
ERIK NORMAN DZWIZA-OHLSEN
Husserl Archives Cologne
edzwiza@uni-koeln.de

DEMENTIA AS SOCIAL DISORDER – A LIFEWORLD ACCOUNT

abstract

Due to the severe impairments in intra- and interpersonal interaction and communication, dementia will be hypothesized as a social disorder. Despite the increasing societal relevance of dementia this aspect is surprisingly under-researched in phenomenological philosophy. First, the symptomatic disturbance of the dynamic relationship between orientation, language and memory in Alzheimer's Dementia (AD) is analyzed with the tools of a phenomenological psychopathology in terms of a lifeworld account. Due to the severe impairments of AD, two therapeutic strategies are discussed: first, the situation-specific strategy, which examines communication resources in the here and now in the face-to-face situation; second, the context-specific strategy, which examines whether habitus can soften the disruption of contextual knowledge by making it accessible as a resource of meaning that informs and thus orients the here and now. The guiding question of this enquiry is how AD changes the social experience in intra- and interpersonal terms.

keywords

Alzheimer's dementia, phenomenology, psychopathology, trouble générateur, language, orientation, memory, indexicals, pointing, habitus

1. Introduction: sociality as forgotten dimension of dementia?

More and more people are suffering from dementia – currently there are about 50 million people with dementia worldwide, 82 million estimated in 2030 and as many as 152 million in 2050 (WHO, 2018, p. 6). However, it is not only those affected who are experiencing these diseases, but also their families, friends, caregivers and doctors. Accordingly, dementia diseases can be seen as one of the central challenges of the present and the future, as they affect the whole of society both quantitatively and qualitatively by bringing not only modern medicine to its limits, but also the self-image of humankind by questioning our autonomy, dignity and reason. Against this backdrop, it seems understandable that the greatest concern for the future of Germans is to be “demented in old age and dependent on care” (zdfheute 2020, my translation) and at least comprehensible that Alzheimer’s Disease (AD) has become a “much-feared stigmatizing label that carries with it a sentence of social death” (Kontos, 2012, p. 1), frequently accompanied by the story of the “confused, helpless’ A.D. sufferer” (Sabat & Harré, 1992, p. 457). This emotionally charged perspective is reflected in the social environment of those affected: In most cases, neither nursing homes and nursing staff nor relatives and friends are prepared for the specific needs of a person with dementia. Especially regarding the massive restrictions in communication and interaction, the concern of those affected is, with good reason, mainly directed towards social consequences like “the feeling of loss, the petty conflicts, the lost hopes, the family disputes, the anxieties and financial hardships” (Clegg quoted by Brockmeier, 2014, pp. 85f.). In this light it is convincing, that “depression, or anger, or embarrassment is not a symptom of AD in the same way that fever is a symptom of malaria, but is quite often an entirely appropriate reaction to the loss of this or that valued ability” (Sabat, 2021, p. 237). In other words, it is not only the disease itself, but also the reaction of both the person affected and the social environment to it that makes living with dementia so demanding. Obviously, the social environment can either support or prevent those affected from performing as the unique social selves they are (cf. Sabat & Harré, 1992). This is of great importance for society as a whole, because “the degree of independence and general well-being that persons diagnosed can maintain is directly related to the cost of care for those persons and the well-being of their care partner,” as Sabat (2021, p. 232) concludes. In this light, it seems particularly alarming when Sabat (2009), considering the currently dominant naturalistic paradigm of dementia research, states that up until now “two very important considerations are virtually ignored: the inner life of the person diagnosed and the social situation in which the person lives” (p. xii). Thus, dementia is primarily understood as a neurodegenerative disease of the brain, which is reflected both in the world’s most influential

classification systems (such as the *DSM-V* and *ICD-10*) and in internationally renowned research on guiding conceptual frameworks (e.g. Stern *et al.*, 2021, linking resilience to “cognitive reserve”, “brain reserve”, and “brain maintenance”). The present contribution takes a different path by aiming to explore both the inner life of the person and the social situation in which the person lives in their constitutive intertwining. To this purpose, I use the method of *Phenomenological Psychopathology* and apply it to AD, the most frequent form of dementia (WHO, 2018, p. 6).¹ This general perspective is specified in two ways: *Pathologically*, I investigate the complex intertwining of the threefold loss in AD, concerning *language, orientation and memory*. In this respect it is important to track the reverberations of this loss of communication and interaction for those affected within their social environment. *Phenomenologically*, I go ‘back to the roots’ and focus on the early theorem of the *Lifeworld* developed by Husserl in his *Ideas II* (1989, pp. 173–302; cf. Sommer, 1984), which was highly influential on thinkers like Heidegger, Merleau-Ponty, Ricœur, and Stein. This approach is sharpened in terms of *Structural Psychopathology* (Stanghellini, 2010, p. 319), in order “to understand the meaning of a given world of experiences and actions grasping the underlying characteristic modification that keeps the symptoms meaningfully interconnected”. This holistic account has the advantage that it is not only *non-naturalistic*, since the lifeworld experience of a person is the starting point of the scientific investigation, but also *non-reductionistic*, since it focuses on the relationship of an “embodied, situated, and enactive” (Carel, 2016, p. 14) person with their feelings, thoughts and actions in a social world characterized by expressivity, culture and history (Husserl, 1989, pp. 173–302; this is why I prefer to speak of intra- and interpersonal instead of intra- and intersubjective experience). Ultimately, this account enables us to perform a fundamental change of perspective – which has become apparent in interdisciplinary research in recent years (Brooker, 2008; Kitwood, 1997; Kontos, 2005; Kontos & Martin, 2013; Kruse, 2010; Sabat, 2018, 2021) – with at least *three* advantages: *Firstly*, dementia can be understood not only as a neurodegenerative *disease* of the brain but also as a psycho- and socio-degenerative *illness*, “the ‘what is it like’ qualitative dimension as it is experienced and made meaningful by the ill person” (Carel, 2016, p. 17).² *Secondly*, it focusses both the deficits, which are crucial from a diagnostic point of view, and the resources, which are crucial from a therapeutic point of view that is by its “nature much more linked to the subjective, the personal, and the social” (Carel, 2016, p. 16). Since the ‘lived body’³ is the structural interface between person and environment, it serves *thirdly* as an important antidote to one-sided conclusions, such as the revocation of personhood in late phases of dementia. All these aspects are appreciated by the lifeworld account, which is of particular importance in view of the lack of a phenomenological examination of dementia in general and AD in particular, although vital work has been done (Fuchs, 2012, 2018; Summa, 2011, 2014; Tewes, 2020).⁴

In summary, our method is phenomenological, the guiding theorem is that of the lifeworld, the Archimedean point is the lived body and the application is AD. The main questions are how AD changes the social dimension of experience and what we can do as a ‘caring society’ to meet these changes with dignity and humanity.

1 On the general symptoms of AD cf. Tölle & Windgassen (2012, pp. 302–306).

2 In a second step, it is possible to relate the naturalistic investigation of the disease to the personalistic investigation of the illness, as *cum grano salis* demonstrated by Jaspers (1997) more than 100 years ago.

3 Husserl (1989) differentiates between the sensible ‘Leib’, translated as “Body” with a capital b, and the physical ‘Körper’, translated as lowercase b “body” (p. 240). For reasons of clarity, I will speak of ‘lived body’ for Leib and of ‘body’ for Körper.

4 Since all these contributions focus on the problem of selfhood and personal identity in dementia, which indicates an intricate discussion in its own right, I will discuss especially the question of selfhood only peripherally.

2. Between experience and expression: the intertwining of language, orientation, and memory

According to the self-understanding of the West, language is intimately linked to truth, reason and being human, and is of invaluable importance for our everyday interaction and communication: Whether it is the clarifying conversation with our loved ones, the good book at a late hour or the street sign that guides us home safely. Tragically, loss of speech is a central symptom in AD: According to Kempler (1991), it almost always occurs, mainly affects lexis, semantics and pragmatics, impairs both speech production and understanding, has no motor causes and can be almost complete in the late phase of the illness. Interestingly, a very special form of linguistic expressions, which guides our further considerations, has proven to be a powerful “deficit indicator” (Wendelstein & Felder, 2012): indexical expressions.

If we look at both speech comprehension and speech production, the following observation emerges: People with AD use pronouns (i.e. indexical expressions) to a significantly higher degree than their healthy peers, but they have a significantly lower ability to understand them; therefore, they benefit in conversation (unlike their healthy peers) when less informative pronouns are replaced by more informative nouns (Almor *et al.*, 1999). These deficits are also reported by Brydon (2005): “A real difficulty in speaking [i.e. conversing] is words like ‘we’, ‘they’, ‘I’, ‘you’, ‘he’ – when I have to work out who is doing that to whom” (pp. 118f). And in line with this, Hydén and Nilsson (2015) have shown empirically that couples with one of the partners affected by AD were much less successful in referring to the long-term unity of their partnership using the pronoun ‘we’ than couples with neither partner affected by AD.

To interpret these observations, we can use the terminology provided by Bühler’s *Theory of Language* (1990), according to which “situation and context are [...] the two sources that in every case contribute to the precise interpretation of utterances” (p. 149). In everyday conversation it is clear that both aspects constantly permeate each other: Thus the context with its “synsemantic field” represents a linguistically constituted knowledge resource that informs the situation with its “deictic field” (Bühler, 1990, p. 81). This in turn forms a sensually constituted knowledge resource that orientates us in the fundamental sense of the “Origo” (Bühler, 1990, p. 102), the “here-now-I system of subjective orientation” (Bühler, 1990, p. 149). This is exactly the junction where Bühler meets Husserl, who uses indexical expressions to indicate the ‘central’ function of our lived body for orientation in spatial, temporal and personal terms (a remarkably dense passage is § 1 of Husserl, 1973b). Indexical expressions thus not only reveal the fundamental relationship between spoken language and bodily orientation,⁵ but in particular the structural modification of consciousness in AD.

In AD, the integration of contextual information of the *synsemantic* field into the *deictic* field seems to no longer succeed. This explains the deficits in understanding indexical expressions; after all, we need the *synsemantic* field to understand their concrete meaning. According to Husserl (2001), indexical expressions are “essentially subjective [...] expressions,” which are distinguished by the orientation of their “actual meaning to the occasion, the speaker and the situation” (pp. A80f.). Therefore, a ‘we’ can either mean a temporary unit, which differs in size (me and my interlocutor vs. a larger group) or a longer lasting unit, like a couple. At the same time, indexical expressions have the social function of positioning us and our interlocutors: “Positioning [...] is the discursive process whereby selves are located in conversations as observably and subjectively coherent participants in jointly produced story lines” (Davies & Harré, 1990, p. 48; cf. Sabat & Harré, 1992). The deficits reported by Almor *et al.* (1999), Bryden (2005), and Hydén and Nilsson (2015) therefore have a huge potential for conflict, as a central

⁵ I have explained this idea in detail elsewhere (Dzwiza-Ohlsen, 2019).

instrument of the intra- and interpersonal constitution of identity is working worse and worse.

These considerations help to understand why and how this language deficit is closely related to two other central symptoms in AD, namely the memory and orientation deficit. On the one side, those affected experience significant performance deficits in working memory, which reduce not only the understanding of pronouns, because contextual information is less available during conversations (Almor *et al.*, 1999, pp. 211-220), but also makes everyday life considerably more complicated. On the other side, those affected can no longer remember important events in their lives: during the loss of temporal orientation, a “time grid disorder” occurs (AMDP, 2018, p. 40, my translation). In other words, the bond that tightly links the sum of individual experiences to the grid of culturally shaped time measurement and makes our life appear as a narrative, loses its integrity (on the importance of ‘speechless’ narrativity in dementia see Brockmeier, 2014, pp. 77f.). “Consequently,” Summa (2011) concludes, “the disturbance is based on the unavailability of explicit and reflected knowledge regarding the respective spatio-temporal and social content of a situation” (p. 164, my translation).⁶ Thus, although one could argue that in the course of AD a minimal situational orientation is preserved – via the “situational Body-memory” (Fuchs, 2018, p. 56, my translation) and a pre-reflective “perspectival ownership” (Zahavi, 2017, p. 194) in the sense of the ‘I-here-now’ displayed by the competent use of (first person) indexicals and gestures (Sabat & Harré, 1992, pp. 449-452) – those with AD find it increasingly difficult to mentally transcend their current situation and integrate contextual information such as addresses, dates, weekdays or names (Summa, 2014, pp. 481-483). These disturbances in integrating contextual information into the present situation in AD – measured by the widely used “Mini-Mental-State Examination”-Test (Tölle & Windgassen, 2012, pp. 305f.) – deeply affect the structural integrity of language, orientation, and memory and could therefore be interpreted as the “‘trouble générateur’” of AD (Minkowsky quoted by Stanghellini, 2010, p. 321).

These insights into the structure of the illness can change our perspective and shed new light on frequently observed phenomena. I would like to illustrate this with three examples of intra- and interpersonal meaning-constitution: Firstly, the declining awareness of deficits on the part of those affected, as well as their inattentiveness to the perspective of their counterpart, can be interpreted as positioning deficits, which, especially in the absence of a diagnosis, are often misunderstood as a change of character. Secondly, the typical confusion of living and already deceased persons, which is accompanied by jumps in space and time, can be understood as attempts at orientation that are intended to create a consistent, familiar and thus also reassuring situation despite the lack of contextual knowledge in general, as well as an indication of the constitutional mechanism of social positioning in particular, as Sabat and Harré (1992) have impressively demonstrated. And thirdly, care support – whether it is done privately, professionally, in an ambulant or stationary setting – can be seen as a radical reorientation in terms of sociality, temporality and spatiality. Suddenly, others I might not have chosen as interaction partners help me to do something that I was previously able to do myself and at a place and time that I cannot necessarily decide myself.

With this last example, we move almost naturally from the diagnostic perspective, which looks at deficits, to the therapeutic perspective, which considers resources. What can be done in a

⁶ Elsewhere, I have interpreted these findings as a three-dimensional loss of orientation in social, temporal and spatial terms, which characterizes the pathological structure of AD (Dzwiza-Ohslen, 2021). Even if the social dimension is foregrounded here, both the temporal and spatial dimension cannot be excluded. Furthermore, the concept of orientation could help shed light on the often-overlooked diversity of persons with dementia (cf. Kontos & Martin, 2013, p. 296) by addressing sexual, political or religious orientation.

therapeutic sense when disorientation, speechlessness and forgetting become basic features of existence? When the natural self-evidence as a fundamental element of the lifeworld becomes fragile in its double-meaning of a ‘familiarity with’ (things, actions, people) and ‘trust in’ (oneself, others, the world)? (Fuchs, 2015, pp. 101–105)

3. The moment in the here and now: pointing in the face-to-face situation

If it were possible to identify alternative resources of communication, the often-failed interaction with those suffering with AD could be minimized and their frequently low quality of life maximized, but it could also be acknowledged that “their ability to understand and communicate is far more intact than they have been given credit for on the basis of standard neuropsychological assessments” (Sabat, 2009, p. xiv; cf. Sabat, 2021, pp. 236). To achieve this goal, two strategies might be suggested: First, a *situation-specific* strategy examines the communicative resources in the here and now in face-to-face situations. Second, a *context-specific* strategy investigates whether *habitus* can soften the disruption of contextual knowledge by making it accessible as a resource of meaning that informs the here and now. Both strategies can be explored starting from Husserl’s analysis of the *Spiritual World* (cf. Husserl, 1973a, pp. 62–111; 1989, pp. 173–302). Here, expression is considered in all its richness and can be either with or without the intention to communicate and is accordingly called “communicative” (1) or “non-communicative” (2); can be performed both “verbally” (3) and “non-verbally” (4); and can become “habitual” (5) in a variety of ways (Husserl, 1973a, p. 63, my translation). Expression is of fundamental constitutive relevance: Without expression there is no communication, without communication there is no sociality and without sociality there is no lifeworld at all (cf. Husserl, 1989, pp. 186–197, 241–244).

Given the severe loss of verbal language in AD, non-verbal communication seems to be a promising resource. Persons with AD “can perceive everyday situations in an emotionally differentiated way and express their emotional state non-verbally, regardless of the stage of their illness” (Deutscher Ethikrat, 2012, p. 26, my translation). Facial expressions can help to make these emotions understandable, our gestures can support the understanding of verbal language in an “synsemantical” way (Bühler, 1990, p. 39; for dementia cf. Hydén, 2018, pp. 232–234), and the voice can influence general responsiveness – whereby the improvement in responsiveness is related to a reduction in negative behavior (Smith *et al.*, 2011, p. 259). This reveals the expressive body as the interface of embodied intersubjectivity and inter-affectivity which allows “empathy into persons” (Husserl, 1989, p. 244) despite the deficits of AD. These insights into the “importance of bodily-affective interaction” (Meyer, 2014, p. 108, my translation) are not just of particular interest for advanced dementia, but also for rethinking the concept of institutionalized care by contrasting surveillance, discipline and standardization with individual bodily rhythms (for eating, sleeping, toileting, bathing, etc.) and non-verbal bodily expressivity (mimic, gesture, intonation, etc.; cf. Kontos & Martin, 2013). As a result, this approach “shifts the focus of care from dysfunction and control to support of the intentional, meaningful, and even creative ways that persons with dementia can express themselves” by using arts (like music, painting, dancing, theatre etc.; Kontos & Martin, 2013, p. 294).

In the following, I will concentrate on the pointing function of non-verbal, bodily expression in face-to-face interactions (Stukenbrook, 2015). The idea is that the ability to point can be used in AD not only as a *deficit* indicator but also as a *resource* indicator. This thesis shall be clarified with regard to four unique characteristics of pointing: *Firstly*, pointing to the visible is a simple way of referring to something concrete that is around our body without having to use the *synsemantic* field of symbolic language. *Secondly*, pointing to the visible potentially involves the whole range of bodily expression in communication – it can be done through facial expression, gestures, posture, even through the timbre of our voice. Furthermore, it is crucial

for the entire system of language, because *thirdly*, we can refer to individuals, things and facts without knowing the proper names and nouns, in order to (re)learn them. And *fourthly*, pointing can provide an interpersonal synchronization of attention, enabling us “to direct our attention to the same objects together with a reference person (joint attention)” (Fuchs, 2008, p. 25, my translation). Pointing is thus the meeting point of embodied intersubjectivity and collective intentionality.

These four qualities of pointing could also be made fruitful for interaction and communication with persons with AD, who themselves make use of these qualities, as Sabat & Harré (1992, p. 452) have described. Instead of directly confronting your grandmother, who is in the middle stage of AD, with her birthday – which presupposes abstract concepts such as the calendar year or the ‘narrative self’ (Schechtman, 2011) – it would be much easier to start a conversation by pointing to the visible in the mode of ‘I-here-now’, in order to start from the initially intuitive face-to-face situation that Husserl describes as the “natural world of experience in the narrowest sense” (Husserl, 2008, p. 708, my translation). Thus, even the pointing reference to the ‘bad weather out there’ can be enough to synchronize intentionality and initiate potentially successful communication.

Finally, we can use the whole spectrum of bodily expression to improve our communication and thus signal to the other person that we understand (or: do not understand) them when they increasingly use vague expressions, filler words, “dense words” (i.e. indicating complex meaning lacking verbal explication, cf. Hydén, 2018, p. 234) or neologisms (Wendelstein & Felder, 2012, p. 152; van Neer & Braam, 2016, pp. 190f.; Meyer, 2014, pp. 104f.). On the basis of this synchronized intentionality – through which we thus share an “intersubjective horizon” in the sense of a “community of understanding” (Husserl, 2008, p. 710f., my translation) – it should be easier to explore the environment together, share the feelings and thoughts of the other and eat a birthday cake together – even if both parties do not necessarily know who’s birthday it is at all.⁷ This example shows what counts: That the need for communication is appreciated (Smith et al., 2011, p. 259), thus keeping the open process of the social self-constitution going (Sabat & Harre, 1992) instead of clinging to the “fiction of competent adulthood” (Nussbaum, 2006, p. 318). If one modifies basic assumptions of communication – for example that “connections of meaning and thematic continuity” have to be constantly established on the basis of a “reference to shared knowledge” (Meyer, 2014, p. 104, p. 105, my translation) – then persons with dementia are available as communication and interaction partners.

One major challenge which is associated with these modifications is to preserve a reciprocal relationship of trust (see Fuchs, 2015, p. 104) and maintain the “communicative power” (Reichertz et al., 2020, p. 219, my translation) of the other. With regard to the rich communicative and emotional resources another crucial task is to activate them on an individual and situation-specific level (cf. Berendonk & Stanek, 2010), i.e. “one must understand what has been and still is important to that person, how that person communicates, relates to others, reacts to adversity now and how he or she has done so in the past.” (Sabat 2021, 233; for a socio-phenomenological perspective on ‘situations of care’ see Elsbernd 2000). If one considers the general asymmetry in communication and interaction in care for the elderly (Sachweh according to Döttlinger, 2018, p. 17), which is closely

⁷ The impressive example of an inter-bodily, almost non-verbal interaction – which could be interpreted in terms of a phenomenological therapy along the lines of responsivity (Waldenfels, 2019, pp. 290-310) and resonance (Fuchs, 2020, pp. 359-379) synchronizing rhythm and tempo – between Gladys Wilson, who suffers from AD, and her therapist Naomi Feil can be watched at <https://www.youtube.com/watch?v=CrZXz10FcVM>.

associated with malignant social interaction (cf. Sabat, 2021, 245f. with regard to Kitwood), it seems urgent – besides a fundamental change in the political, economic, and institutional framework – to unlock all resources of communication and interaction to realize care as a dialogical relationship and thus to interact with each other instead of doing something to someone.

4. The past in the present: habitus, expression and personal identity

Habitualization is of prominent interest for the philosophical investigation of dementia: habitūs (pl.) can be understood as a sedimented history of our life made of our personal achievements. In this way they function as a kind of implicit context that shapes our being as a whole: They orient our lives and make it comprehensible why we feel, think and act the way we do (Casey, 2000, p. 149). In the sense of an implicit memory, habitūs operate as an important corrective in the one-sided debate about personal identity in dementia. By focusing on the reflective accessibility of one's own past through *declarative* memory – and its differentiation into *episodic* memory for the temporally structured chain of events, *semantic* memory for linguistically coded knowledge and *autobiographical* memory – persons with AD are all too hastily denied personal identity (Brockmeier, 2014, pp. 73–76; Fuchs, 2012, 2018; Tewes, 2020).

As Fuchs (2008) has emphasized, habitualizations can be differentiated in *procedural*, *situational* and *intercorporeal* terms and reactivated in specific ways to make autobiographical aspects (like a former profession) available that are not or no longer accessible to explicit memory (pp. 53–56).⁸ For example, I learn from my early childhood on to use my lived body as the most familiar “organ of the will” (Husserl, 1989, p. 153), containing pre-reflective knowledge of the practical possibilities available to me by movement,⁹ posture, and gesture in certain situations and social contexts based on individual skills (Husserl, 1989, § 38; Kontos, 2012, pp. 3f.;¹⁰ Tewes, 2020, p. 383). The therapeutic potential of such an approach is obvious: Where reflective access to contextual knowledge is no longer possible, the activation of pre-reflective sources is indicated. Especially the case of *expressive* habitualization makes the complex intertwining of *intrapersonal* and *interpersonal* constitution of identity visible.

Expressive habitūs can be seen as a resource that makes the individual person identifiable despite their deficits, since every person has “a way of walking, a way of dancing, a way of speaking” (Husserl, 1989, p. 240), referring to an “individual habitus” (Husserl, 1989, p. 295; on intonation cf. Kontos, 2012, p. 10; for an empirical investigation of gesture cf. Hydén, 2018, pp. 230–239). Words like ‘character’ or ‘style’ indicate individual-typical manners, in which, like an amalgam, the manifold affective, practical and intellectual achievements have been fused together throughout our history. When even Husserl (1989) speaks of style, this is not limited to the “style of life in affection and action” (p. 270); one may also think of the style of clothing (Twigg & Buse, 2013), hair or cosmetics, which allow us to not just identify but also draw conclusions about the respective personality of our counterpart. In this way, it is possible to understand why even persons with severe dementia recognize their loved ones and interact with them with pleasure, even if they cannot retrieve contextual information such as name, profession or age (Kontos, 2012, pp. 7–9).

⁸ A famous example of bodily habitualization through profession is the video of former ballerina Marta Cinta, who suffers from AD: <https://www.youtube.com/watch?v=OT8AdwV0Vkw>. For the example of painting see Kontos (2012, pp. 5–7).

⁹ It can only be pointed out here that movement is a central way of orientation, whose analysis is of particular relevance for the urge to move in persons with dementia (cf. Dzwiza-Ohlsen, 2021).

¹⁰ Notabene: Konto’s approach, highly compatible with ours, combines Merleau-Ponty’s remarks on the lived body with those of Bourdieu’s concept of habitus.

The robust texture of this social bond becomes even more tangible when we consider that expressive habitualization is not only personal, but always takes place interpersonally: Common interests give rise to shared practices, such as dance or football, which become entrenched in structures of “communal spirit” (Husserl, 1989, p. 190), as is the case with friendship, partnership or membership (Husserl, 1989, p. 200).¹¹ Interpersonal expressive habitualizations thus shape our thinking, feeling and acting and lead to the intersubjective synchronization of meanings, values, and processes constituting embodied and culturally embedded practices like “rituals and commemorations” (Tewes, 2020, p. 381). From a therapeutic point of view, it would be advisable to pay more attention to this kind of “social practice” (Kontos, 2012, p. 11) performed by interpersonal expressive habitus. As the example of “musical expressivity” (Tewes, 2020, p. 382) shows, interpersonal expressive habitus have the power to (re)activate collective emotions, thus improving empathic interaction; and they have the power to strengthen, analogous to Husserl’s “I-can” (1989, p. 253), our “fundamental self-confidence” (Fuchs, 2015, p. 103, my translation) in the sense of a cooperative ‘We-can’.¹² Since expression is habitualized in the objects of daily use and in the living environment, familiar objects of daily use act as windows into the past, with which bodily, pre-reflective affects and practices can be reactivated: “The Object”, as Husserl (1989) vividly puts it, “knocks at the door of consciousness [...], it attracts, and [...] wants to be taken up” (pp. 220f.).¹³ The strength of such an approach becomes apparent when we consider that cultural familiarity with such things also leads to the habitualization of complex systems of rules, as can be found, for example, in dance or ball sports (Fuchs quoted by Tewes, 2020, pp. 382f.). Expressive habitualization allows those affected to transfer abstract knowledge into the here and now – an achievement that is typically only ascribed to declarative memory and must remain concealed from the “standard view of memory, identity, and autobiographical time” (Brockmeier, 2014, p. 74).

More than 100 years ago, Husserl (1973a; 1973b) described the lived body as the central interface between thing, space and intersubjectivity, which is why it is of fundamental importance for the entire being of a person (1989, p. 277). Therefore, it is of great therapeutic relevance in AD to activate the situational Body-memory, through which even persons with AD can orientate themselves in familiar surroundings (such as the home, a neighborhood or landscape) for a relatively long time and activate pre-reflective abilities and thus strengthen their self-confidence in an atmosphere of security and safety (cf. Fuchs, 2018, pp. 53–56). In particular, the possibilities of new technologies, such as virtual reality (VR), seem promising: Together with the VR Studio *Weltenweber* and the therapists of the *Helios Klinikum Hüls*, patients in the early stages of AD were able to reconstruct and virtually explore the environment of their childhood.¹⁴ In this way, attention, memory and orientation were stimulated and even the social dimension of affectivity was activated through the participatory design.

If we improve in activating the resources of interaction and communication, unsuccessful interaction with those affected with AD could be minimized and low quality of life maximized. To achieve this, a fundamental change of perspective is of great importance – because AD does

5. Concluding remarks

¹¹ For the possibility of co-habitualization with pets see Dzwiza, 2018.

¹² Whether this interpersonal unit of action, which can also weaken and disable the person concerned (cf. Sabat & Harré, 1992, p. 456ff.), can be understood in the sense of Vygotsky’s “Great-We” is discussed by Reichertz *et al.* (2020, pp. 233f.). Regarding the possibility and reality of *personal assistance*, which strengthens social participation even before the need for care, see Klie (2019).

¹³ This idea can be found in the ‘affordance theory’ (Gibson, 1979), whose therapeutic relevance for dementia is obvious, but still requires comprehensive interpretation.

¹⁴ For an instructive video watch <https://www.youtube.com/watch?v=h43HcYlnN6M>.

not mean that the ‘memory module’ of a brain is defective, but that persons of our lifeworld struggle with the severe consequences of an illness. The lifeworld account is sensitive to precisely this circumstance, capturing the interaction of a bodily-oriented person with their socio-cultural environment. Finally, the immediate social environment’s intimate contextual knowledge about the person affected – of family, friends, relatives, and therapists – is of crucial importance for the interpersonal constitution of meaning. Thus, non-verbal forms of expression in situation-specific terms and habitualized forms of expression in context-specific terms have been identified as an important resource, which becomes particularly valuable when linguistically and reflectively composed knowledge begins to disappear. Regarding the “social side of vulnerability” (Waldenfels, 2019, p. 306, my translation) there is an acute danger that those affected will become socially isolated and, consequently, dehumanized or depersonalized – whether indirectly through science and society or directly through nurses, doctors or even close friends and relatives (Sabat, 2009, p. xii; Kitwood, 1997). The lifeworld approach, which is surprisingly ill-researched, allows us to identify the *trouble génératrice* in terms of structural phenomenology and to view AD not only as an irreversible and neurodegenerative disease to which those affected are fatefully exposed, but also as a psycho- and socio-degenerative illness for which we, as a society, bear responsibility. Or, in the words of René van Neer, who is suffering from AD: “One person alone cannot bear this”, but “meeting another is of ecstatic value to me” (van Neer & Braam, 2016, p. 7, my translation).

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