

DISRUPTED INTERCORPOREALITY AND EMBODIEDNESS IN DEMENTIA CARE DURING THE COVID-19 CRISIS

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During the COVID-19 pandemic, intersubjective experience of *being-in-the-world* has altered; *being-with* has turned, at least in part, into *being-apart*, *being-masked*, or *being-isolated*. The collateral effects of the severe acute respiratory syndrome coronavirus (SARS-CoV) on our lived experiences have confronted us with our fundamentally social and existentially shared nature, since being together can no longer be taken for granted. Sociability has been redefined in terms of “social distancing” and imposed physical distance, with this becoming the “new normal.”¹

In Western societies, health systems tend to be based on principles such as “economies of scale” or “curing the symptom instead of the cause.” Illnesses are considered foremost on a biomedical and individual level, rather than considering social and political context. Both COVID-19 and dementia challenge our social understanding of illness and embodiment with respect to solidarity and sociability. A more widespread understanding of dementia as a culturally and socially shaped illness is needed to better illuminate perceptions of, experiences of, and responses to people with dementia and dementia care.² As Dolezal and Petherbridge (2017) put it, social injustices and inequalities are not abstractions played out in the realm of law or politics; rather, they are matters that impinge on our embodied lives and our lived relations with others (2). In times of social isolation, interrupted and alienated bodily communication, the disruption of care, and questions of triage, this statement is truer than ever. By exploring the entanglement of lived experiences that frame the “new

¹ Sociability, understood as interaction through which solitariness becomes togetherness, has largely been explored without reference to bodily sources of agency. For an expanded discussion on sociability in dementia, including embodied selfhood as a source of interactive practices, see Kontos (2012). In a recent WHO report (2018), dementia is defined as a syndrome of cognitive impairment that affects memory, cognitive abilities, and behavior, and that significantly interferes with a person’s ability to perform daily activities. Alzheimer’s disease is the most common form of dementia, accounting for approximately 60-70% of cases.

² For phenomenological descriptions and empirical findings of dignified dementia care, see Kontos (2011; 2012; 2017), Odzakovic (2021), Leibing and Lawrence (2006), or Dzwiza-Ohlsen (2021).

normal” under social distancing policies, we can understand how intersubjective and intercorporeal relations are simultaneously constitutive of and constituted by subjects and forms of sociality. As much as social distance and mask-wearing offer physical protection against spreading the virus and thus have strong ethical justification, the very same kind of social and spatial distancing undermines certain requirements and demands of care, i.e., being touched and cared for by another person. This kind of distance affects human dignity in differential and arbitrary ways.³ With the risk of infection, disease, death, and resulting post-traumatic experiences, COVID-19 has affected our lives painfully, while dementia remains a major global health concern.⁴ Both of these widespread illnesses contradict and challenge our view of a stable and linear concepts of health, safety, and advanced medicine.

In this paper, I address the effects of social distancing from a critical phenomenological perspective—both with respect to our embodied lived experience and interpersonal dementia care. I also explore changes relating to COVID-19 in the broader structures and discursive practices that shape our perceptual and social frameworks, which have increased and intensified senses of isolation and disembodiment.

The paper is divided into four parts. The first focuses on the problem of marginalization and disembodiment, addressing the issue of social distancing in dementia care homes. The second addresses the social and embodied nature of the self. The third focuses on intercorporeal resonance and therapies which could alternatively address the intersubjective and multisensory dimensions of embodied being-in-the-world. The fourth reflects on our senses of self during illness in general and dementia in particular. In line with Carel’s (2012) *Phenomenology of Illness* and Kontos’ (2011; 2017) concept of an embodied and relational self, I propose overall a reading of illness not as a mere sense of loss or deficit but as a sense of embodied selfhood that corresponds to an existential feeling—even if this means feeling fragmented or partially disembodied.

My analysis resonates with a recent shift in dementia research from a focus on the individual’s loss of abilities to how individuals can use their remaining capabilities in joint activities. For instance, in her phenomenological analysis of joint musical activity in dementia care, Zeiler (2014) defends an intercorporeal understanding of personhood against the prevailing Western conception of a cognition-oriented being-in-the-world. This

³ A distinct clarification is needed as to whether protection and care may restrict the dignity of a given person. Addressing this issue in more detail, however, would go beyond the scope of this paper. We already find an ambiguous formulation in the German phrase “die Würde des Menschen ist unantastbar” (translated as “the dignity of the human being is inviolable”). *Unantastbar* means “not to be touched (upon)” in the sense that someone’s identity cannot be harmed or questioned, and this could be understood also in relation to the body. Ironically, this is precisely what has played out in the care context during COVID-19, in locked care homes where even close relatives were denied access and where necessary protective measures such as masks and gloves have prevented and complicated caring touch between individuals. In this context, one should not forget the extent to which care practitioners and relatives faced a serious ethical dilemma in interpreting how to best take care of people with dementia, since social distancing and embodied responses to existential needs were, at this point, options that were at odds with one another.

⁴ See Kontos (2012) and a report by the WHO (2018).

latter view refuses the importance of pre-reflective social awareness in constituting parts of the self with others and thus cannot appreciate the supportive potential of therapeutic atmospheres in care encounters. Joint musical activities not only evoke philosophical questions regarding bodily dimensions of social cognition but also enable people with dementia to engage meaningfully in their lifeworld (Fuchs and De Jaeger 2009; Fuchs and Koch 2014). While dementia, without a doubt, involves thoroughgoing changes to a person's situation and how her bodily subjectivity is lived and experienced, these changes do not imply that the person is no longer situated in relation to her surroundings or no longer experiences her own embodiment and situation. Nonetheless, many traditional and cognitivist conceptions of personhood often fail to acknowledge the role of embodiment.⁵ By contrast, Lindeman (2014) argues that if we consider personhood as a social practice, others can sustain us in personhood when we can no longer engage socially without support from others. The real “tragedy of Alzheimer's” is therefore not that dementia deprives people of their personhood, but that society is morally responsible for “holding them in personhood”—and often fails to do so. By questioning a strict one-body-one-person logic, Zeiler (2017) provides a philosophical basis for this idea that others can hold us in personhood. She thereby offers an alternative conception of personhood from within the tradition of phenomenology of the body. Thus, in a phenomenological framework, a loss of cognitive and other bodily functions does not automatically lead to a disappearance of the person. Instead, the person is understood in terms of their lived embodiment, situated in a world, and interrelated with others.

For the reasons stated above, considering the social distancing measures during the COVID-19 pandemic, questions about the constitution of our shared intercorporeality are more pertinent than ever. Just as important is the question as to what ethical obligations are implied by our embodied relationality to ensure humane and person-centered dementia care. Attending to personhood is an important effort in recovering the strengths and potential of the person with Alzheimer's Disease (AD). This approach helps to counterbalance theoretical focus on cognition and neurological changes in the brain, which has dominated the dementia discourse for a long time. According to Leibing and Lawrence (2006), these different approaches—focused alternately on holistic personhood and on abstracted cognition—elicit very different responses from people with AD in practice. These different types of bodily responses will be addressed in this paper.

⁵ Fuchs (2020), Tewes (2021), and Kontos et al. (2017) argue against rationalist Cartesian assumptions of a dualistic nature of the person that traditionally account for a separation between body and mind. In rationalist or cognitivist views, the person's body is regarded as the mere carrier of a brain, which is an organ that produces and processes only mental states. A person's identity only extends as far as their proper memory. Relatedly, the cognitive theory of personal identity is characterized by psychological continuity, a capacity for thought and memory, and the ability to make rational decisions. Under this premise, dementia threatens personhood as soon as a person with dementia can no longer remember previous experiences (Fuchs 2020, 49). A cognitivist mindset therefore contributes to the subordination of the body in analysis. What is neglected and therefore critical here is the importance of pre-reflective bodily processes of perception, which are formative of our experiences and constitute the identity of the self.

I. MARGINALIZATION AND DISEMBODIMENT IN DEMENTIA CARE

The phenomenon of “social distancing” can be regarded critically in order to examine relations such as proximity and distance, self and other, body and mind, and nature and culture. If a relatively healthy and fit person can suffer as a result of social distancing requirements, then it is not very hard to imagine that they could negatively affect someone already experiencing illness.

In the context of dementia care, the bodily and expressive dimensions of communication are of utmost importance. Social distancing, however, undermines these aspects severely. Wearing facemasks affects intersubjective understanding and participatory sense-making, and not just in clinical and care environments. So far, a small number of representative studies have shown how difficult it is for people with dementia in long-term care facilities to adhere to the new health and social policies. In qualitative studies, Brown et al. (2020) and Wang et al. (2020), as well as Geyer et al. (2020), emphasize that the measures implemented to combat the pandemic have far-reaching consequences for the everyday lives of people with dementia and their carers. Brown et al. (2020) describe the negative effects caused by limited or suspended care interaction as follows:

Common non-pharmacologic interventions for ADRD in general, and BPSD in particular, involve social and physical contact such as social groups, exercise groups, and pet therapy. A limitation on resources and a need for physical distancing will not merely suspend these interventions, it will also result in increased isolation, a lack of physical exercise, decreased social engagement, and a suspension of purposeful activity. While confined at home, many people are now using technology to socialize and even exercise in group; individuals with ADRD may not be able to use electronic tools and software. (714)⁶

The disruption of a structured daily routine due to the closure of day care facilities and treatment—such as singing groups or physiotherapy services—as well as temporary bans on admission to nursing homes, increase stressful experiences for people with dementia, since this social contact provides a sense of regularity and security. At the same time, it is difficult for people with dementia to understand the necessity of wearing masks or keeping a distance and to adhere to them accordingly, which in turn increases the risk of infection. Of course, the effects and consequences of the social distancing requirements vary in certain degrees—for example, these will be experienced differently in institutionalized long-term care homes compared to the context of care provided by family at home. In many cases, there is a mixture of these two care situations. That is, in the mid-stages of dementia, people will likely go to day care facilities to meet other people with dementia and get

⁶ ADRD stands for Alzheimer’s Disease and Related Disorders whereas BPSD stands for Behavioural and Psychological Symptoms of Dementia, which include emotional, perceptual, and behavioral disturbances that are similar to those seen in psychiatric disorders.

involved in shared activities, such as singing, drawing, eating together, and the like. Jiloha (2020) and Brown et al. (2020) indicate that older people with cognitive impairment, such as dementia, are likely to suffer increased symptoms of anxiety, agitation, and anger as a result of social distancing. Consequently, they withdraw more from their habitual lifeworld interactions and engagement. These studies suggest how protection of older people from COVID-19 can, in fact, further isolate and marginalize them. Such social constraints could potentially compound cognitive impairment, creating a vicious circle. All this raises serious questions about how the measures put in place to protect those most at risk are also harming these people's overall quality of life.⁷

Moreover, personal protective equipment (PPE) in general, and face masks in particular, can and should be seen as having caring intentions, in that they aim to protect others from droplets and sources of infection from the wearer. However, they are not unproblematic in the context of care. For instance, people with hearing impairments have called for transparent masks to be made more readily available, since the impossibility of lip-reading through a mask has created exclusionary communication difficulties. PPE also veils facial features and expressions that play a significant role in expressing emotion and forming relationships between people. In fact, Rushton and Edvardsson (2020) describe depersonalization as a risk of face masks and PPE due to the reduced visual cues relating to subjectivity and identity.

Kitwood's (1997) work is relevant here, which argues that a "malignant" social context can create a vicious circle of cognitive and bodily deterioration for someone with dementia. Where social context is "benign," neurological impairment can be mitigated by positive interaction, such that it becomes possible for the person with dementia to make sense of herself and her surrounding world as much as possible, and thus retain a sense of well-being, self, and personhood. A "malignant" social context (e.g., an isolating or monotonous one) triggers stress and might contribute to structural changes in the brain and behavior, while a "benign" social context—coupled with an enriched environment—might even facilitate some regeneration (WHO 2018; Odzakovic et al. 2021). In Kitwood's model, the central implication is the need for high-quality interpersonal care that affirms personhood. At the basis of this person-centered approach to care, there are four key aspects: 1) valuing people with dementia and those who care for them, 2) treating people as individuals, 3) looking at the world from the perspective of the person with dementia, and 4) providing a positive social environment. The current pandemic politics of care for people with dementia is marked by isolation and distance, which seem at odds with Kitwood's recommendations. So how can the risk of depersonalization be counteracted? A possible answer is given by Rushton and Edvardsson (2020):

As nurses, we may now need to increase our attention to how to convey caring actions as well as caring expressions of familiarity, compassion, welcoming, happiness and care more with our eyes, and in other embodied ways beyond the facial. Reflective and purposeful nursing presence and

⁷ For a controversial discussion of the COVID-19 measurement implications, see Kidd and Ratcliffe (2020).

use of touch may be a strategy to counteract depersonalization, despite some of the intuitive and physical barriers to touch introduced by PPE. (2)

It seems that the COVID-19 crisis might prompt reflection on a much-needed paradigm shift, potentially integrating aspects of a phenomenological view of the body as the foundation of our lived experiences and as the means of expressivity and communication in the care process.

II. SOCIAL AND EMBODIED PERSONHOOD IN DEMENTIA

Against theories of a progressive loss of the self in people with dementia, several scholars—for instance, Kitwood (1990), Kontos (2017), and Fuchs (2020)—have argued that the selfhood of dementia patients is and can be preserved. Hughes et al. (2006), for instance, propose that it is possible to recognize a narrative self in dementia patients, even though disturbances to explicit (autobiographical and semantic) memory can undermine the possibility of these people relating a self. As such, phenomenological descriptions, together with the results of more recent empirical research on self-experience in dementia patients, allow us to consider how loss of memory affects the reflective layer of the autobiographical or narrative self.⁸ While largely accepting the notion of a basic layer of pre-reflective self-awareness, Summa (2014, 20), Kontos (2012), and others link self-narratives strictly to participation in an intersubjectively shared contexts of meaning. They suggest that other people, by integrating their own narratives with the life history of the dementia patient, may help to keep the patient’s narrative and autobiographical self alive.⁹ The question of how therapeutic encounters can access this self is thus highly important for empirical research and philosophical investigation.

The ambiguous conception of personhood in dementia is addressed by a wide range of authors (Hydén et al. 2014; Kontos 2012; Summa 2014; Snyder 2006; Tewes 2021; Wray 2020). Many of them argue that personhood is constituted in social practices. Such a view accounts for the bodily expression of the feelings, thoughts, desires, and intentions that constitute a human personality, recognized by others, through which a person responds to situations they encounter. Käll (2018), for instance, discusses the case of Auguste Deter, a

⁸ With reference to Summa (2014), Fuchs (2018), and Zahavi’s (2017) descriptions of the self in dementia, we might conclude that, in ADRD, there is limited access to explicit and reflective knowledge of spatio-temporal and social situations. That is why, despite the fact that minimal situational orientation is preserved in ADRD—via the “situational body-memory” and a pre-reflective “perspectival ownership”—persons with ADRD find it increasingly difficult to mentally transcend their current situation and integrate contextual information such as addresses, dates, weekdays, or names (Fuchs 2018; Zahavi 2017; Dzwiza-Ohlsen 2021).

⁹ For critical remarks on Zahavi’s notion of the “minimal self” (2017), see Summa (2014) and De Monticelli (2020). Unlike Zahavi’s minimal self, which refers to basic layers of pre-reflective experiences made by the self, these authors present a more nuanced theory of selfhood in which the pre-reflective self amounts to an integral and substantive part of a “narrative self.”

51-year-old known for having the very first diagnosed case of dementia (Alois Alzheimer diagnosed her in 1901). She was unable to remember her own name and explained, “I have, so to speak, lost myself.” This should not be considered testimony of simple loss of selfhood. What makes this self-observation remarkable and valuable, according to Käll (2018), is that it precisely demonstrates a “presence of self, experiencing the loss of her own self.” It is an account of a “unique and irreducible subjective first-person perspective on the world and on her own self-experience of losing herself” (22). Ironically, in Western culture, many illnesses are conceptualized as losses of selfhood, which leads to depersonalization, devaluation, and inhibition of agency and being-in-the-world. The experience of losing oneself, while remaining a self who is experiencing that loss, requires other ways of conceptualizing loss as such. It is precisely a phenomenology of embodied subjectivity and phenomenology of illness that can help us to make sense of loss not primarily in quantifiable terms of reduction, but instead in qualitative terms of transformative experience.

In *Phenomenology of Illness* (2012), Carel advises us that all disorders—acute, somatic, and mental; congenital or acquired—give rise to a change in one’s body and world. When studied phenomenologically, it is therefore no surprise that mental disorders, which may seem to affect the mind rather than the body, reveal substantial changes to one’s sense of embodiment, bodily possibilities, and bodily feelings (74). In Carel’s phenomenological account, she refers to Toomb’s (1972) conception of illness as states of losses. According to Toombs, illness disrupts the fundamental features of embodiment, which would be: “being in the world, bodily intentionality, primary meaning, contextual organization, body image, and gestural display” (72). Consequently, illness is experienced as a chaotic disturbance and a sense of disorder (Carel 2012, 45).

In the following I would like to emphasize that this picture, while not wrong, is one-sided; Toombs’ reading of illness as loss needs an extension to emphasize a person’s positive capacities. Such a complementary view would shift the focus from a totally pathological embodied being to a relatively capable embodied being who shares a sense of being in the world with others—something which Fuchs and De Jaeger (2009) have proposed, from an enactivist perspective, as “participatory sense-making.” Instead of reading illness merely as a series of losses, I suggest we should seek to understand the existential feelings associated with loss as potentially reducing senses of disembodiment and disorientation. This could facilitate more acceptance and tolerance for experiences such as feeling fragmented, uncertain, limited, unstable, or alienated. In the encounter with the other we should consider that:

- (1) loss of experienced wholeness creates a sense of being fragmented,
- (2) loss of experienced certainty creates a sense of uncertainty,
- (3) loss of experienced control creates senses of contingency and limitation,
- (4) loss of experienced freedom creates a sense of limitation, and a
- (5) loss of the familiar world creates senses of instability and alienation.

If the self is not an atomistic entity with clearly defined boundaries, a loss of self cannot be thought in terms of a simple quantitative subtraction from an original whole (Käll 2018, 24). Instead, loss may be regarded as resulting in a qualitative restructuring of the self, so that the self after loss is qualitatively presented in a different way. In this sense, having undergone a life-changing experience during the COVID-19 pandemic, we could normalize the aforementioned existential feelings as simply part of our existence, regardless of whether we experience illness directly or indirectly. This view acknowledges health or illness as a process of bodily transformation, i.e., healthy and ill bodies are on a continuum. Alternatively, we might think about the healthy and ill body as discontinuous. Health and illness are distinctive bodily states in which modes of being and experience differ radically (Carel 2012, 58). This latter assumption operates through binary dichotomies and categories of experience instead of providing a more inclusive and processual approach to understanding bodily existence.

A phenomenological or existential perspective acknowledges the importance of bodily perception, as understood and assessed by others, as impacting how the body is subjectively experienced and lived. Husserl and Merleau-Ponty's distinctions between the body-object and the lived body, along with their concept of habitualization, show that the lived body is more than a manifestation of individual intentions.¹⁰ Social and cultural norms and values are inscribed in our bodies. Our concepts of subjectivity, body, and mind in relation to dementia also have ethical and political implications, as do the COVID-19 protective policies in relation to senses of self and agency in dementia. Theories that conceive of dementia as a slow deterioration and disappearance of the person ignore these insights and, I argue, prevent practitioners from being able to respond to people with dementia with respect, dignity, and justice.

III. INTERBODILY RESONANCE AND BODY MEMORY

By examining clinical practice in dementia care, Fuchs, Käll, Kontos, and Zeiler have revealed how subjective capacities are intercorporeally constituted and how such practices ground relational capacity building. Here, intercorporeality opens new possibilities for the ongoing, dynamic configuration of bodily space, which is important for understanding dementia (Käll 2017). Subjectivity can be understood phenomenologically as an expressivity experienced through our intercorporeal relations with others, in which interiority is expressed and disclosed. As we share a corporeal existence with other beings, we have a level of shared knowledge of sensory experience that is both tacit and explicit. Shared corporeal existence gives us an understanding of the experience of others—such as hunger, fear, and sadness—and thereby facilitates connection to the selfhood of another person.

¹⁰ This distinction goes back to Husserl's (1989) *Ideas* in which he differentiates between the sensible body in the sense of a *Leib* and the physical body in the sense of *Körper* (240). In *Phenomenology of Perception*, Merleau-Ponty (1962), focuses further on the lived body (*Leibkörper*) and introduces, for instance, the concept of motor intentionality in order to emphasize the intertwinement of body and mind.

Thus, intercorporeal capabilities do not exist outside of specific interactions and shared space.

Fuchs (2018) emphasizes that the life story of a human being manifests itself in their body memory, and he presents a phenomenological understanding of the lived body as situated in a specific lifeworld. Body memory is derived through habitualizations that can be differentiated as *procedural*, *situational*, and *intercorporeal*.¹¹ If body memories are reactivated in specific ways, they make autobiographical aspects of life history available that are no longer accessible as explicit memory. Body memory is therefore an implicit form of memory and pre-reflective capacity that is maintained in dementia until the latest stages (Summa 2014). This is why Fuchs speaks of a basic self-experience in dementia: we have always been familiar with ourselves, and this self-familiarity is something that is felt physically, rather than explicitly known (50). In other words, the knowledge of the “self-as object” is preceded by the experience of the “self-as-subject,” which is a continuous pre-reflective self-experience that does not have to be made explicit or put into words. For the vast majority of our everyday lives we are not made aware of who we are, do not think about ourselves, and do not have to call up autobiographical memories in order to be self-evident and present. On the one hand, “possible access to that knowledge for our narrative identity” seems important; on the other hand, “self-being in a fundamental sense . . . is not bound to biographical memory or knowledge of one’s own person.” Basic self-experience is therefore “a characteristic of the continuous stream of consciousness itself . . . which ultimately represents the subjective side of the life process itself and does not require a reflexive form of self-identification” (Fuchs 2020, 51, author’s translation). According to Fuchs, it is precisely this self-experience that is maintained even in the late stages of dementia.

On this view, in every social encounter, two features of embodied affectivity become intertwined and thereby continuously modify each person’s affective affordances and resonance. In fact, research about infants demonstrates how the mutual bodily resonance of facial, gestural, and vocal expression engenders our primary affective attunement to others. Such processes of embodied interaffectivity are of major importance for psychiatry and psychotherapeutic interactions and are often addressed in embodied music and dance therapies (Fuchs and Koch 2014). Interestingly, the emphasis on the pre-reflective, atmospheric dimension of such encounters is important, as people with advanced dementia stages are particularly susceptible to atmospheres (Sonntag 2013). This susceptibility is due to their dwindling ability to shape their own environment or to distance themselves cognitively (especially from atmospheric effects). Their affective focus on physical sensations means that people with dementia often depend on the caring attention of accompanying persons. However, this also enables them to rediscover elementary aspects of human lived experience.

In these social and therapeutic encounters, we often find the double effect of moving and being moved, similar to Merleau-Ponty’s concept of intercorporeality. A bodily

¹¹ Fuchs refers to Husserl’s concepts of *habitus* and *lived body*. In Husserl’s (1989) work, the lived body is the most familiar “organ of the will” that we use from our early childhood to learn and to evolve (153).

organism responds to the stimuli of the environment through resonance in the body or by “tuning into” them. Merleau-Ponty (1962) speaks here of a “pairing of bodies” in the “attunement of their intentions” as a “reference to a single sensual world in which all can participate” (295).

One example of such an encounter is provided by a filmed validation therapy session between the 87-year old Gladys Wilson, diagnosed with AD, and her therapist Naomi Feil.¹² In this session, we can witness how both Gladys and Naomi “create a shared space of dynamic intercorporeal engagement” (Zeiler 2014). By expressing themselves through posture, touch, eye contact, and movement, this shared space is created through intercorporeal capabilities such as singing or engaging in a rhythm. This is one particular example of intercorporeal and interaffective processes in therapy, which Fuchs and Koch (2014) call *interbodily resonance*. The film thus presents us with a moment of transition during which a highly asymmetrical relation turns into a symmetrically resonating one, exemplifying participatory sense-making principles and meaningful affordances created by bodily responsiveness through intercorporeality (De Jaeger and Fuchs, 2009). Consequently, such practice should be understood as a relational practice or a form of *responsive therapy* in dementia care, in particular highlighting how the capabilities of dementia patients are fostered and encouraged intercorporeally (Waldenfels 2019).¹³ Such practices of relational capacity building powerfully show how subjective capacities are intercorporeal.

IV: THE RELEVANCE OF SOCIAL TOUCH IN EMBODIED PERCEPTION AND DEMENTIA CARE

Philosophers such as Ratcliffe (2018), Kearney (2020), and Paterson (2020) emphasize the importance of touch for theories of embodied perception and its meaning in interpersonal engagement.¹⁴ According to Ratcliffe (2018), touch is “an effective exemplar for enactivism because it depends upon bodily activity to a greater *extent* than the other senses and/or in a distinctive *way*.” Bearing this in mind, he later claims that “one might consider various claims that touch is the most fundamental sense, the only sense that is essential to the having

¹² A link to the video can be found in the references list (Memory Bridge 2009).

¹³ Bernhard Waldenfels’ responsive phenomenology is a rethinking of the self by highlighting the experience of the other. Since a self is generated due to its response to the demand of the other in the broadest sense, the self and the other co-originate in this responsive process and bring to light the significance of the sentient or lived body of a self. In therapeutic dialogue or interaction this interbodily co-constitution is particularly emphasized. See Käll (2017) or Fuchs (2018, 2020).

¹⁴ According to Käll (2017), this kind of social encounter is based on a constitutive openness and accessibility to the other, which is prefigured in the experience of the “double sensation,” in which the subject has a double experience—for example, when touching one hand with the other. The self becomes self through the interactive engagement with, and bodily presence of, the other. The double sensation as described by Husserl discloses a reversible structure, one that is constitutive of identity and extends to interrelation with others and the world. Husserl (1989) refers to the double-sensation and offers an explication of the relationship between tactile and visible domains in *Ideas II*.

of a body, to the capacity to interact with one's surroundings, to animal being" (Ratcliffe 2018, 2). He argues, however, that there are insufficient grounds for maintaining that touch is somehow "more enactive" or embodied than other senses. I agree with Ratcliffe that touch is not more fundamental than the other senses, or more intimately bound up with bodily nature. It can be said, however, that touch is a highly heterogeneous way of perceiving, and it does not present as a single sense modality. The multimodal nature of touch contributes to its diversity and enrichment of meaning-making in interactive encounters.¹⁵ We know, for example, how important touch is for newborns to thrive and fully develop their communicative and cognitive skills (Aguirre et al. 2019). As Kearney (2020) summarizes:

"Tender touch" alleviates anxiety, bolsters the immune system, lowers blood pressure, helps with sleep and digestion, and wards off colds and infections. It feeds us in body and soul. In short, tactile communication is absolutely vital to our physical and mental wellbeing. (4)

This holds true for everyone but is even more vital for people experiencing a greater degree of dependence in illness. As much as new technologies help us communicate across distance, what they cannot overcome is bodily distance. Interpersonal touch is often communicative, and patterns of communicative tactual interaction with another person can feed into holistic perceptions of that person. It is unclear whether or how the communicative and perceptual functions of touch can be separated (Ratcliffe 2018). In a recent study, Kelly et al. (2020) describe how physicians use touch to share emotions and to demonstrate empathy and presence to patients. Touch is described as embodied empathic communication, in which non-verbal patient cues like facial expressions and body language are carefully interpreted to determine whether touch is appropriate. Since this kind of "social touch" is vital for our embodied perception and self-experience, I argue that it is not simply desirable but essential to maintain touch as part of therapeutic encounters. It may help counter the risks of depersonalization generated by masks and full PPE, as well as the sense of bodily alienation fostered by social isolation.

Among other examples of embodied therapies applied in dementia care, Snoezelen rooms represent a multisensory environment (MSE) that offers varied sensory stimuli and interaction.¹⁶ By means of music, aroma or special light diffusions, a varied sensory

¹⁵ To consider how touch is multimodal, one just has to think of temperature, pressure, or different surface qualities that feed into the sense of touch. Recent research on the so-called "C-tactile fibers" indicates that we experience touch by others in a completely different manner than self-touch (Aguirre et al. 2019). It thus reveals the social nature of touch as being a kind of "social sensitivity," which sustains phenomenological interpretations of touch as a form of interbodily resonance.

¹⁶ The Snoezelen approach was initiated in the Netherlands in the late 1970s. Snoezelen stands for *doezelen* (to doze) and *sniff* (to sniff). It refers to a multisensory therapeutic setting in which environmental and interpersonal affordances offer a space of relaxation and controlled sensory stimulation. It is used in around 75% of nursing homes in the Netherlands. The aim of the intervention is to strike a balance between relaxation and activity in a safe, adapted environment supported by an intermediary.

environment creates a vivid or relaxing atmosphere. As mentioned before, joint activities such as making music or cooking can also support a multisensory experience and create meaningful engagement. The benefits of MSE and Snoezelen for dementia patients suffering from hearing, sight, smell, and taste disorders have been identified in an increasing number of studies in the field of integrated sensory therapy (Fowler 2008), showing improvements in physical and mental health. Sensory, cognitive, and affective stimuli are offered to each client through visual, auditory, tactile, and olfactory modalities and according to their personal choice (Van Weert 2003). The mutual benefits can be described as follows. First, it is easier for the nurses to get in touch with residents, which in turn provokes a positive response. Second, nurses found that residents who exhibit agitation, restlessness, or aggression become calmer and more relaxed through these embodied therapies. There are a number of studies on the effects of multisensory therapy which show a link between intermodal embodied perception and enhanced wellbeing that requires further analysis (Van Weert 2003, Fowler 2008, Nocon 2008). From a phenomenological viewpoint, the Snoezelen or MSE approach implies a potential break with the traditional idea of strict modularity and hierarchy in sense perception. Instead, they emphasize an intermodal, integrated, and pluralistic form of embodied perception. From an embodied and enactive perspective, it would indeed make sense to integrate more natural sensory stimulation into the person's regular environment. To overcome their institutional character, I suggest that care homes should design common and individual spaces with respect to their residents' needs and facilitate their participation in the design. Ideally speaking, they would offer both access to a natural environment—such as a small garden or park—and a space for social, synaesthetic bodily encounters.¹⁷

All this is a far cry from lived realities under COVID-19. Bodily alienation through social distancing and masking has revealed to us the ontological ambiguity of being a body among others and having a body resonating with others (Dolezal 2020). Experiences of the pandemic ought to push philosophers to more seriously consider how the body contextualizes perception, always with awareness of the body as “a being that relates to itself and at the same time withdraws from itself” (Waldenfels 2016, 79, author's translation). Vulnerability and finitude (including limits to our ability to think and imagine otherwise) under COVID-19 call for an ethical response. I argue that awareness of loss and fragmentation of the self, in the ways I have examined in this article, will help practitioners to attend to vulnerability and finitude responsibly as the pandemic evolves. These aspects of selfhood factor into dynamically negotiated states of health and illness in which a lifeworld horizon of the “I can” is central; this insight could help facilitate better understanding of the relation between embodied knowledge, vulnerability, and responsiveness, improving intercorporeal communication processes and making the lifeworld of people with dementia more accessible.¹⁸

¹⁷ Buist et al. (2018) refer to recent examples of innovating dementia care providing green care farms in long-term care settings.

¹⁸ Richard Taylor (2007) eloquently voices his concern at how, as his disease progresses, the ground rules change regarding what he is permitted to do, of what he is considered capable, and how others view and judge him. From his perspective, he is still the same person, just undergoing alarming and difficult

Such an embodied phenomenological approach to dementia and care enables us to take account of how particular practices and habits are reiterated in our lived bodies in an active manner, becoming sedimented embodied habits and forms of perception (Fuchs 2020; Dolezal and Petherbridge 2017). Moreover, the phenomenological approach helps to highlight what happens when these social and cultural embodied practices are suspended before, during, and after the COVID-19 pandemic. Brooker (2007) phrases the existential needs of people living with dementia as follows:

Many people [living with dementia] never get to put on a hat and a coat and outdoor shoes, to go on a bus or to visit the pub, shop or place of worship. These are the activities that people take as part of ordinary life. They help us to maintain our identity and our interest in life in all its variety. People with dementia need this variety as much as anyone else.
(110)

Practitioners should bear in mind that the lived embodiment of a person with dementia is not exclusively pathological. Given that people with dementia continue to explore their lifeworlds through intercorporeality, it is crucial that appropriate responses in dementia care, during the pandemic and afterwards, are sought out.

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challenges. Wray (2020) argues that recognizing difference in *degree* rather than *in kind* makes response-based empathy both possible and appropriate. We could, for instance, start by asking ourselves how we conceptually position people with dementia in the social encounter i.e., as *different in kind* or *different in degree*. Furthermore, by applying *response-based empathy* rather than *self-based empathy*, we gain a better understanding of the person with dementia through her reactions and responses: “We all know what it’s like not to recall what we went upstairs for or where we parked the car. We’ve all realized we couldn’t recall someone’s name. . . . Everyone deserves to be understood and, on the basis of that understanding, treated according to the same social codes. Caring for people different only in *degree* entails creating experiences for them that we would want for ourselves: we look at their situation from the inside.” (212)

REFERENCES

- Aguirre, Marie et al. 2019. “Infants Discriminate the Source of Social Touch at Stroking Speeds Eliciting Maximal Firing Rates in CT-Fibers.” *Developmental Cognitive Neuroscience* 36: 100639. <https://doi.org/10.1016/j.dcn.2019.100639>.
- Brooker, Dawn. 2007. *Person-Centred Dementia Care: Making Services Better*. London: Jessica Kingsley Publisher.
- Brown, Eric et al. 2020. “Anticipating and Mitigating the Impact of the COVID-19 Pandemic on Alzheimer’s Disease and Related Dementias.” *American Journal of Geriatric Psychiatry*. 28 (7): 712-21.
- Buist, Yvette et al. 2018. “Innovating Dementia Care; Implementing Characteristics of Green Care Farms in other Long-term Care Settings.” *International Psychogeriatrics*. 30 (7): 1057-68.
- Carel, Havi. 2020. “Cardiff Annual Lecture - RIP - Havi Carel, ‘Phenomenology of Social Distancing.’” *Royal Institute of Philosophy*. Accessed September 3, 2020. <https://www.youtube.com/watch?v=BT8CPW3b3Cw>.
- Carel, Havi. 2016. *Phenomenology of Illness*. Oxford: Oxford University Press.
- De Monticelli, Roberta. 2020. “The Lesson of Coronavirus: Experiencing Values, Experiencing Oneself.” Presented at the online workshop, “Conversations on values and value experience.” IEA, Paris.
- Diprose, Rosalyn. 2017. “The Body and Political Violence. Between Isolation and Homogenization.” In *Body/Self/Other: The Phenomenology of Social Encounters*, edited by Luna Dolezal and Danielle Petherbridge, 21-45. Albany: SUNY Press
- Dolezal, Luna. 2020. “Intercorporeality and Social Distancing: Phenomenological Reflections.” *The Philosopher* 108: 18-24.
- Dolezal, Luna and Danielle Petherbridge (eds.). 2017. *Body/Self/Other: The Phenomenology of Social Encounters*. Albany: SUNY Press.
- Dzwiza-Ohlsen, Erik Norman. 2021, in press. “Dementia as Social Disorder – A Lifeworld Account,” *Phenomenology and Mind* special issue “Phenomenology of Social Impairments,” edited by Valeria Bizzari, Oren Bader, & Thomas Fuchs.
- Ettlinger Nancy. 2017. “A Relational Approach to an Analytics of Resistance: Towards a Humanity of Care for the Infirm Elderly – A Foucauldian Examination of Possibilities.” *Foucault Studies* 23: 108-40.

- Fowler, Susan. 2008. *Multisensory Rooms and Environments: Controlled Sensory Experiences for People with Profound and Multiple Disabilities*. London: Jessica Kingsley Publishers.
- Fuchs, Thomas. 2018. *Ecology of the Brain: the Phenomenology and Biology of the Embodied Mind*. Oxford: Oxford University Press.
- . 2020. “Embodiment and Personal Identity in Dementia.” *Medicine, Health Care and Philosophy* 23 (4): 665-76.
- Fuchs, Thomas, and Hanne De Jaeger. 2009. “Enactive Intersubjectivity: Participatory Sense-making and Mutual Incorporation.” *Phenomenology and the Cognitive Sciences* 8: 465-86.
- Fuchs, Thomas and Sabine Koch. 2014. “Embodied Affectivity: On Moving and Being Moved.” *Frontiers in Psychology* 5. <https://doi.org/10.3389/fpsyg.2014.00508>.
- Geyer, Jennifer et al. 2020. “Die Lebenssituation von Menschen mit Demenz und pflegenden Angehörigen während der Coronavirus-Pandemie Eine qualitative Studie.” *Pflege*. 33 (4): 189-97. <https://doi.org/10.1024/1012-5302/a000750>.
- Hamilton, Heidi Ehernberger. 2019. *Language, Dementia and Meaning Making. Navigating Challenges of Cognition and Face in Everyday Life*. London: Palgrave Macmillan.
- Hughes, Julian C. (ed.). 2006. *Dementia. Mind, Meaning, and the Person*. Oxford University Press.
- Husserl, Edmund. 1989. *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy. Second Book: Studies in the Phenomenology of Constitution*. Translated by Richard Rojcewicz & André Schuwer. Dordrecht: Kluwer.
- Hydén, Lars-Christer and Eleonor Antelius (eds.). 2017. *Living with Dementia. Relations, Responses and Agency in Everyday Life*. London: Palgrave Macmillan.
- Hydén, Lars-Christer, Hilde Lindemann, and Jens Brockmeier. 2014. *Beyond Loss. Dementia, Identity, Personhood*. New York: Oxford University Press.
- Jiloha, R.C. 2020. “COVID-19 and Mental Health.” *Epidemiology International* 5 (1): 7-9.
- Käll, Lisa F. 2017. “Intercorporeal Expression and the Subjectivity of Dementia.” In *Body/Self/Other: The Phenomenology of Social Encounters*, edited by Luna Dolezal, and Danielle Petherbridge, 359-386. Albany: SUNY Press.
- . 2018. “Towards a Phenomenological Conception of the Subjectivity of Dementia.” In *Living with Dementia. Relations, Responses and Agency in Everyday Life*, edited by Lars-Christer Hydén and Eleonor Antelius, 14-28. London: Palgrave Macmillan.

- Kearney, Richard. 2021. *Touch. Recovering Our Most Vital Sense*. New York: Columbia University Press.
- Kearney, Richard and Treanor, Brian. 2015. *Carnal Hermeneutics. From Head to Foot*. New York: Fordham University Press.
- Kelly, Martina et al. 2020. "Being Vulnerable: A Qualitative Inquiry of Physician Touch in Medical Education." *Academic Medicine: Journal of the Association of American Medical Colleges* 95 (12): 1893–99.
- Kidd, Ian and Matthew Ratcliffe. 2020. "Welcome to Covidworld: Trying to understand Covidworld, our new altered reality where accepted norms do not apply." *The Critic*. Accessed July 19, 2021. <https://thecritic.co.uk/issues/november-2020/welcome-to-covidworld/>
- Kitwood, Tom. 1997. *Dementia Reconsidered: The Person Comes First*. New York: Open University Press.
- Koch, Sabine. C., Thomas Fuchs, and Michela Summa. 2012. "Body Memory and Kinesthetic Body Feedback: The Impact of Light versus Strong Movement Qualities on Affect and Cognition." *Memory Studies* 7 (3): 272–84.
- Kontos, Pia C. 2011. "Alzheimer Expressions or Expressions Despite Alzheimer's? Philosophical Reflections on Selfhood and Embodiment." *Interdisciplinary Studies in the Humanities* 4.
- . 2012. "Rethinking Sociability in Long-term Care: An Embodied Dimension of Selfhood." *Dementia: The International Journal of Social Research and Practice* 11 (3): 329-46.
- Kontos, Pia, Karen-Lee Miller, and Alexis P. Kontos. 2017. "Relational Citizenship: Supporting Embodied Selfhood and Relationality in Dementia Care." *Sociology of Health & Illness* 39 (2):182-98.
- Koskinen, Camilla and Lisbet Nyström. 2017. "Hermeneutic Application Research - Finding a Common Understanding and Consensus on Care and Caring." *Scandinavian Journal of Caring Sciences* 31 (1): 175–82.
- Leibing, Annette and Lawrence Cohen. 2006. *Thinking About Dementia. Culture, Loss, and the Anthropology of Senility*. New Brunswick, NY: Rutgers University Press.
- Memory Bridge. 2009. "Gladys Wilson and Naomi Feil." *YouTube*. Accessed July 19, 2021. <https://www.youtube.com/watch?v=guRoWTYfxMs>
- Merleau-Ponty, Maurice. 1962. *Phenomenology of Perception*. Translated by Colin Smith. London: Routledge.

- Merrick, Kate. 2021. "Affective Touch." *Therapy Today* 32 (1): 42–45.
- Nocon, Marc. 2008. "Efficacy of Multi-Sensory Stimulation in Patients with Dementia—A Systematic Review." *European Journal of Integrative Medicine* 1 (23).
- Odzakovic, E., Hellström, I., Nedlund, A. C., & Kullberg, A. 2021. "Health Promotion Initiative: A Dementia-Friendly Local Community in Sweden." *Dementia* 20 (6): 1971-87.
- Paterson, Mark. 2020. *The Senses of Touch. Haptics, Affects, and Technologies*. London: Routledge.
- Petherbridge, Danielle. 2018. "How Do We Respond? Embodied Vulnerability and Forms of Responsiveness." In *New Feminist Perspectives on Embodiment*, edited by Clara Fischer, and Luna Dolezal, 57–79. London: Springer International Publishing.
- . 2019. "Beyond Empathy: Vulnerability, Relationality and Dementia." *International Journal of Philosophical Studies* 27 (2): 307–26.
- Plessner, Helmuth. 1970. *Philosophische Anthropologie*. Frankfurt a. M.: Fischer.
- Ploner-Grissmann, Heidi Maria. 2018. "Therapeutic Touch® - Compassionate Touch for Persons with Dementia: A pilot review." *Journal of Alternative Medicine Research* 10(3): 211-13.
- Ratcliffe, Matthew. 2008. *Feelings of Being. Phenomenology, Psychiatry, and the Sense of Reality*. Oxford: Oxford University Press.
- . 2018. "Perception, Exploration, and the Primacy of Touch." In *The Oxford Handbook of 4E Cognition*, edited by Albert Newen, Leon De Bruin, and Shaun Gallagher, 281-99. Oxford: Oxford University Press.
- Rushton, Carole and David Edvardsson. 2020. "Nursing, Masks, COVID-19 and Change." *Nursing Philosophy*. 00: e12340. <https://doi.org/10.1111/nup.12340>.
- Ryoo, Nayoung et al. 2020. "Coping with Dementia in the Middle of the COVID-19 Pandemic." *Journal of Korean Medical Science* 35: 42 e383. <https://10.3346/jkms.2020.35.e383>.
- Schellhammer, Barbara. 2020. "'Social Distancing'? Proximity and Distance in Crises Situations – a Phenomenological Study of Embodiment." *Zeitschrift für Praktische Philosophie* 7(2): 335–58. <https://doi.org/10.22613/zfpp/7.2.14>.
- Summa, Michela. 2014. "The Disoriented Self: Layers and Dynamics of Self-Experience in Dementia and Schizophrenia." *Phenomenology and the Cognitive Sciences* 13: 477-96.

- Taylor, Richard. 2007. *Alzheimer's from the Inside Out*. Baltimore, MD: Health Professions Press.
- Tewes, Christian. 2021. "Embodied Selfhood and Personal Identity in Dementia." In *Time and Body. Phenomenological and Psychopathological Approaches*, edited by Christian Tewes and Giovanni Stanghellini, 367-89. Cambridge: Cambridge University Press.
- Toombs, S. Kay. 1993. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*. Amsterdam: Kluwer.
- Van Weert, Julia. 2003. *Multi-Sensory Stimulation in 24-hour Dementia Care, Effects of Snoezelen on Residents and Caregivers*. Wageningen: Verlichtingsdienst.
- Waldenfels, Bernhard. 2016. *Grundmotive einer Phänomenologie des Fremden*. Frankfurt a. M.: Suhrkamp.
- . 2019. *Erfahrung, die zur Sprache drängt*. Frankfurt a. M.: Suhrkamp.
- Wang, Huali et al. 2020. "Dementia care during COVID-19." *Lancet*. 11 395 (10231): 1190-91. [https://doi.org/10.1016/S0140-6736\(20\)30755-8](https://doi.org/10.1016/S0140-6736(20)30755-8).
- WHO. 2018. *Towards a Dementia Plan: a WHO Guide*. France.
- Wray, Alison. 2020. *The Dynamics of Dementia Communication*. New York: Oxford University Press.
- Zahavi, Dan. 2017. "Thin, Thinner, Thinnest: Defining the Minimal Self." In *Embodiment, Enaction, and Culture. Investigating the Constitution of the Shared World*, edited by Christoph Durt, Thomas Fuchs, and Christian Tewes, 193-99. Cambridge, MA: Massachusetts Institute of Technology Press.
- Zeiler, Kristin. 2014. "A Philosophical Defense of the Idea that Individuals Can Be Held in Personhood by Others: Intercorporeal Personhood in Dementia Care." *Medicine, Health Care and Philosophy* 17: 131-41.