). As Lowe argues, Locke seems to be "strongly committed to the view that if you cannot currently recollect the past thoughts and deeds of some person, then you simply are not the same person as the person who had and did them" (Lowe, 2013, p. 112). For Locke then ultimately, persons are defined or "constituted by streams of conscious thoughts and feelings suitably interconnected by memory" (Lowe, 2013, p. 117).

Locke's account of personal identity, bound as it is to a narrow account of explicit memory and temporality, as well as consciousness and rationality at the expense of embodiment, clearly poses problems for considering whether individuals with dementia qualify as persons. However, Locke's view, and those theories that derive elements from it, are not the only predominant views of self and personal identity that potentially cause problems for understanding and categorizing individuals with dementia. Certain aspects of Locke's account have been developed into a range of other predominant theories of self, most notably, accounts of narrative self.

3. The Narrative Self

The notion of the self as defined through language or, more specifically, through narrative or narrative construction, including self-interpretation and reflexivity, has become one of the most prominent ways of understanding the self in contemporary philosophy. Charles Taylor, Alasdair MacIntyre, Hannah Arendt and Paul Ricoeur, in different ways, all stress the normative and ethical, temporal, communal, interpretational, and linguistic nature of narrative self. In basic terms, proponents of the narrative approach suggest that "the self is the product of a narratively structured life" (Zahavi, 2005, p. 107). In this sense, to understand who one is means being able "to tell the story of a life" (Ricoeur, 1988, p. 246) and to have an awareness "of oneself from the first-person perspective" (Zahavi, 2005, p. 107). According to Ricoeur, "without recourse to narration, the problem of personal identity would be ... condemned to an antinomy without solution" (Ricoeur, 1988, p. 246). In this respect, identity is dependent on one's ability and access to the narrative function. In a similar fashion and echoing Locke's diachronic account, MacIntyre, not only suggests that the self is narratively constructed but that it "resides in the unity of a narrative which links birth to life to death as narrative beginning to middle to end" (MacIntyre, 1985, p. 205). As Marya Schechtman, a strong proponent of the narrative view of self puts it, "We constitute ourselves as persons ... by developing and operating with a (mostly implicit) autobiographical narrative which acts as the lens through which we experience the world" (Schechtman, 2014, p. 100), and "that persons are self creating" because they are "narrative in form" (Schechtman, 1996, p. 93).

The narrative view of self potentially poses difficulties when applied to persons with dementia. For example, in adopting a strong narrative approach to self, Jerome Bruner, argues that dynarrativia as encountered in Alzheimer's disease "is deadly for selfhood and that there would be nothing like selfhood if we lacked narrative capacities" (Bruner, 2002, p. 86, p. 119; Gallagher & Zahavi, 2008). Bruner, who advances a theory of the self as a narrative

construction, argues that in fact “we *become* the autobiographical narratives by which we ‘tell about’ our lives”. This includes social and cultural shaping such that we also “become variants of” particular social and cultural forms (Bruner, 1987, p. 15). Bruner’s constructivist thesis is so strong that he argues that over time, “the culturally shaped cognitive and linguistic processes that guide the self-telling of life narratives achieve the power to structure perceptual experience, to organize memory” and to constitute the ‘events’ of one’s life (Bruner, 1987, p. 15). Bruner in fact argues that life narratives become habitual and therefore not only structure experience but also lay “down routes into memory” that both interpret and constitute the past but also project into the future (Bruner, 1987, p. 31).

Clearly this view of the narrative self or self as a narrative construction poses potential challenges for arguing that individuals with dementia retain personhood. This is particularly the case if the emphasis is placed on language, higher level reflectivity, explicit or declarative memory and temporality as narratively reconstructed, leading to the view that the self is only maintained if narratively constituted. Although in some narrative accounts of self, the stories we tell about our lives are open-ended and dynamic, rather than static, allowing for a notion of self as evolving and changing over a lifetime, such theories undervalue the more phenomenological, embodied and habitual aspects of self, that are crucial for understanding self and personhood generally, and this has specific consequences in the case of dementia.

A third now strongly influential and persuasive account of the self, which has developed out of some phenomenological approaches is associated with the idea of the minimal experiential self.⁵ The minimal self is that which is defined in relation to all the experiences it undergoes. That is, all experiences have the same structural feature in that they are ‘mine’. For example, only *I* experience the pain when I step on a piece of glass in bare feet. In this account, the self is understood in terms of what Husserl referred to as the ‘pure ego’ or what might be conceived as a ‘core self’, or merely the formal self of experience. As Husserl puts it, the self “in its original mode, is *merely* his own, which therefore can be *given originally* to no other subject.” Such a self “has appearances that are exclusively his own, and each one has lived experiences which are exclusively his own. Only he experiences these in their very flesh, utterly originally” (Husserl, 1989, §51, p. 208).

Gallagher and Zahavi (2008; 2021) adopt a version of this kind of explanation based on Husserl’s insights with their reference to the ‘minimal self’. On this account, the minimal self is understood as a kind of empty and formal category of individuation, referring to the ‘mine-ness’ of all my experiences. As Zahavi puts it, “the most basic form of selfhood is the one constituted by the very manifestation of experience.” The self is not therefore understood as standing above or as separate from the stream of consciousness or its experiences “but is rather a feature or function of this givenness” (Zahavi, 2005). This notion of self, then, although constantly accommodating changing experiences throughout a lifetime, importantly has a structure that remains stable across time.

This basic, core or minimal self, forms somewhat of a foundational level, and beyond this level other ‘higher’ layers of self are built, those associated with memory, language and sociality (often associated with what is termed a narrative self). However, these higher levels presuppose a minimal experiential self at the core. In this sense, the self is never found in isolation, in that it is also shaped by its embeddedness in the world, particularly a social and cultural world, and is shaped by passively and actively acquired habits and inclinations. However, it is notable that the notion of minimal self “does not refer to personal character,

4. The Minimal Self and the Formal Structure of Experience

5 Claire Petitmengin suggests all of the major figures in phenomenology assume some kind of ‘minimal’ or ‘core’ self.

or at least a detailed personal history, or reflective evaluations, or social and cultural aspects associated with narrative self.” The notion of minimal self, then, seems to refer to no more than formal individuality, whereas the notion of narrative self is needed to describe the substantial individuality of a human person understood both individually and collectively (Gallagher & Zahavi, 2021, p. 309). As Zahavi has noted, in some literature there is a danger that in the context of some pathologies such as dementia the minimal form of self might be “encountered in its purity” (Zahavi, 2011, 332-33; 2005, p. 130). One of the consequences of this claim (which is perhaps an unintended conclusion), is that individuals who suffer from Alzheimer’s disease, are in fact devoid of personhood and therefore effectively reduced only to a minimal form of self, with no overarching awareness of their own self-experience. It is unclear whether or not, according to this account, individuals with dementia are considered to be devoid of personhood (in the Husserlian sense) and reduced only to a basic or minimal self.

Jaakko Belt has queried whether an emphasis on the formal nature of minimal self adequately addresses the embodied nature of the minimal self (Belt, 2019, p. 312). For example, Belt raises the question of whether more consideration should be given to “developmental changes in our bodily capacities [that] transform or extend the minimal self?” (Belt, 2019, p. 312), particularly in relation to its experiencing. As will be discussed below, if we take Belt’s suggestion that bodily capacities and habituality are inadequately accounted for by a theory of minimal self, we need to look elsewhere to develop a more complex picture. To do so, we also need to focus on the notion of ‘personhood’ or ‘personal-identity’ in the Husserlian sense, as a means of emphasizing embodied habits, character traits, motivations and patterns of expressive behaviour. As will be discussed in the following section, if we take Husserl’s later genetic account of personhood seriously, it is very difficult to claim that individuals with dementia are devoid of either self or personhood, and the two should be taken together as comprising a more encompassing whole.

5. Embodied Self and Personhood

In contrast to the above notions of self- and personal-identity, such as those proposed by Locke or proponents of the narrative self, in the phenomenological account reconstructed here for heuristic purposes, the notion of core or minimal self is distinguished from the notion of personhood. In this sense, personhood in Husserl’s work is much richer and more diverse than the notion of ‘narrative self’ and encompasses a greater array of fundamental features that are not well captured by the notion of narrative self.

In Husserl’s work, it is possible to suggest that a notion of self or self-identity can be distinguished from the notion of ‘person’ or personal-identity. Notably, in *Ideas II*, Husserl provides a rich account of “personhood” or “personal identity”, which includes a person’s embeddedness in intersubjective relations, and a cultural and social world. In contrast to the notion of “pure ego,” or what might be termed the ‘core’ or ‘minimal’ self, the concept of “personhood” refers not only to the concrete individual as a person with unique abilities, dispositions, habits, interests, character traits, and convictions, but also to the way in which personal identity is shaped through interactions with others and the world. As Husserl writes, “The development of a person is determined by the influence of others ... This influence determines personal development ... [and] character. Others’ thoughts penetrate my soul; they can exercise various influences ... the demands of morality, of custom, of tradition ... ‘one’ judges this way, ‘one’ has to hold his fork like this, and so on” (Husserl, 1989, § 60, pp. 281-82). Here Husserl points not only to habits related to convictions and values, but also to embodied habits such as the food one enjoys and the utensils one uses to eat as being socially and culturally shaped.

In Husserl’s genetic account explored in *Ideas II*, the notion of habit is central to his concept of personhood, and habits are generally conceived in a positive manner in the sense

that they enable normality and provide the subject with a stable, familiar, and coherent way of experiencing the world (Wehrle, 2016, p. 57). In this sense, habitual behaviour forms the basis for normality and provides “a necessary criterion for every possible experience” (Wehrle, 2018, p. 51). Habitual life largely unfolds at a pre-reflexive level that often remains taken-for-granted at the level of everyday life. Certain dispositions, emotional and affective states, as well as acts of willing become sedimented and form an enduring habitus that shape the “abiding style of the ego” (Moran, 2011, p. 29). These habitual layers are formed at an embodied level and develop an individual’s bodily ‘habitus’ or particular bearing in the world. Gestures, mannerisms and facial expressions ‘inhabit’ our body and take on particular inflections, such as a particular way of smiling. The embodied subject acquires habits and patterns that are incorporated into a particular habitual style, such as particular facial expressions or the way one talks. Some of these capacities can be enhanced, developed or strengthened, for example, through learning to play a musical instrument or training oneself to comport oneself in a particular manner, but all such capacities shape a particular form of individual experiencing. Certain tastes and preferences might also gradually become more prominent or cultivated, but they nonetheless are maintained through a life, even if they recede and remain only as sedimented traces (Moran, 2011, p. 32).

For example, by learning to play the piano, I develop a set of skills and a bodily-practical relation to the world, that once learned is a set of embodied habits and actions that I readily employ on a daily basis without having to reflect upon what I am doing. As Merleau-Ponty has observed, in relation to the example of an organist, even when having to change instruments or play in a new venue with an unfamiliar organ, it does not take long for a skilled musician to gear into the keys and pedals of the new organ (Merleau-Ponty, 2012). We can speak of habituality not only in terms of the individual but also in regard to the social and cultural spheres, or what might be referred to as social habitus (Husserl, 1989, 281; Bourdieu, 1990). In this sense, embodied subjects not only express a particular embodied style and develop a particular bodily relation to the world, but can also be understood as the “bearers of meaning for all interpretations” in a social and communal context (Husserl, 2006, pp. 168-9; Moran, 2014, p. 41). Habit, then, provides a sense of normalcy or optimality, and a large part of the familiarity of individual experience is due to the social and cultural context in which one is embedded.

There is also a temporality and historicity to habitual life. As Edward Casey suggests, habit extends into the past as much as it is orientated towards the future (Casey, 1984, p. 284; Merleau-Ponty, 1962, p. 144). In this respect, in habitual life, “our experience is always guided and shaped by expectation, by a directedness towards the future that nevertheless reflects a determinate past” (Howell, 2015, p. 324). We can understand the relation between habituality and temporality in terms of the notion of sedimentation, which indicates the temporal relations between acts. In relation to the individual, the notion of habit can be understood in terms of the relation between earlier and later acts or associations, which may be “‘sediments’ of earlier acts” or habits taken-up or learnt over time (Husserl, 1989, pp. 233-234). These notions of habit and sedimentation are central to understanding personhood in dementia.

Husserl thematizes this in terms of the relation between passive and active levels of agency or ego-consciousness, or what he refers to as “activity in passivity” (Casey, 1984, p. 285). In his genetic account, Husserl makes a distinction between passivity and activity, or active and passive synthesis (Husserl, 1973, 2001). The notion of passivity refers to a kind of primordial constitution at the passive level of experience (Steinbock, 2004, p. 23). It denotes pre-reflexive and pre-linguistic forms of experience at the passive level, which form the basis for more active levels of experience and make them possible. In this sense, passive experience occurs in the background of our intentional awareness and can be understood in terms of a ‘broad lived

experiential field' (van Mazijk, 2016, p. 276). In terms of an analysis of habit, we can distinguish between habits 'taken-up' at both passive and active levels. For example, we might make an active decision about attending piano lessons in a neighbouring suburb every week, but on a passive level, we might walk to the lesson without reflecting on the manner in which we walk, as walking is most often 'passively' taken-up or learned in infancy. The significance of the phenomenological account in relation to both passive and active levels, is that it helps to illuminate an analysis of embodied habit in relation to persons with dementia.

The element of embodied habit is also linked to embodied memory. Even when persons with dementia seemingly become non-verbal, they still retain embodied habits and a capacity for communication. As Fuchs (2020) argues, although there may be a loss of higher level forms of reflexivity, autobiographical and narrative memory, "vast ranges of implicit memory remain unimpaired even in the late stages of the illness" and habits and abilities are retained in forms of *body memory*. Fuchs also highlights the aspect of social habituality and what he terms intercorporeal and incorporative body memory. According to this view, habits and embodied patterns are taken up through social interaction, just as attitudes and roles have often been taken over from others and incorporated as an embodied personality structure (Fuchs, 2020, p. 670). In this vein, even when cognitive abilities diminish or explicit memory is challenged, subjects often still maintain a particular bodily style or express themselves in an embodied manner that indicates a constancy of selfhood and personhood. A phenomenological examination of dementia based on these attributes demonstrates that persons with dementia do have personhood.

This is demonstrated in a well-known filmed interaction between dementia therapist, Naomi Feil, and eighty-seven-year old Gladys Wilson, who was diagnosed with Alzheimer's disease and considered to be non-verbal.⁶ By playing music that was especially meaningful to Wilson earlier in her life, therapist Feil fosters Wilson's embodied musical habits and memories by rhythmically tapping the arm of the chair she is sitting in with her hand while singing along. In response, Wilson tries to match this movement and audibly whispers the lines and sings along with Feil. As the interaction progresses, Wilson speaks with Feil and responds to her questions, indicating several levels of communication both embodied and verbal between them. These modes of interaction can be understood as forms of intense joint-activity or dynamic-engagement that foster embodied memories and habits through embodied and sensory forms of communication. Significantly, dynamic embodied forms of joint-activity also foster selfhood and personhood, particularly through embodied habits built-up over a lifetime.⁷

6. Recognition, Relationality and Dynamic-Engagement

As Kristin Zeiler (2014) demonstrates, even individuals who seem to have lost cognitive capacities and who cannot "remember their name or past events still have a bodily know-how with regard to how to engage with others" (Zeiler, 2014, p. 140; p. 134). Moreover, as Zeiler suggests, although dementia sufferers may not have verbal skills or be able to remember and recount past events linguistically, they still comport themselves with a particular bodily style, using particular gestures or bodily expressions that persist over time. Zeiler argues that individuals therefore retain their individuality through their bodily style of being and that

⁶ Zeiler's and Käll's analyses are based on a film entitled 'Gladys Wilson and Naomi Feil'. *There is a Bridge*. Memory Bridge. <http://www.memorybridge.org/documentary.php>. Feil practices a form of what she terms 'validation therapy' which was developed as a way of relating to dementia sufferers with affirmation and empathy. In this context, validation includes forms of affirmation, respect and dignity that are communicated to the other through various mediums, as well as creating a space in which dementia sufferers can express themselves.

⁷ The themes discussed here are also partially explored but in an alternative manner in Petherbridge (2019).

a person should be taken to be “a unified being” not only if she can express herself through speech but also through gesture and bodily forms, or interactions with others (Zeiler, 2014, p. 135).

However, Zeiler makes the important claim that we should not consider a person to be a being who qualifies as such based *only* on certain bodily capacities. She suggests that extending beyond the cognitive account of personhood based on bodily capacities is a first crucial step. In a second step, she emphasizes that a body-orientated account of personhood should be conceived in relational terms rather than monadic ones. In this respect, she takes-up an insight from dyadic and mixed-cognition accounts of personhood, which argue that *recognition* of someone as a person by others is also a condition for personhood. Her main point is to argue for both a relational conception of personhood but also to shift the emphasis away from accounts based solely on cognitive capacities to embodied ones. In this light, she argues for an account of personhood that is based on embodied capacities and intercorporeality as well as forms of embodied acknowledgement.

As Zeiler highlights, “joint activity makes it possible for the participants in an activity to qualify as distinct yet thoroughly relational persons *because* it allows both of them to express themselves as unique-subjects-acting-together in a joint fashion” (Zeiler, 2014, pp. 138-9). This conception of joint activity and intercorporeal capacities also allows for a conception of personhood that is maintained across time even when cognitive abilities are diminished (Käll, 2017, pp. 138-139). Such forms of ‘dynamic intercorporeal engagement’ may also include ‘micro-embodied’ interactions such as intense face-to-face engagement at meal times or in basic daily activities. For example, Lars-Christer Hydén (2014), has undertaken empirical research to examine the importance of face-to-face joint activities. This is particularly important in the context of care-settings, where maintaining direct eye contact and touch, as well as speaking to persons whilst feeding or interacting is crucial for fostering both self and personhood through relationality. Hydén (2014) also describes joint-story-telling activities in this manner as scaffolded collaborative activities, in which family members address communicative problems in the context of Alzheimer’s disease by taking over some of the functions the person has lost. Thus, some functions are externalised, and storytellers assume more responsibility for pursuing the story and organizing the interaction and, through scaffolding the collaboration, both participants may be able to jointly tell a story. Of course, some of the pitfalls of relying on narrative are evident in externalized forms of narrative construction, as not only is there a risk that the person will become a nonparticipant and fall out of the conversation, but at a more fundamental level, the emphasis is placed on a second-person perspective rather than first-person experience as highlighted in phenomenology.

Pia Kontos draws on Merleau-Ponty’s work to argue for an embodied account of selfhood that highlights both the pre-reflective body and the subject’s embodied movements (visual, tactile and motor aspects) as well as interactions with the world, including social and cultural forms of habituality (Kontos & Martin, 2013, p. 291). She particularly underscores the importance of gestural communication, including facial expressions, intonation of the voice and body movements to better understand not only communication but also selfhood in dementia. Kontos emphasizes Merleau-Ponty’s notion of basic intentionality as “providing the corporeal foundation of selfhood evidenced by the existential expressiveness of the body” in such a way that the body is pre-reflectively directed towards the world (Kontos 2011, p. 331; Merleau-Ponty, 1964). She makes clear that her conception of selfhood is premised on “the primacy of perception as providing the foundation for selfhood, and therefore argue[s] that selfhood, at the most fundamental level, must be understood as inhering in the existential capacity of the body to engage with the world” (Kontos 2011, p. 331).

Although I agree with this important claim about selfhood, I argue that we need to develop an account that includes various layers of self and personhood to provide a more robust and complex picture. This also enables a means to refute the claim that people with dementia are somehow ‘reduced’ only to a minimal version of self in its purity but are devoid of certain aspects associated with personhood or personal-identity as found in the Husserlian account. An alternative view of self and personhood is required to be able to extend to ‘pathological’ cases such as dementia and thereby not only enrich the philosophical understanding of self and personhood more generally but also to understand the subjectivity of dementia. To complete this picture of self and personhood in dementia it is, however, also necessary to move to a final discussion of self-awareness and self-experience in dementia.

**7. Self-awareness
and
Self-experience
in Dementia**

As Claire Petitmengin suggests the relation between experience, self-awareness and selfhood is a fundamental one. This also raises a question about whether every episode of experience necessarily involves “a *subject* of experience” and whether self-awareness must be associated with “awareness of a self” (Petitmengin, 2005, p. 270). As discussed above, different theories of the self have ramifications in terms of the way in which people with dementia are both constructed, categorised and treated. As Michela Summa suggests, however, even among quite divergent positions, there seems to be a general agreement that “there is something like a self and self-experience” or self-awareness (Summa, 2014, p. 478).

Following Husserl, as Zahavi suggests, it is possible to suggest there are “two types of experiential self-givenness, a reflective and a pre-reflective” (Zahavi, 2005, p. 41). We might identify the notion of minimal self with the most basic, “pre-reflective form of awareness” that is associated with a sense of mineness or ownness in all experience. In contrast, the notion of narrative self in its myriad permutations, tends to designate a “higher and richer form of self-awareness, which presupposes the possibility of recognizing oneself as actor within a life history.” However, Summa raises an important point by questioning whether in fact we should ever assume that “*there is any experience at all that is limited to the minimal self*” (Summa, 2014, p. 478). In particular, as we have seen, important questions can be asked in regard to the relation between the minimal self, its bodily relatedness and habit, as well as bodily awareness and temporality. Also important is the situatedness of the self in a web of relations and intersubjective context or lifeworld. However, the discussion of different ‘layers’ in this context should be understood in a heuristic sense as a means of examining how, for example, dementia impacts upon a particular layer or component of the self. As Summa suggests, persons with dementia appear to be more affected by a particular form of disorientation related to “disturbances of the higher faculty of reflective self-distancing.” Thus, persons with dementia find it difficult to “de-centre themselves” and to separate living through an experience rather than being conscious of reflecting about an experience or situation (Summa, 2014, p. 479). Accordingly, even though persons with dementia have a “basic sense of self in relation with others and with a particular situation (here and now) ... they lack ... a reflective knowledge of what they immediately live through and how their present experience connects with their life history” in a more abstract sense. There may be a lack of explicit self-knowledge due to the inability to take a reflective distance from themselves, the lived situation and relations with others. For this reason, persons with dementia feel at home or are embedded in a particular environment or social context with which they feel familiar, and this often includes certain forms of scaffolding relationships (Summa, 2014, p. 482).

As Summa argues, it is evident that *pre-reflexive self-awareness* is mostly preserved in dementia. It seems clear from empirical studies, “that the experiential dimension of the self as situated” remains central in dementia. In this sense, “the centrality of the ego as reference pole and the first-person givenness are essential moments” that are retained, and persons

with dementia still understand themselves “as the ‘centre’ of experience” (Summa, 2014, p. 483). This is supported in research by Stanley Klein (2012), who describes the examination of an elderly woman in the late stages of Alzheimer’s dementia. As Klein explains, the woman scored very poorly on standard tests for diagnosing cognitive decline in dementia (the Mini Mental State Exam), considerably lower than the norm for her age group. However, upon interviewing her, Klein argues that it was clear the woman “maintained a sense of herself as a conscious entity.” This was the case, even though she also felt confused, fearful and worried, particularly by lapses in her mental life. Although she “had difficulty identifying things in her environment”, Klein claims that “her subjective sense of her self as a living, experiencing entity, was intact: Her subjective point of view ... did not collapse as a result of her cognitive deficits. While she lost access to a variety of self-relevant sources of knowledge, this was not accompanied by a phenomenological dissolution” (Klein, 2012, p. 482).

Klein’s observations are significant and appear to support Summa’s arguments about self-awareness in dementia. Moreover, as Summa suggests, persons with dementia “are pre-reflexively aware of the mineness of their own body.” Most notably, this self-reference is evident not only through language but also movements and gestures, and therefore primarily through the lived body, and such pre-reflexive awareness is particularly prevalent in intersubjective contexts and forms of relation with others (Summa, 2014, p. 483). As the work of Kontos (2004) has also demonstrated, “Even though the faculty of explicit recollection is damaged, dementia patients still seem to be familiar with certain habitual patterns of experience ...”; they recognize people, sounds, places and situations, even if unable to express themselves linguistically. “Such a pre-reflective experience of familiarity is made possible by the preservation of implicit body memory in its different forms” (Summa, 2014, p. 483; Kontos, 2004). As Summa importantly suggests, it is therefore possible to conclude “that implicit body memory also belongs to the sphere of basic, pre-reflective self-experience” (Summa, 2014, pp. 483-484).

These insights are significant, as they suggest that the assumption that individuals with dementia lose self or personhood should be rejected. Importantly, as we have seen, individuals with dementia not only retain a core or minimal self but also personhood understood in terms of both the social and cultural aspects of personhood, and the forms of embodied habit that build up over time that are fostered within embedded intersubjective contexts. It also demonstrates a third related point that is often underestimated in persons with dementia. In addition to revealing that persons with dementia retain or continue to express both self and personhood, they also retain some form of self-awareness or self-recognition that unites pre-reflective self-experience. Such a self-awareness is retained as we have seen even into the later stages of dementia, but additionally, some persons in the earlier stages of dementia retain “higher order competences” that are indicative of a “higher degree of self-consciousness” (Summa, 2014). For example, as mentioned above, some persons with earlier stages of dementia are quite aware of the illness and although they are unable to take an abstract reflexive stance towards it, they certainly exhibit an awareness, for example, through displaying various emotions or forms of pride, shame, frustration or anger at their situation and an awareness of changes that have occurred to them. As Summa suggests this kind of expressivity, for example through emotions such as sorrow and shame, clearly seems to “go beyond the most basic layer of the minimal self” (Summa, 2014, p. 484). It is therefore also important to recognize that the different layers of self-experience and self and personhood should not be understood as clear-cut distinctions “but grey zones” that are part of a more encompassing whole (Summa 2014, p. 478; p. 484). Taking this complexity into account, in the following section, I conclude by briefly considering why a more complex account of self and personhood in dementia is important in the context of care.

8. Personhood and Person-Centred Care: Intersubjectivity and Intercorporeality in Dementia

Given the turn to person-centred care in certain health-care settings, recent research has demonstrated that healthcare providers' beliefs about personhood and dementia influence how care for such persons is conducted (Hunter et al., 2013). However, there tends to be little understanding let alone consensus about what is meant by the term 'personhood', despite the centrality of the notion for conceptualising care. In this sense, while person-centred approaches to care have become a principle in some national dementia care strategies, they do "not fully bear out the principle of personhood at its core" (Hennelly & O'Shea, 2019, p. 1821).⁸ A reassessment of the notions of self and personhood in dementia, not only has philosophical ramifications but is central to defining what person-centred care refers to and what it should aspire to be.

As Kontos and Naglie well highlight, the dominant paradigm of dementia and dementia care tends in fact to *lead to a 'loss of self and personhood'* through widespread practices of "infantilization, intimidation, stigmatization and objectification" (Kontos & Naglie, 2007, p. 551). As Kontos and Grigorovich argue, "the care of persons living with dementia is restricted to attending to basic bodily needs and the management of 'challenging behaviours' using high levels of psychotropic medications" (Kontos & Grigorovich, 2018, 39). As a consequence, what is overlooked in forms of care, is that the "actions of persons living with dementia are not always symptomatic of dementia itself", but as Kitwood also argues, are often a product of a lack of "purposeful and meaningful" interaction and communication (Kontos & Grigorovich, 2018, p. 39). Kitwood has argued that infantilizing and stigmatising treatment of persons with dementia can lead to a form of "'malignant social psychology' that damages self-esteem and personhood" (Kitwood, 1990; 1998; Kontos & Naglie, 2007, p. 551). This is evident in the ways persons with dementia are tormented by their disabilities or find certain care practices damaging for a sense of pride or dignity, suffering humiliation and shame as a consequence. As discussed above, these emotions and feelings are not only representative of deficient and problematic forms of care, they also point to the fact that persons with dementia *do indeed retain a sense of self-awareness at a basic level*, despite cognitive impairment and challenges to higher levels of reflectivity.

Kontos and Naglie (2007) suggest that part of the problem in many care settings is that there is a common assumption that persons with advanced dementia have lost all vestiges of self and personhood. This can sometimes lead to a misconception by carers that persons with dementia do not experience shame, embarrassment or humiliation. These views can negatively impact forms and quality of care such that "individuals with dementia ... are treated as objects rather than persons worthy of dignity and respect" (Kontos & Naglie, 2007, p. 551; Kitwood, 1997b). In this respect, as indicated in the discussion above, recognition of personhood despite cognitive impairment is vital for person-centred care and for ensuring that "the humanity" of care recipients is maintained (Kontos & Naglie, 2007, p. 557). Moreover, recognition of bodily expression is also important in terms of fostering personhood in dementia and embodied forms of interaction are a central modality for communication, especially for persons with diminished linguistic skills. In this manner, it is possible to enable habitual, social, cultural and embodied manifestations of personhood in dementia care (Kontos & Naglie, 2007, p. 565; p. 549).

The phenomenological analysis developed in this paper offers an alternative understanding of self and personhood in dementia, highlighting not only self-experience and self-awareness but also the importance of embodied habit and relationality in understanding personhood.

⁸ A brief part of this discussion of person-centred care was also presented with Natalia Burakowska in a paper at the *British Society for Phenomenology* conference in 2020.

Such an approach considers the ways in which persons with dementia are intersubjectively constituted and can express themselves through embodied modalities. This suggests a more complex approach to the relationality of dementia that emphasizes not merely linguistic but specifically corporeal dimensions.

It also means that an individualistic idea of personhood or one based solely on individual cognitive capacities and memory is one that should be contested. Rather, the account of the subject as demonstrated here is a relational one based on intersubjective and intercorporeal capacities, such that a person is understood in essential relations with others rather than in individualistic terms. The view offered here is a body-orientated and relational view of self and personhood. It not only assumes that cognition is always already embodied but significantly that embodiment is central to personhood, and highlights the ways in which selves or persons are constituted and affirmed through relation with others. None of these aspects alone is sufficient but taken together they offer a complex or thickly conceived account of self and personhood, one that continues and manifests in alternative ways throughout the lifecycle to provide a dynamic account of self and personhood in dementia.

REFERENCES

- Boeker, R. (2021). *Locke on Persons and Personal Identity*. Oxford: Oxford University Press;
- Bruner, J. (1987). Life as Narrative. *Social Research*, Spring, 54 (1), 11-32;
- Bourdieu, P. (1990). *The Logic of Practice*. Cambridge: Cambridge University Press;
- Čapek, J. & Loidolt, S. (2021). Phenomenological Approaches to Personal Identity. *Phenomenology and the Cognitive Sciences*, 20, 217-234;
- Drummond, J. J. (2021). Self-Identity and Personal Identity. *Phenomenology and the Cognitive Sciences*, 20, 235-247;
- Fuchs, T. (2020). Embodiment and Personal Identity in Dementia, *Medicine, Health Care, and Philosophy*, 23(4), 665-676;
- Gallagher, S. & Zahavi, D. (2021). *The Phenomenological Mind*, Oxon: Routledge;
- Hennelly, N. & O'Shea, E. (2019). Personhood, Dementia Policy and the Irish National Dementia Strategy, *Dementia*, 18(5), 1810-1825;
- Hunter, P., et al. (2013). The Personhood in Dementia Questionnaire (PDQ): Establishing an Association Between Beliefs about Personhood and Health Providers' Approaches to Person-centred Care'. *Journal of Aging Studies*, 2, 276-287;
- Husserl, E. (2006). *The Basic Problems of Phenomenology from the Lectures, Winter Semester, 1910-1911*. Translated by Ingo Farin and James G. Hart. Dordrecht: Springer;
- Husserl, E. (2001). *Analyses Concerning Passive and Active Synthesis: Lectures on Transcendental Logic*. Translated by A.J. Steinbock. Dordrecht, Boston & London: Kluwer Academic Publishers;
- Husserl, E. (1989). *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy, Second Book. Studies in the Phenomenology of Constitution*. Translated by R. Rojcewicz and A. Schuwer. Dordrecht: Kluwer Academic Publishers;
- Husserl, E. (1973). *Experience and Judgement*, translated by J. Churchill and K. Ameriks Evanston: Northwestern University Press;
- Käll, L. (2017). Intercorporeal Expression and the Subjectivity of Dementia. In *Body/Self/Other: The Phenomenology of Social Encounters* (Eds) L. Dolezal and D. Petherbridge, Albany: SUNY Press, 359-385;
- Kitwood, T. (1998). Toward a Theory of Dementia Care: Ethics and Interaction. *Journal of Clinical Ethics*, 9(1), 23-34;
- Kitwood, T. (1997a). The Experience of Dementia. *Aging & Mental Health*, 1(1), 13-22;
- Kitwood, T. (1997b). *Dementia Reconsidered: The Person Comes First*. New York: Open University Press;

- Kitwood, T. (1990). The Dialectics of Dementia with Particular Reference to Alzheimer's Disease. *Aging and Society*, 10, 177-196;
- Klein, S. (2012). The Self and Its Brain. *Social Cognition*, 30(4), 474-518;
- Kontos, P. & Grigorovich, A. (2018). Rethinking Musicality in Dementia as Embodied and Relational. *Journal of Aging Studies*, 45, 39-48;
- Kontos, P. and Martin, W. (2013). Embodiment and Dementia: Exploring Critical Narratives of Selfhood, Surveillance, and Dementia Care. *Dementia*, 12 (3), 288-302;
- Kontos, P. (2011). Rethinking Sociability in Long-term Care: An Embodied Dimension of Selfhood, *Dementia*, 11(3) 329-346;
- Kontos, P. & Naglie, G. (2007). Bridging Theory and Practice: Imagination, the Body and Person-Centred Dementia Care. *Dementia*, 6(4), 549-569;
- Kontos, P. (2004). Ethnographic Reflections on Selfhood, Embodiment and Alzheimer's Disease. *Aging and Society*, 24, 829-849;
- Locke, J. (1975). *Essay Concerning Human Understanding* (Ed) P.H. Nidditch. Oxford: Clarendon Press;
- Lowe, E. J. (2013). *Locke's Essay Concerning Human Understanding*. London: Routledge;
- MacIntyre, A.C. (1984). *After Virtue: A Study in Moral Theory*, 2nd edn. Notre Dame: University of Notre Dame Press;
- van Mazijk, C. (2016). Kant and Husserl on the Contents of Perception. *The Southern Journal of Philosophy* 54(2), 267-287;
- McMahon, J. (2002). *The Ethics of Killing: Problems at the Margins of Life*. Oxford: Oxford University Press.
- Merleau-Ponty, M. (1962). *Phenomenology of Perception*. Translated by C. Smith. London & New York: Routledge;
- Moran, D. (2014). 'The Ego as Substrate of Habitualities': Edmund Husserl's Phenomenology of the Habitual Self. *Phenomenology and Mind*, 6, 24-39;
- O'Connor, D. (2007). Personhood in Dementia Care: Developing a Research Agenda for Broadening the Vision. *Dementia*, 6(1): 121-142;
- Petherbridge, D. (2019). Beyond Empathy: Vulnerability, Relationality and Dementia. *International Journal of Philosophical Studies*, 27(2), 307-326.
- Petitmengin, C. (2011). Is the 'Core Self' a Construct? *Constructivist Foundations*, 6(2);
- Ricoeur, P. (1988). *Time and Narrative*, Vol. 3. Translated by K. Blamey & D. Pellauer. Chicago: University of Chicago Press;
- Schechtman, M. (1996). *The Constitution of Selves*. New York: Cornell University Press;
- Schechtman, M. (2014). *Staying Alive: Personal Identity, Practical Concerns, and the Unity of a Life*. Oxford: Oxford University Press;
- Singer, P. (2021 [1980]). *Practical Ethics*. Cambridge: Cambridge University Press.
- Summa, M. (2014). The Disorientated Self. Layers and Dynamics of Self-experience in Dementia and Schizophrenia. *Phenomenology and Cognitive Science*, 13: 477-496;
- Wehrle, M. (2015). 'Feelings as the Motor of Perception'? The Essential Role of Interest for Intentionality. *Husserl Studies* 31: 45-64;
- Wehrle, M. (2016). Normative Embodiment. The Role of the Body in Foucault's Genealogy. A Phenomenological Re-reading. *Journal of the British Society for Phenomenology* 47:1 56-71;
- Zahavi, D. (2005). *Subjectivity and Selfhood: Investigating the First-Person Perspective*. Cambridge, MA: MIT Press;
- Zahavi, D. (2014). *Self and Other: Exploring Subjectivity, Empathy, and Shame*. Oxford: Oxford University Press.