

Forum

# Self-experience in Dementia

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**Abstract** This paper develops a phenomenological analysis of the disturbances of self-experience in dementia. After considering the lack of conceptual clarity regarding the notions of self and person in current research on dementia, we develop a phenomenological theory of the structure of self-experience in the first section. Within this complex structure, we distinguish between the basic level of pre-reflective self-awareness, the episodic sense of self, and the narrative constitution of the self. In the second section, we focus on dementia and argue that, despite the impairment of narrative self-understanding, more basic moments of self-experience are preserved. In accordance with the theory developed in the first part, we argue that, at least until the final stages of the illness, these self-experience in dementia goes beyond the pure minimal self, and rather entail forms of self-reference and an episodic sense of self.

**KEYWORDS:** Narrative Self; Episodic Self; Minimal Self; Dementia; Self-disturbances; Phenomenological Psychopathology.

**Riassunto** *L'esperienza del sé nella demenza* - Questo articolo sviluppa un'analisi fenomenologica dei disturbi dell'esperienza del sé nella demenza. Dopo aver considerato l'assenza di una piena chiarezza concettuale circa le nozioni di "sé" e "persona" nella letteratura sulle demenze, la prima parte dell'articolo sviluppa una teoria fenomenologica dell'esperienza del sé. In questa struttura complessa distingueremo il livello dell'esperienza preriflessiva del sé, il senso episodico del sé e la costituzione narrativa del sé. Nella seconda parte ci concentreremo sulla demenza, sostenendo che, malgrado la compromissione dell'esperienza del sé narrativo, restano preservati momenti più elementari dell'esperienza del sé. Coerentemente con la teoria presentata nella prima parte, sosteneremo che, quantomeno nelle fasi finali della malattia, questi momenti non si limitano alla dimensione del puro *sé minimo*, ma implicano forme di autoriferimento e un senso episodico del sé.

**PAROLE CHIAVE:** Sé narrativo; Sé episodico; Sé minimo; Demenza; Disturbi del sé; Psicopatologia fenomenologica.



ONE OF THE MAIN FOCUSES of current research in phenomenological psychopathology is the understanding of psychiatric illness-

es as self-disturbances.<sup>1</sup> Therefore, the relation between phenomenology and psychopathology can be seen as a two-way relation.

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On the one hand, phenomenological analyses of self-experience are adopted to understand the experiential features of specific illnesses. On the other hand, those results of the empirical studies concerning those illnesses can also provide insights to further refine or better determine the theory of self-experience. Thus far, there are relatively few phenomenological studies focusing on dementias.<sup>2</sup> However, we believe that the phenomenology of self-experience and its disturbances can also offer a very fruitful approach to addressing such pathologies. Conversely, the study of dementias provides further insights to more concretely address the complexity of self-experience.

Currently, questions related to the preservation of the self, self-identity, and personhood in Alzheimer's disease and other dementias are debated in psychiatry as well as in clinical and social psychology. These questions are of crucial importance not only for theoretical reasons, but also for ethical, clinical, and social reasons. An overview of the debate, however, shows that there is no complete agreement among researchers about the definition of self and person, and consequently there is also none concerning how self and person are affected in dementia. The definition of both concepts, indeed, is alternatively based on different criteria, e.g., psychological, ethical, sociological, theological, interactional, etc.<sup>3</sup>

The concepts of self and person are sometimes considered as equivalent, at other times the concept of person is internally articulated and entails different aspects of human existence, ranging from the biological basis of the organism up to social and moral dimensions. This lack of conceptual clarity generates some confusion as to whether we can talk about the preservation of self and person in dementia. These problems particularly emerge from two somehow conflicting agendas: on the one hand, the attempt to provide descriptive observations concerning how dementia affects self-experience (e.g., memory disturbances, lack or loss of moral responsi-

bility, etc.) and, on the other hand, the need to ethically and socially legitimate person-oriented models of dementia care, which are precisely based on the recognition of person of personhood and the personal dignity of dementia patients.<sup>4</sup>

In this paper, we shall concentrate on the descriptive aspect, and only marginally touch on ethical questions. Rather than trying to disentangle the descriptive, ontological, and ethical dimensions of the concept of person, we shall focus on the concept of self and on the complexity of self-experience. Particularly, we shall address the articulation of pre-reflective and reflective moments of the self. We understand the self as fundamentally grounded in self-experience, i.e., in how one experiences oneself as a living being in a given environment. In our view, the questions related to personhood should also be considered to be grounded in this basic layer of self-experience.<sup>5</sup>

Our leading question, thus, will not be whether we can attribute the status of persons to dementia patients, in relation for instance to their dignity. Without a thorough analysis of the disturbances of self-experience, this question risks confusing the psychological and psychiatric analyses of the disease with the evaluation of the moral, social, and juridical treatment of dementia patients. We believe, however, that the phenomenological analysis of the disturbances of the self and self-experience in dementia offers a fruitful basis, which may be further developed also to also investigate these issues.

One of the problems underlying the above-mentioned conceptual confusion seems to be related to the idea that selves are constitutively narrative unities, i.e., that they are constituted or constructed in and through coherent narrations. Although we believe that narrations play a role in the formation of our self-understanding as persons, we also contend that there are more basic layers of self-experience, which do not have such a narrative structure. Such basic layers, as we will argue, are internally articulated and can en-

tail both pre-reflective self-awareness and reflective moments, which presuppose language but not necessarily narrations.

Discussing the so-called narrative theory of self, in the first section of this paper, we argue that this theory does not offer an exhaustive understanding of self-experience. Based on the phenomenological inquiries into self-experience, an alternative account, which considers the self as fundamentally related to the sense of “mineness”, will be proposed. In the second section, we will more directly focus on dementia and argue that, although higher-order forms of narrative self-understanding are severely impaired, more basic moments of self-experience are preserved. We argue that, at least until the final stages of the illness, these moments go beyond the pure idea of a minimal self, and rather entail the capacity for self-reference, self-other distinction, implicit memory, and emotions.

### ■ Sense of self, self-reference, and narrative

In this section, we introduce some important distinctions concerning the nature of self-experience, self-reference, and narrativity, which will guide our understanding of the disturbances of self in dementia. The narrative account of the self, with its many variants, currently counts among the most widespread theories aiming to define what a self is and how it is constituted. Several authors coming from different philosophical traditions have developed different versions of such a theory.

As it has been shown, these theories differ from one another in some essential respects, and there is little consensus on what the narrative view of the self should entail.<sup>6</sup> Nevertheless, there are some shared presuppositions of the different narrative accounts of the self. The most important presupposition seems to be the idea that the concept of self applies to beings who are capable of “making sense” or giving meaning to their lives in a

social and cultural context. From this perspective, the notion of narrative self also becomes relevant within the ethical discourse.

Indeed, as Strawson points out,<sup>7</sup> considering the narrative accounts of the self, two main theses can be distinguished: the “psychological Narrativity thesis” and the “ethical Narrativity thesis”. Whereas the former is a straightforward empirical and descriptive thesis about how human beings experience their lives, the latter entails the normative claim according to which conceiving or living one’s life as a narrative unity is *per se* a good thing. Depending on how one understands narrativity, one can subscribe to or reject both theses altogether, or one can subscribe to one of them but not to the other. As we shall see, however, in several accounts of the narrative self, the two theses seem to be, more or less explicitly, connected.

Our critical assessment of some implications of the narrative accounts of the self is not intended to deny the crucial role that the elaboration of self-narrations can play in understanding ourselves as moral beings in a community. Nevertheless, we shall argue that there are dimensions of our lives, which we would still recognize as constitutive of the self, that do not have such a narrative structure, although they can entail basic forms of self-reference. In other words, we do believe that the idea of a narrative self is suitable for elaborating a theory of the person as a moral, responsible, and social being. Yet, we also defend a larger understanding of the self, which not only entails aspects that are relevant for ethical and cultural discourse, but also more basic aspects that relate to our active and passive experience and engagement with the world and with others, mostly at the sensory and affective levels, as well as the capacity for self-reference.

Also, we do not claim that narrativists would simply neglect that there are such aspects, although they do not seem to consider them relevant for a theory of the self. And this precisely because the concept of self they adopt seems to come closer to the full-fledged

ged idea of person. In the second section of this paper, we shall argue that, although several moments of the narrative self and personhood are impaired in dementia, more basic aspects, which entail not only immediate and direct experience but also elementary forms of self-reference, are preserved up to the advanced stages.

The claim that both our sense of self and our lives are constitutively narrative in their structure and that such narrative self-constitution has an impact on our self-understanding as moral and social beings has been defended, from partially different perspectives, by Ricoeur, MacIntyre, and Taylor.<sup>8</sup> Also, Dennett,<sup>9</sup> despite considering the self as nothing more than a useful fiction, claims that such a fiction is necessarily constituted through narrative. However, he also emphasizes that we should distinguish the narrator of the story (in his view, the brain as a narrative generating machine) from the protagonist of the story, which is precisely generated by the narrating brain.

Despite all the differences among these and other positions on what it means that selves are constituted through narrative, which we cannot discuss here, it is possible to highlight some important and reciprocally interconnected implications of the very idea of a narrative self, independently of the specific nuances of each theory. We shall now introduce and then critically discuss four of these implications, which are particularly relevant for our interpretation of self-experience in dementia.

*First*, narrative accounts of self presuppose a specific understanding of temporality. Narrative temporality, indeed, is not reducible to either objectively measurable, physical time, or to the subjective experience of pure lived-duration. It is rather the temporality of a story, with its development that unfolds from the beginning to the end.<sup>10</sup> In this sense, as Strawson emphasizes,<sup>11</sup> narrations are based on the sense of diachronicity, i.e., on the conception of oneself as something that was there in the further past and will be there in

the further future.<sup>12</sup>

*Secondly*, if the self is an interpreting being and if it is constituted in and through narratives, then it should also be conceived as the product of the reflection on and the interpretation of singular episodes and their diachronic interconnections. These episodes, as well as their interconnections and diachronic articulation within the overarching unity of a life-history, are understood as meaningful unities. Accordingly, self-narratives, although they do not need to really assume the shape of an autobiography, are grounded in what is generally addressed as autobiographical memory. Moreover, they necessarily have a meaningful structure and are symbolically mediated.<sup>13</sup>

*Thirdly*, the meaningfulness of one's life-history should be primarily understood in relation to the valuable or significant aspects in one's own life and to purposeful agency in social and cultural contexts.<sup>14</sup> What we include in our self-narratives is "what matters" to us: not merely something that we experience or that happens to us, but rather moments of our personal agency. Narrativity, in this sense, applies to both singular actions, characterized by purposefulness and unfolding in a given time-span, and to the unity of a life-history. Accordingly, on this account, narratives have ethical relevance and axiological implications: the narrative interpretation of actions depends on what we recognize as values, aims, ideals, etc.

*Fourthly*, narratives will be considered as related to intersubjectivity, sociality, and culture. This is primarily because stories are elaborated to be narrated to others or to be read by others. Therefore, a more or less explicit communicative and social endeavor is entailed by the very definition of narrativity. Moreover, given that through narratives we primarily understand ourselves as agents, we will recognize that actions generally assume their meaning only within a cultural domain, that they can ground the recognition of cultural membership, and that they mostly have an interactive component. These implica-

tions of the narrative accounts of the self converge in two main points.

On the one hand, narrative accounts of the self are deeply related to the attempt to make sense of human life and particularly human agency. Therefore, they have the power to give shape and meaning to the temporality, the events, the decisions, and the actions of one's own life. In this respect, however, it is questionable whether such shape and such meaning are there from the beginning, or rather whether they are exactly what the narrative produces. This is notably implied by the fact that narratives, as we mentioned, are the result of acts of reflection and entail an interpretation of what has already happened in relation to larger meaningful and diachronic unities. On the other hand, if the self is understood as a narrative unity, and if the narration is what expresses the ultimate aim and meaningfulness of each of our actions, then the self is supposed to inherently have a teleological nature. Its ultimate aim is that of living a good life.<sup>15</sup> Although this ethical/teleological dimension is not equally present in all narrative accounts of the self, it seems to be implied whenever emphasis is put on the relation between self and agency, as well as on the relation between agency, moral values, and deliberations.

Although we would agree with the claim that telling stories about one's life, giving a meaningful shape to one's actions, and understanding one's own life-history in terms of the "things that matter" play an important role in one's own self-understanding and in the constitution of ourselves as persons, we do not believe that the narrative accounts are really exhaustive concerning the question of self-experience.

More precisely, we consider that such approaches set too high requirements for talking about the self and, in so doing, they underestimate more elementary forms of self-experience. Accordingly, we agree that narratives help us in making sense of our lives – think of the importance of self-narration in

therapeutic settings, or even more commonly, on how we often try to sort out our lives by talking with friends. However, we also believe that, first, meaning and coherence are something that we often retrospectively elaborate on the basis of the interpretation of what has already happened, or that they relate to some future or "prospective" sense-making, which however remains indeterminate. Secondly, we do also have some pre-narrative forms of self-experience, which can entail not only moments related to an immediate sense of mineness, but also forms of reflective self-reference. We shall now expand on these points by critically replying to the four above mentioned implications of the narrative account of the self.

### ■ The temporality of self-experience

When we look at the train passing, when we listen to a melody, or when we write a letter, we are not only consciously aware of what we are attending to. We are also aware of the temporality of our action or of our perception.<sup>16</sup> This is not only true when we act or when we perceive change, but also when we perceive something unchanging, like an enduring note. As is well known, Husserl<sup>17</sup> develops a micro-analysis of time-consciousness by showing how each and every experience is based on the temporal interweaving of original impression, retention, and protention. The just elapsed note of the melody is still present to us while we perceive the next one, and we implicitly anticipate that yet another is coming.

Without discussing all the details of the complex phenomenological analyses of time consciousness, it is important to highlight that such a micro-structure of experience, going through to the whole stream of consciousness, entails a most basic kind of self-awareness, which is not articulated in a narrative form. We shall be disappointed if the melody is suddenly interrupted, which means that we have a sense for the temporal unfolding not only of the object in question, but al-

so of our perception thereof. Such a spreading-out of experience, however, does not have the structure of an unfolding story, with a beginning, a meaningful, and an end. It is experienced, in Bergson's terminology, as duration.<sup>18</sup>

Moreover, the temporality of the self is often episodic, rather than diachronic and narrative. As Strawson argues, our sense of self emerges in each experiential episode, i.e., the sense of self does not necessarily presuppose that we conceive of ourselves as something that was there in the further past and will be there in the further future.<sup>19</sup> The structure of episodic temporality is still that of the retentive-protentive interweaving, yet the episode we are living-through does not need to be coherently situated within the overarching unity of a life-history. We are present to us as temporal beings in each and every episode.

This idea of episodic temporality can also be found in Husserl's theory of perception. Indeed, every act of perception, according to Husserl, certainly has spatial and temporal horizons and is intertwined with other acts. However, each and every act of perception is also a concrete unity in itself, within which we can reflectively select singular and smaller unities, all having the character of unitary episodic perceptions.<sup>20</sup> Grounded on the more original and unbroken unity of the temporal stream of consciousness, which is also the condition of possibility for every narrative self-interpretation,<sup>21</sup> this possible "fragmentation" highlights the partial autonomy of each perceptual episode and consequently of the self in each perceptual episode.<sup>22</sup>

This view has clear implications for the role of memory in self-experience. In narrative accounts, the relevant memory is explicit, and notably autobiographical. In the account of self-experience we are privileging here, the relevant memory is instead implicit: it entails, in the most fundamental sense, the retentive awareness of our past, embodied habits and other kinds of bodily and situation-related associative memories.<sup>23</sup>

## Self-awareness, self-reference, and narrativity

In phenomenology, it has often been emphasized that the self cannot be considered as a monolith; it rather has a complex structure, within which basic layers of self-experience are distinguishable from higher layers, involving reflection on one's own experience.<sup>24</sup> The notion of minimal self is often adopted in current research in order to name such basic layers of experience. When I am seeing a tree, listening to a melody, or desiring to eat a piece of cake, I am certainly primarily aware of the tree, the melody, and the cake as the objects which my acts are directed to. However, in all cases, I am also aware that it is "me" who is seeing, listening, and desiring.

The "sense of mineness", which all my experiences have in common, grounds the sense of self in the most fundamental and comprehensive sense. And this for two reasons: first, because this sense of mineness characterizes all experiences, even those that are not reflected upon, and secondly, because it extends from the domain of bodily sensations up to the higher sphere of predicative thought.

Being based on autobiographical memory and self-reflection, self-narrations are nevertheless grounded in this basic pre-reflective self-awareness. Besides such awareness, however, self-narrations also entail self-reflection, identification over time, and the faculty to give a meaningful shape to the succession of one's own experiences. This being said we also believe that the relation between the minimal and the narrative self should be more closely investigated.

First, whereas the notion of narrative self, in spite of all the nuances of the various interpretations, is quite consistently defined, the notion of minimal self is rather ambiguous. For instance, different claims have been made as to whether the minimal self does or does not entail something like temporal spreading-out and implicit memory, as to whether it should or should not be consid-

ered as relational and social, etc.<sup>25</sup> In our account, the minimal self should be understood as related to the basic sense of mineness, which also implies a sense of otherness and is grounded in sentience, and in the micro-structure of temporal spreading-out we described above. This kind of awareness can be said to be immediate, since it is not grounded in any self-reflection and identification over time, but rather only on the implicit awareness of my being episodically “present” in my thinking, feeling, moving, etc.

Secondly, it is hard to find the pure form of this elementary kind of self-experience. Forms of non-narrative, episodic linguistic mediation, like indexical or gestural self-reference, as we will see, are preserved even in cases of highly impaired cognitive capacities. Such self-reference already entails a form of self-reflection, and accordingly goes beyond the minimal level of sentience, but it does not entail any narrative self-understanding. Referring to myself as “me”, I do not remain on the level of purely living-through an experience, nor do I *eo ipso* elaborate a story about myself, although I accomplish a form of episodic self-reflection. Such moments of self-reference are presupposed by the elaboration of self-narratives, since there cannot be a narrative about oneself which does not include self-referential terms. Accordingly, we suggest that these forms of self-reference, together with an extended awareness of diachronicity, can define the basis for the transition from the minimal sense of self to higher levels of narrative self-experience.

Understood in relation to self-reference, the sense of self entails the possibility of becoming aware of the “polarization” of our experience, which is implied while we experience ourselves as being affected by something other and as being the source of possible actions.<sup>26</sup> Finally, the sense of self is primarily mediated by the body, as the carrier of sensations, as the centre of orientation, and as the source of movement. Bodily self-experience is further essentially affected by implicit body memory.<sup>27</sup>

## Values and emotional experience

As we mentioned, narrative accounts of the self often entail the reference to values and to a teleological understanding of self-experience as oriented towards a “good life”. Also, in this case, we do not want to neglect that, in making sense of our lives through the elaboration of stories about ourselves, we tend to emphasize the moments that are relevant to us: ideals, decisions, and generally experiences that matter. Nevertheless, facts and experiences that make up our lives are often interpreted as meaningful only *ex post facto*, as if reflectively related to some form of “teleological” development in our self-understanding.

Even prospective narrations about how we imagine ourselves in the future are embedded in such “teleological” self-understanding and do not fully determine the way we experience ourselves in specific contingent situations (otherwise we could not explain, for instance, how something like the experience of being surprised about oneself is possible). Thus, we contend that what structurally comes “before” such a meaningful interpretation also has the character of self-experience. Moreover, we shall emphasize that not all experiences in which we are aware of ourselves can be understood as purposeful actions. A sense of self also emerges in very elementary experiences like sensing, bodily moving, perceiving, etc. And finally, the constitution of values can be considered as grounded in feelings and emotions,<sup>28</sup> and both feelings and emotions are vehicle for self-awareness.

In some recent studies, the claim has been made that emotions also have a narrative structure. For instance, according to Goldie,<sup>29</sup> narration is responsible for synthesizing the intentionality of feelings (feelings toward) and their bodily relatedness (bodily feelings) in the unity of an emotion. Accordingly, emotions are unities grounded on feelings and are themselves further organized within the larger narrative unity of a personal life-

history. Slaby<sup>30</sup> understands feelings and emotions as expressing the subjective apprehension of the value of an object or a situation. He further argues that the meaningfulness of feelings and emotions can be explicated in a narrative way. Thus, narrativity is considered to shape a structural unity embracing the different partial aspects of affective states and to synthesize them. The narrativity of emotions, then, refers to both the unity of singular episodes and the embedding of such episodes in the larger unity of subjective life.

With regard to this theory, it is again questionable whether the temporality of feelings and emotions corresponds to that of a narrative. Feelings and emotions are primarily something that affects or surprises us as a kind of *Widerfahrnis*.<sup>31</sup> Accordingly, the narrative explication of feelings and emotions is something retrospective and presupposes what we have called pre-reflective experience, in which specific emotions and feelings passively emerge.<sup>32</sup> Such experience is also grounded upon the threefold structure of inner time consciousness (presentation, retention, and protention), yet it also entails moments that are more closely related to our lived-body.

In all cases, I am aware that it is “me” who experiences an emotion or who is affected by a feeling. Accordingly, we contend that the sense of mineness also emerges in emotional experience before the explicit thematization of the emotion itself and before the thematic constitution and apprehension of values, and notably of moral values.

## ■ Self and other

As we mentioned above, intersubjectivity plays an important role in narrative approaches to the self. Narrations only make sense within an intersubjective context, in which we communicate to others what we consider to be meaningful about our lives. Moreover, as Zahavi points out,<sup>33</sup> intersubjectivity is crucial in the very formation of narratives. Even if I can be both the narrator

and the main character of my life-history, I certainly cannot be its sole author. I am not responsible for the beginning of my own story, which has always already been made for me by others. Also, my choices and decisions, and more generally my “being in the world” always involve others. In this sense, self-narratives should indeed be considered as the result of “co-authorship”, since others and my relationships to others essentially contribute to shaping “who I am”. Self-narrations are always embedded in larger social, historical, and cultural forms of sense-making, and they acquire their meaningfulness only against that background.

Emphasizing the meaning of sociality and co-authorship, however, does not mean that we can simply “delegate” to others the task of making (narrative) sense of our lives. As we shall see, this option has been defended in some studies on dementia. Yet, on our account, self-experience primarily concerns me, and it is not something I can delegate to someone else. In other words, the emphasis on the role of intersubjectivity and sociality in the constitution of meaning, and in shaping the narratives of our lives as meaningful unities, should not be understood as something that overcomes the fundamental asymmetry between self and other.

Despite all intersubjective communication and sharing of a common world, there is a sense in which the experiences of the other remain inaccessible to me, and conversely there is a sense in which my own experiences are inaccessible to others. Or, to put it in a better way, there is a fundamental and inevitable asymmetry between how I experience my own pain, anger, or happiness, and the way my pain, anger, or happiness are experienced by others.

Again, narrations are not the primal way in which we experience ourselves in intersubjective relationships. As Zahavi argues,<sup>34</sup> this claim can be substantiated both from a developmental-psychological and from a phenomenological point of view. Developmentally, children engage in sophisticated forms



of social interactions (e.g., through eye-contact, expression, and bodily behavior) much before they acquire the capacity to tell stories. Moreover, our experience of the other's feelings, desires, and beliefs is arguably not only mediated by the stories the other tells about him/herself. Primarily, such an experience is mediated by bodily behavior and expression in a meaningful context. I do see the pain on your face when I see you crying, although I am also immediately aware that I do not experience that pain in the same way as you do.<sup>35</sup>

Our sense of self, thus, is deeply intertwined with a sense of otherness, which precedes and grounds the elaboration of narratives, although it can also entail some pre-narrative forms of self- and other-reference. Such experience of otherness does not imply autobiographical explicit memory, and yet it can also entail moments of implicit awareness of our past interactions, mostly embodied in concrete attitudes, behavior, gestures, expressions, role-taking, etc.<sup>36</sup>

In the next section we shall discuss the implications of these remarks on the complexity of the self for the phenomenological analyses of the disturbances of self-experience in dementia.

### **Self-experience in dementia: A phenomenological account**

In the previous section we addressed the complexity of self-experience by critically discussing some central aspects of the narrative theory of the self. Specifically, we have seen that self-narratives are relevant for making sense of our lives as well as for understanding ourselves as responsible persons and moral beings. Yet, self-narratives should be considered as grounded upon a more basic sense of self, which accompanies each and every experience, and also upon forms of self-reference that do not originally have a narrative structure, but can be considered as episodic. Concretely speaking, what we have addressed as the basic sense of self and epi-

sodic self-reference can be analyzed by considering those cases in which the capacity for narrative self-reference has not been developed yet, as in very early infancy, or in cases in which it has been impaired. Dementia is an example of the latter case.

Dementias, indeed, comprehend a complex set of neurodegenerative diseases, characterized by the progressive impairment of several cognitive capacities.<sup>37</sup> Such impairments, and notably those related to autobiographical memory and the sense for diachronicity, clearly impinge on the narrative capacity. The question concerning the preservation of the self in the current research on dementia is often motivated by observations related to such impairments. This shows how the narrative theory of the self, even when it is not explicitly thematized, at least implicitly shapes the discussion in several disciplines and in the public discourse.

As has been argued,<sup>38</sup> although there are several differences among those theories and although there is no univocal interpretation of what the self and self-experience are, many theories seem to converge on the idea that the self is diachronically, narratively, and socially constructed. The previous account of the complex relation between the basic sense of self, self-reference, and self-narratives can allow us to better identify which layers of experience are affected in dementia and which are preserved in spite of the mentioned cognitive impairments.

In what follows, we shall proceed along the lines of the previous discussion and focus on the four main points we have assumed as guiding threads in the first section of this essay: (1) the temporality of self-experience; (2) self-awareness and self-reference; (3) values and emotional experience; and (4) the relationship between self and other.

### **Temporality**

As is well known, memory impairments are among the first symptoms characterizing dementia. For our argument, the impairment

of autobiographical memory is particularly relevant, since such memory, related to the consciousness of diachronicity, plays an important role in shaping our self-narratives. The suggestion we have made in the previous section is that we can still talk about a sense of self in temporal unfolding, without presupposing autobiographical memory and diachronic self-understanding (i.e., without conceiving of oneself as existing in the further past and future).

In his seminal work on lived time and the disturbances of temporal experience, Minkowski<sup>39</sup> develops some important insights into the relation between the basic sense of self and the experience of time in dementia. He particularly emphasizes that dementia patients, in the early and intermediate stages of the illness and when they are still capable of expressing themselves through language, tend to situate themselves in precise and episodically contingent temporal coordinates ("today", "right now"), even when this does not seem to be required.

According to Minkowski, this is strictly related to the patients' need to establish some sense of familiarity in the present moment, or to their search for orientation in the experienced situation. This tie to the present situation somehow works as a compensation for the incapacity to locate oneself in the larger diachronic horizon of time in the world. Emphasizing the bond with the present situation, these remarks indicate that dementia patients are aware of themselves as episodically experiencing beings in this concrete situation, in which they try to find some backing sense of familiarity.

The situational relatedness of dementia patients' pre-reflexive temporal experience, however, does not exclude the possibility that the past, although not recollected or articulated in a narrative way, also plays a role in shaping such experience. As we mentioned above, our episodic experience of a situation entails a fundamental implicit relation with our past, which we understand under the heading of implicit memory and body memory.<sup>40</sup> Differ-

ent from explicit memory, and notably from autobiographical memory, implicit memory is not grounded upon an explicit sense of diachronicity and does not mentally "reproduce" the past through an act of recollection. In implicit memory, the past is rather enacted or has a pre-thematic impact on our present experience without a conscious presentification of specific objects, experiences, or events. Besides, if we do not reduce experience only to mental processes, but rather take its concrete unfolding into consideration, we shall recognize that implicit memories are strictly related to the lived-body. Our episodic sense of self is deeply shaped by implicit body memory, which can be considered to entail the totality of those dispositions which are mediated by bodily experience.

The preservation of implicit memory until later stages of the development of dementia has been demonstrated, on the one hand, on the basis of priming studies and the analysis of habitual learning.<sup>41</sup> These studies show how, despite the cognitive impairments that affect explicit categorization and word-finding, dementia patients are familiar with patterns they have habitually acquired. On the other hand, preservation of implicit memory in dementia patients has also been investigated through qualitative interviews<sup>42</sup> and anthropologically based studies on posture, bodily habits and the capacity to properly use tools or musical instruments.<sup>43</sup>

On the basis of these studies, it has been argued that, different from explicit memory, the impairment of implicit memory is not among the main symptoms of the illness until its later stages. This, on our view, has important implications for the basic sense of self in dementia patients. Up to the later and most advanced stages, dementia patients are still familiar with certain habitual perceptual and experiential patterns, and tend to enact the schemas of behavior they are familiar with. Moreover, they implicitly recognize those familiar faces, places, and situations which have shaped their lives, although they are not able to give them a name or to explicitly reflect on

how such an experience of familiarity relates to them as experiencing beings. Finally, they may still be affected by an earlier traumatic experience, despite being incapable of explicitly recollecting the traumatic event.<sup>44</sup>

### ■ Self-awareness and self-reference

In their seminal studies, both Minkowski<sup>45</sup> and Tatossian<sup>46</sup> focus on the description of self-experience in dementia. Both emphasize a characteristic kind of “disorientation” as an important feature of this experience. Unlike other pathologies, such as for instance schizophrenia, this disorientation is not related to the basic layers of bodily, spatio-temporal situatedness, but rather affects patients’ capacity to distance themselves from their being in a given situation, here and now.<sup>47</sup> Correspondingly, dementia patients may well be able to navigate their familiar environment and at the same time be unable to draw a map of their home.<sup>48</sup> In other words, bodily or functional spatial orientation is preserved in dementia patient, although they are not capable of mentally constructing an image of their rooms relative to each other. Similarly, patients with beginning dementia have been shown to perform better in egocentric than in allocentric spatial orientation tasks.<sup>49</sup>

According to Tatossian,<sup>50</sup> dementia patients are mostly unable to decenter themselves, or to move from the immediate living-through [*vivre*] a situation to the reflective apprehension of themselves as the ones who experience that situation [*se vivre*]. Accordingly, dementia is understood as a disturbance of self-reflection and therefore also of the capacity to elaborate a consistent and meaningful story about oneself. Although an episodic sense of self as experiencing the contingent situation here and now is still preserved, these patients are incapable to develop a reflective account of their experience, to elaborate on its meaning, and to explicitly connect the present episode with the diachronic unfolding of their life-history.

Such impairments, which clearly impinge on narrative capacities, are precisely related to the previously mentioned difficulties in distancing themselves from the “here and now”. For this reason, patients seem to feel more at ease in what they implicitly recognize as a safe and familiar milieu, and they try to maintain stability in such a milieu, for instance, as we mentioned, by referring to its spatio-temporal coordinates.

Suggesting that self-relatedness in dementia patients is not elaborated in a consistent narrative way, however, does not mean that the capacity of reflective self-reference is totally absent. As we saw in the previous section of this essay, besides the minimal and immediate sense of self, we will also count the capacity for self-reference as more fundamental than, and as a pre-condition for, the elaboration of self-narratives. This capacity already entails a form of reflection and is articulated either linguistically, through the use of indexical terms, or through self-related bodily expressions and gestures.

Both forms of self-reference have been recognized up to the later stages of the illness. For instance, the competent use of first-personal pronouns and other self-related indexicals,<sup>51</sup> as well as competent self-reference through mimicry, language and gestures,<sup>52</sup> indicate that dementia patients not only experience a basic sense of self, but also display a capacity for self-reference which is mediated by the centrality of one’s body. Discussing how dementia patients constantly refer to their own bodies, Tatossian speaks about a kind of «narcissism reduced to one’s own body and its stereotypical activity».<sup>53</sup> As has further been shown, dementia patients are still aware of the centrality of their own body and of the sense of mineness that characterizes bodily experience.<sup>54</sup>

Certainly, all these forms of self-reference do not usually entail any sense of diachronicity and they are not consistently articulated in a narrative form. They remain episodic, although they seem to reach beyond the immediate, pre-reflective self-awareness.

## Values and emotional experience

Due to the cognitive impairments characterizing the illness, dementia patients cannot be properly considered as morally responsible subjects: they are often not aware of the consequences of their actions in the public sphere and they do not seem to be able to fully recognize the moral values that are assumed within a given culture. Accordingly, dementia patients are also not properly able to think about themselves as morally responsible agents. This becomes manifest not only in discourses about general values and their meaning but also in concrete, everyday behavior, for instance in the way patients address people in hosting institutions or relatives.

The inappropriateness of dementia patients' social behavior and the lack of social competences seem to be connected both with the difficulties in recognizing conventions that are linked to culturally accepted values and to the incapacity to recognize others as moral subjects. Based on these remarks, some researchers have argued that the lack of social competences generates a progressive "loss" of the self. Fontana and Smith explicitly talk about "unbecoming a self" as a characteristic process in dementia.<sup>55</sup> Also, Kitwood and Bredin, despite emphasizing the need to recognize the personal dignity of dementia patients, describe dementia as a process of «drifting toward the threshold of unbeing», thereby precisely focusing on the disturbances of social competences.<sup>56</sup>

The difficulties in "self-decentering", which we have previously considered, also impinge on social interactions, for they imply impairments in capacity of explicit perspective-taking. Dementia patients also have difficulties in recognizing themselves and others as equal members of a community. And all this certainly has ethical implications, related to the difficulty of recognizing moral values and the disturbance of moral feelings such as respect. We consider these disturbances to be connected to narrative self-understanding, in so far as narrativity, as we have seen in the pre-

vious section, is strictly related to the meaning we give to our lives and to the reformulation of the conception of the moral agent.

As in the previous section, we shall connect the experience of values with emotional experience, which also entails an evaluation of lived situation, although not necessarily elaborated in explicit and narrative terms. Recognizing the disturbances of what we would call the understanding of oneself as person in a full-fledged sense, we believe that, at different stages of the development of the illness, the emotional experience of dementia patients also testifies to the progressive alteration of their sense of self.

The development of emotional experience in dementia patients reveals to us once more that, although narrative self-understanding is impaired, the self-experience of dementia patients cannot be *eo ipso* limited exclusively to the pre-linguistic and pre-reflective sphere. The capacity of episodic self-reference, which we have previously considered in relation to the use of self-related indexicals and gestures, is often connected to self-related feelings and mostly mediated by the power of implicit memory. For instance, despite the disturbances of autobiographical memory, lexical impairments, and difficulties in articulating a consistent interpretation of a situation, in the initial and intermediate stages of dementia, patients appear to be quite well aware of their illness and its possible consequences.

Although they are not able to properly compare their actual with their previous condition, they often show frustration when they feel or grasp that something has radically and irreversibly changed. Moreover, they often show clear signs of regretting something they have lost of their previous life, even without being able to name that something. This is the case, for instance, in two patients' interviews discussed by Sabat and Harré.<sup>57</sup> Both interviewed patients held an academic degree and, despite their problems in word finding and their incapacity to recollect the years of their academic activity, they

experienced with great sorrow, frustration, and shame their current lack of the rhetoric capacities they once used to have.

Moreover, these patients showed pride when their intellectual capacities were still recognized by the interlocutors.<sup>58</sup> These self-related feelings and emotions certainly go beyond the most basic layer of pre-reflective self-awareness. And this shows us once again that we need to recognize self-reference as something that surpasses the immediate experience of mineness, while still not being articulated in narrative terms.

Besides, in the initial stages of the illness, self-reference, albeit episodic, also entails at least some openness to the near future. This is what often generates feelings of concern or anxiety when anticipating the development of the illness as something one does not have under control. Towards the final stages of the illness, instead, emotional experience seems to be rather confined to the present. Again, the search for stability in the present situation compensates for the disorientation and the loss of openness to the future, even in the “negative” sense of not being able to predict what will happen to oneself. In the intermediate and final stages, self-relatedness is mostly mediated by bodily feelings and by the need for stability and a sense of familiarity.<sup>59</sup>

## Self and other

As we mentioned, the assumption that narrativity is constitutive of the self characterizes some of the approaches aiming to legitimize the idea that the self is preserved in dementia.<sup>60</sup> However, these approaches regard the preservation of the self as strictly related to social constructions. For instance, it has been suggested that its persistence can be grounded upon the stories others tell about the patients. Such narrations would constitute the identity of the self on the basis of “collective authorship”<sup>61</sup> and of a “web of interlocutions”.<sup>62</sup>

Although we do consider a self-narrative as something that acquires its meaning only

in an intersubjective context, we also contend that one should not ignore the fundamental asymmetry between self and other and the irreducibility of the first-person-perspective. These approaches tend to neglect the sense of mineness that uniquely characterizes my experience and the meaning of self-reference. Accordingly, they also tend to consider the self as being exclusively socially determined. Consistent with the approach we have been defending throughout this paper, we believe that the inquiry into the self needs to be primarily anchored in self-experience and that self-experience is not something we can delegate to others.

Rather than focusing on the attempt to legitimate the narrative sense of self, we regard the relation between self and other in dementia patients as based on their bodily sense of self and their capacity for self-reference, which entails the faculty of differentiating self and other. Some studies conducted from both a socio-linguistic and an anthropological point of view substantiate this view by revealing that self- and other-relatedness in interactions is not completely lost in dementia.<sup>63</sup> It has been shown that patients are able to implicitly distinguish what belongs to them, and that they react with disappointment and get into conflicts if that primary sphere of one’s own property is somehow violated by others.<sup>64</sup>

This certainly testifies to what we have previously addressed as the centrality of self-experience and sometimes also for the lack of social competence and the incapacity to explicitly take the perspective of the interacting other, i.e., to understand the other’s wishes or motivations. However, this also reveals that patients are aware of the distinction between what belongs to one’s own sphere and what belongs to others, and that they try to protect their own sphere. Moreover, dementia patients are often capable of mimicry and imitation, which seems to testify to at least an elementary capacity to take the perspective of the other, namely to reproduce characteristic traits of the other’s behavior even with-

out being aware of the intentions underlying such behavior.<sup>65</sup>

All of the mentioned forms of interaction are primarily related to intercorporeality, since they are based on the experience of the centrality of one's own lived-body and on the distinction of the "here" of one's own body from the "there" of the other's body. Although they do not entail the explicit recognition of the other as a moral agent, and although they are often characterized by some lack in social competences, intercorporeal interactions play an essential role in self-experience. Strictly related to emotional experience, they may be understood as grounding an "atmospheric dimension of contact" with others<sup>66</sup> which also entails moments of conflict and the capacity to set boundaries.

## Conclusion

The aim of this paper was to investigate the disturbances of the self and self-experience in dementia from a phenomenological standpoint. To introduce our approach to self-experience, in the first section, we have critically addressed some central assumptions of the narrative accounts of the self.

Focusing on the discussion of four main implications of the narrative account, related to (1) temporality, (2) self-awareness, (3) values and emotions, and (4) intersubjectivity, we were able to highlight the layers of self-experience that ground all narrative self-understanding. In particular, we suggested that the narrative sense of self, which may be considered constitutive for our self-understanding as persons and moral agents, is grounded on the minimal sense of self, notably including the pre-reflective feeling of mineness and sentience.

Critically assessing some disagreements in current approaches to the minimal self, we argued that, despite characterizing all experiences, such a minimal sense of self can hardly be found in its pure form within human experience. Only the very ultimate phase of dementia may perhaps be an example there-

of. Therefore, we suggested that the capacity for episodic self-reference, which already includes at least a proto-kind of reflection and language (at least indexicals) but is not articulated in a narrative way, should also be considered as a pre-condition for elaborating self-narratives. Besides the episodic sense of self, the elaboration of self-narratives also requires the sense of diachronicity and hermeneutic capacities.

In the second section, we followed the same path by reconsidering the four mentioned points in connection to studies related to the experience of dementia patients. We argued that what is characteristic of such experience is the impairment of narrative coherence, with other layers of self-experience still being preserved. Thus, the inquiry into dementia seems to substantiate our theoretical claim that both the minimal sense of mineness and the capacity for episodic and indexical self-reference can be preserved in spite of impairments in narrative self-understanding. This is also of crucial importance for person-oriented models of dementia care which are based on an extended notion of personhood. Such a notion regards the person neither as exclusively constituted through a narrative self-concept nor through socially constructed identity criteria, but rather as being grounded in a primary, embodied sense of mineness and self-awareness, which is preserved up until the final stages of dementia.

## Notes

<sup>1</sup> See, among others, T. FUCHS, *Phenomenology and Psychopathology*, in: S. GALLAGHER, D. SCHMICKING (eds.), *Handbook of Phenomenology and Cognitive Sciences*, Springer, Dordrecht, New York, Heidelberg, London 2010, pp. 536-562; S. GALLAGHER, D. ZAHAVI, *The Phenomenological Mind*, Routledge, London, New York 2008; D. ZAHAVI (ed.), *Exploring the Self. Philosophical and Psychopathological Perspectives on Self-Experience*, John Benjamins, Amsterdam, Philadelphia 2000; D. ZAHAVI, *Subjectivity and Selfhood. Investigating the First-Person Perspective*, MIT Press, Cam-

bridge (MA)/London 2005.

<sup>2</sup> See, E. MINKOWSKI, *Le temps vécu. Études phénoménologiques et psychopathologiques* (1933), PUF, Paris 1995; A. TATOSSIAN, *Phénoménologie des états démentiels*, in: «Psychologie Médicale», vol. XIX, n. 8, pp. 1205-1207; T. FUCHS, *Das Leibgedächtnis in der Demenz*, in: A. KRUSE (ed.), *Lebensqualität bei Demenz. Zum gesellschaftlichen und individuellen Umgang mit einer Grenzsituation im Alter*, Akademische Verlagsgesellschaft Heidelberg, Heidelberg 2010, pp. 231-242; M. SUMMA, *Zwischen Erinnern und Vergessen. Implizites Leibgedächtnis und das Selbst am Beispiel der Demenz-Erkrankungen*, in: «Phänomenologische Forschungen», Neue Folge, vol. XI, 2011, pp. 163-182; M. SUMMA, *The Disoriented Self. Layers and Dynamics of Self-experience in Dementia and Schizophrenia*, in: «Phenomenology and the Cognitive Sciences», vol. XIII, n. 3, 2014, pp. 477-496. In this article, we shall further develop this line of thought.

<sup>3</sup> See, B. BURTON, *Levels of Personhood: A Model for Dementia Care*, in: «Geriatric Nursing», vol. XXIX, n. 5, 2008, pp. 324-332; L.S. CADDEL, L. CLARE, *The Impact of Dementia on Self and Identity: A Systematic Review*, in: «Clinical Psychology Review», vol. XXX, n. 1, 2010, pp. 113-126; J.C. HUGHES, S.J. LOUW, S.R. SABAT (eds.), *Dementia. Mind, Meaning, and the Person*, Oxford University Press, Oxford 2006; T. KITWOOD, *Dementia Reconsidered. The Person Comes First*, Open University Press, Buckingham 1997; S.R. SABAT, *The Experience of Alzheimer's Disease. Life Through a Tangled Veil*, Blackwell, Oxford 2001; J.A. SMALL, K. GELDART, G. GUTMAN, M.A. CLARKE SCOTT, *The Discourse of Self in Dementia*, in: «Aging and Society», vol. XVIII, 1998, pp. 291-316.

<sup>4</sup> See, notably, T. KITWOOD, *The Dialectics of Dementia: With Particular Reference to Alzheimer Disease*, in: «Ageing and Society», vol. IX, 1990, pp. 1-15; T. KITWOOD, *Dementia Reconsidered*, cit.; T. KITWOOD, K. BREDIN, *Towards a Theory of Dementia Care: Personhood and Well-being*, in: «Ageing and Society», vol. XII, 1992, pp. 269-287.

<sup>5</sup> See T. FUCHS, *Leiblichkeit und personale Identität*, in: I. RÖHMER, M. WUNSCH (eds.), *Person. Anthropologische, phänomenologische und analytische Perspektiven*, Mentis, Münster 2013, pp. 171-188.

<sup>6</sup> See M. SCHECHTMAN, *The Narrative Self*, in: S. GALLAGHER (ed.), *The Oxford Handbook of the Self*, Oxford University Press, Oxford 2011, pp. 394-416.

<sup>7</sup> See G. STRAWSON, *Against Narrativity*, in: «Ratio», vol. XVII, n. 4, 2004, pp. 428-452.

<sup>8</sup> See P. RICOEUR, *Soi-même comme un autre*, Seuil, Paris 1990; A. MACINTYRE, *After Virtue*, University of Notre Dame Press, Notre Dame 1984; C. TAYLOR, *Sources of the Self*, Harvard University Press, Cambridge (MA) 1989.

<sup>9</sup> See D. DENNETT, *The Self as a Center of Narrative Gravity*, in: F.S. KESSEL, P.M. COLE, D.L. JOHNSON (eds.), *Self and Consciousness. Multiple Perspectives*, Erlbaum, Hillsdale (NJ) 1992, pp. 103-115.

<sup>10</sup> This aspect has been particularly emphasized by Ricoeur, who, after discussing the aporias of both the subjective and the objective accounts of time, considers narrativity as the only consistent way to approach temporality, and notably human time. See P. RICOEUR, *Temps et récit*, vol III, *Le temps raconté*, Seuil, Paris 1985.

<sup>11</sup> See G. STRAWSON, *Against Narrativity*, cit.

<sup>12</sup> As we shall see, diachronicity is not the only way of experiencing oneself. Rather many of our experiences carry what Strawson calls episodic self-experience (see G. STRAWSON, *Against Narrativity*, cit.).

<sup>13</sup> See D. ZAHAVI, *Self and Other as Limits of Narrativity*, in: D. HUTTO (ed.), *Narrative and Understanding Persons*, Cambridge University Press, Cambridge 2007, pp. 179-201.

<sup>14</sup> See A. MACINTYRE, *After Virtue*, cit.; C. TAYLOR, *Sources of the Self*, cit.

<sup>15</sup> See A. MACINTYRE, *After Virtue*, cit.

<sup>16</sup> See D. ZAHAVI, *Inner Time-consciousness and Pre-reflective Self-awareness*, in: D. WELTON (ed.), *The New Husserl. A Critical Reader*, Indiana University Press, Bloomington 2003, pp. 157-180.

<sup>17</sup> See E. HUSSERL, *Zur Phänomenologie des inneren Zeitbewusstseins (1893-1917)*, in: E. HUSSERL, *Gesammelte Werke*, Bd. X, hrsg. von R. BOEHM, Martinus Nijhoff, Den Haag 1966; E. HUSSERL, *Die Bernauer Manuskripte über das Zeitbewusstsein (1917/18)*, in: E. HUSSERL, *Gesammelte Werke*, Bd. XXXIII, hrsg. von R. BERNET, D. LOHMAR, Kluwer, Dordrecht-Boston-London 2001; E. HUSSERL, *Späte Texte über Zeitkonstitution (1929-1934). Die C-Manuskripte*, in: E. HUSSERL, *Husserliana Materialien*, Bd. VIII, hrsg. von D. LOHMAR, Springer, Dordrecht 2006.

<sup>18</sup> See H. BERGSON, *Essai sur les données immédiates de la conscience* (1889), PUF, Paris 2001; H. BERGSON, *Matière et mémoire. Essai sur la relation du corps à l'esprit* (1896), PUF, Paris 2007.

<sup>19</sup> See G. STRAWSON, *Against Narrativity*, cit.

<sup>20</sup> See E. HUSSERL, *Ding und Raum. Vorlesungen 1907*, in: E. HUSSERL, *Gesammelte Werke*, Bd. XVI, hrgs. von U. CLAESES, Martinus Nijhoff Den Haag, 1973, p. 61.

<sup>21</sup> See *ivi*, p. 64.

<sup>22</sup> In this respect, Husserl speaks about a constant "merging" [*Ineinander*] of retentions and protentions. Cf. E. HUSSERL, *Die Bernauer Manuskripte über das Zeitbewusstsein (1917/18)*, cit., pp. 3-15; 15-20; 21-49; 65-90; 142-159. In this respect, see also M. SUMMA *Spatio-Temporal Intertwining. Husserl's Transcendental Aesthetic*, Springer, Dordrecht 2014, notably chapters 4, 5, and 7.

<sup>23</sup> Strawson also emphasizes the "implicit" awareness of the past in episodic self-experience: «Faced with sceptical Diachronics, who insist that Episodics are (essentially) dysfunctional in the way they relate to their own past, Episodics will reply that the past can be present or alive in the present without being present or alive as the past. The past can be alive – arguably more genuinely alive – in the present simply in so far as it has helped to shape the way one is in the present, just as musicians' playing can incorporate and body forth their past practice without being mediated by any explicit memory of it» (G. STRAWSON, *Against Narrativity*, cit., p. 432). Such implicit memory shall be understood as body memory, and is its effectiveness in every episode of our lives is precisely based on the unity of consciousness, which we understood, with Husserl, in terms of the overarching retentive-protentive interweaving. See, T. FUCHS, *The Phenomenology of Body Memory*, in: S. KOCH, T. FUCHS, M. SUMMA, C. MÜLLER (eds.), *Body Memory, Metaphor and Movement*, John Benjamins, Amsterdam 2012, pp. 9-22; M. SUMMA, *Das Leibgedächtnis. Ein Beitrag aus der Phänomenologie Husserls*, in: «Husserl Studies», vol. XXVII, n. 3, 2011, pp. 173-196.

<sup>24</sup> Cf. D. ZAHAVI, *Self-Awareness and Alterity. A Phenomenological Investigation*, Northwestern University Press, Evanston (IL) 1999; D. ZAHAVI, *Subjectivity and Selfhood*, cit.

<sup>25</sup> Partially divergent opinions in the interpretation of the minimal (or core) self can be found, for instance, in A.R. DAMASIO, *The Feeling of What Happens*, Harcourt San Diego (CA) 1999; S. DE HAAN, *Comment: The Minimal Self is a Social Self*, in: T. FUCHS, H. SATTEL, P. HENNINGSEN (eds.), *The Embodied Self. Dimensions, Coherence and Disorders*, Schattauer, Stuttgart 2010, pp. 12-

18; S. GALLAGHER, *Philosophical Conceptions of the Self: Implications for Cognitive Sciences*, in: «Trends in Cognitive Sciences», vol. IV, n.1, 2000, pp. 14-21; G. STRAWSON, *The Minimal Subject*, in: S. GALLAGHER (ed.), *The Oxford Handbook of the Self*, cit., pp. 253-278; D. ZAHAVI, *Minimal Self and Narrative Self. A Distinction in Need of Refinement*, in: T. FUCHS, H. SATTEL, P. HENNINGSEN (eds.), *The Embodied Self*, Schattauer, Stuttgart 2010, pp. 3-11; D. ZAHAVI, *Reply: ...Even in the Absence of Social Interaction?*, in: T. FUCHS, H. SATTEL, P. HENNINGSEN (eds.), *The Embodied Self*, Schattauer, Stuttgart 2010, pp. 18-21.

<sup>26</sup> For Husserl this is centeredness and polarization of the Ego as "Einstrahlungszentrum" of affections and "Ausstrahlungszentrum" of actions. E. HUSSERL, *Zur Phänomenologie der Intersubjektivität. Texte aus dem Nachlass, II. Teil (1921-1928)*, hrsg. von I. KERN, Martinus Nijhoff, Den Haag 1973, p. 30.

<sup>27</sup> See, T. FUCHS, *The Phenomenology of Body Memory*, cit; M. SUMMA, *Das Leibgedächtnis*, cit.

<sup>28</sup> See, in this respect, M. WEHRLE, M. UBIALI, *Feeling and Value, Willing and Action*, Springer, Dordrecht 2015.

<sup>29</sup> P. GOLDIE, *The Emotions. A Philosophical Exploration*, Clarendon, Oxford 2000; P. GOLDIE, *Emotions, Feelings, and Intentionality*, in: «Phenomenology and the Cognitive Sciences», vol. I, n. 3, 2002, pp. 235-254.

<sup>30</sup> J. SLABY, *Gefühl und Weltbezug. Die menschliche Affektivität im Kontext einer neo-existentialistischen Konzeption von Personalität*, Mentis, Paderborn 2008.

<sup>31</sup> B. WALDENFELS, *Bruchlinien der Erfahrung*, Suhrkamp, Frankfurt a.M. 2002.

<sup>32</sup> J.J. DRUMMOND, *Cognitive Impenetrability and the Complex Intentionality of the Emotions*, in: «Journal of Consciousness Studies», vol. XI, 2004, pp. 109-126.

<sup>33</sup> See D. ZAHAVI, *Self and Other as Limits of Narrativity*, cit.

<sup>34</sup> See *ivi*.

<sup>35</sup> Both the idea that I do have a direct and non-inferential experience of the other (e.g., through expression) and the idea that this does not remove the essential asymmetry between my experience of myself and my experience of the other can be detected in phenomenology and in Wittgenstein's philosophy. See, S. OVERGAARD, *Wittgenstein and Other Minds. Rethinking Subjectivity and Intersubjectivity with Wittgenstein, Levinas, and Husserl*, Routledge, New York 2008.

<sup>36</sup> See T. FUCHS, *The Phenomenology of Body*



*Memory*, cit.

<sup>37</sup> See A.R. DAMASIO, T.J. GABROWSKI, *Definition, Clinical Features and Neuroanatomical Basis of Dementia*, in: M. M. ESIRI, V.M.-Y. LEE, J.Q. TROJANOWSKI (eds.), *The Neuropathology of Dementia*, Cambridge University Press, Cambridge 2004, pp. 1-34. It should be immediately noted that "dementia" is a broad category, which entails several and in some respects different neurodegenerative diseases, e.g., Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, etc. Our observations in this paper are based on empirical studies, mostly, but not exclusively, focused on Alzheimer's disease. The features we discuss, however, seem to be common to different forms of dementia. Another important aspect to be kept in mind is the natural history and the progression of the illness. As has been argued, the distinction of stages in the development of the illness, related to the seriousness of the impairments, is of great importance for clinical aims (see, in this respect, A. BIANCHETTI, M. TRABUCCHI, *La valutazione clinica del demente*, in: M. TRABUCCHI (eds.), *Le Demenze*, UTET, Torino 2002, pp. 43-112). More specifically, it is possible to distinguish three stages in the development of dementias. The initial stages are characterized by some light memory impairments, the impoverishment of abstract thought, emotional weakness, in some cases aphasia and apraxia. In the intermediary stages, patients are often incapable of acquiring and remembering new information, they have difficulties in word-finding, and they increasingly experience spatio-temporal disorientation. For instance, they sometimes have problems in explicitly recognizing familiar places (although, as we shall see, they may still "feel at ease" in these places, thus showing that an implicit sense of familiarity is preserved). In the advanced stages, all these symptoms become more severe. Long- and short-term memory are completely or almost completely lost, patients can fall into mutism and become incapable of performing very basic actions. Our remarks concerning the disturbances of self-experience in dementia patients take into consideration studies that are mostly focused on the intermediate and advanced stages of the illness. However, it should be noted that the transition from one stage to the other, at least on the experiential level, is mostly progressive. Moreover, individual histories are very different from each other, and this prevents us from

assigning, as it were, a given sense of self to each stage of the illness. For this reason, what we propose are remarks concerning those features and impairments which, with different level of seriousness, can be considered to be present at the different stages of the development of the illness. Since the development of the illness is largely gradual, we would not, for instance, claim that the autobiographic sense of self fully disappears as soon as memory impairments present themselves, but rather suggest that, like the development of the disease, the alterations in self-experience are of a progressive nature. Yet, in general terms, it can be said that the minimal self is preserved up to the most advanced stages of the illness, and that a more articulated episodic sense of self is present at least until the intermediate stages. In what follows, we shall more thoroughly articulate this suggestion by referring to concrete examples and case studies.

<sup>38</sup> See M. SUMMA, *Zwischen Erinnern und Vergessen*, cit.

<sup>39</sup> See E. MINKOWSKI, *Le temps vécu*, cit.

<sup>40</sup> The concept of implicit memory was notoriously coined in the domain of cognitive psychology to designate the non-declarative and non-representative memory forms as opposed to explicit memory forms (notably autobiographical and semantic memory). See, notably D. SCHACTER, *Implicit Memory: History and Current Status*, in: «Journal of Experimental Psychology», vol. XIII, n. 3, 1987, pp. 501-518; D. SCHACTER, *Searching for Memory. The Brain, the Mind, and the Past*, Basic Books, New York 1996; L. SQUIRE, *Memory Systems of the Brain: A Brief History and Current Perspective*, in: «Neurobiology of Learning and Memory», vol. LXXXII, 2004, pp. 171-177. On the phenomenological account of body memory, see T. FUCHS, *The Phenomenology of Body Memory*, cit.; M. SUMMA, *Das Leibgedächtnis*, cit.

<sup>41</sup> See H. CHRISTENSEN, P. BIRRELL, *Explicit and Implicit Memory in Dementia and Normal Ageing*, in: «Psychological Research», vol. LIII, n. 2, 1991, pp. 149-161; L.L. ELDRIGE, D. MASTERMAN, B.J. KNOWLTON, *Intact Implicit Habit Learning in Alzheimer's Disease*, in: «Behavioral Neuroscience», vol. CXVI, n. 4, 2002, pp. 722-726; D.A. FLEISCHMAN, R.S. WILSON, J.D.E. GABRIELI, J.A. SCHNEIDER, J.L. BIENIAS, D.A. BENNETT, *Implicit Memory and Alzheimer's Disease Neuropathology*, in: «Brain», vol. CXXVIII, 2005, pp. 2006-2015; A. GOLBY, G. SILVERBERG, E. RACE, S. GABRIELI, J.

O'SHEA, K. KNIERIM, G. STEBBINS, J. GABRIELI, *Memory Encoding in Alzheimer's Disease: An fMRI Study of Explicit and Implicit Memory*, in: «Brain», vol. CXXVIII, 2005, pp. 773-787; B. HARRISON, G.R. SON, J. KIM, A.L. WHALL, *Preserved Implicit Memory in Dementia: A Potential Model of Care*, in: «American Journal of Alzheimer's Disease and Other Dementias», vol. XXII, n. 4, 2007, pp. 286-293.

<sup>42</sup> See S.R. SABAT, *Implicit Memory and People with Alzheimer's Disease: Implication for Caregiving*, in: «American Journal of Alzheimer's Disease and Other Dementias», vol. XXI, n. 1, 2006, pp. 11-14.

<sup>43</sup> See P. KONTOS, *Ethnographic Reflections on Selfhood, Embodiment and Alzheimer's Disease*, in: «Aging and Society», vol. XXIV, n. 6, 2004, pp. 829-847; P. KONTOS, *Embodied Selfhood in Alzheimer's Disease*, in: «Dementia», vol. IV, n. 4, 2005, pp. 553-570.

<sup>44</sup> A significant example is provided by A. FONTANA, R. SMITH, *Alzheimer's Disease Victims: The "Unbecoming" of Self and the Normalization of Competence*, in: «Sociological Perspectives», vol. XXXII, n. 1, 1989, pp. 35-46. For a closer discussion, M. SUMMA, *Zwischen Erinnern und Vergessen*, cit.

<sup>45</sup> See E. MINKOWSKI, *Le temps vécu*, cit.

<sup>46</sup> See A. TATOSSIAN, *Phénoménologie des états démentiels*, cit.

<sup>47</sup> For a discussion of the comparison between dementia and schizophrenia, see M. SUMMA, *The Disoriented Self*, cit.

<sup>48</sup> See L. LIU, L. GAUTHIER, S. GAUTHIER, *Spatial Disorientation in Persons with Early Senile Dementia of the Alzheimer Type*, in: «American Journal of Occupational Therapy», vol. XLV, n. 1, 1991, pp. 67-74.

<sup>49</sup> See J. HORT, J. LACZÓ, M. VYHNÁLEK, M. BOJAR, J. BUREŠ, K. VLČEK, *Spatial Navigation Deficit in Amnesic Mild Cognitive Impairment*, in: «Proceedings of the National Academy of Sciences of the United States of America», vol. CIV, n. 10, 2007, pp. 4042-4047.

<sup>50</sup> See A. TATOSSIAN, *Phénoménologie des états démentiels*, cit.

<sup>51</sup> See S. FAZIO, D.B. MITCHELL, *Persistence of Self in Individuals with Alzheimer's Disease. Evidence from Language and Visual Recognition*, in: «Dementia», vol. VIII, n. 1, 2009, pp. 39-59; J.A. SMALL, K. GELDART, G. GUTMAN, M.A. CLARKE SCOTT, *The Discourse of Self in Dementia*, cit.

<sup>52</sup> See G. HUBBARD, A. COOK, S. TESTER, M. DOWNS, *Beyond Words. Older People with Dementia Using*

*and Interpreting Nonverbal Behavior*, in: «Journal of Aging Studies», vol. XVI, 2002, pp. 155-167.

<sup>53</sup> See A. TATOSSIAN, *Phénoménologie des états démentiels*, cit., p. 1206.

<sup>54</sup> See R. GIL, E. M. ARROYO-ANLLO, P. INGRAND, M. GIL, J.P. NEAU, C. ORNON, V. BONNAUD, *Self-consciousness and Alzheimer's Disease*, in: «Acta Neurologica Scandinavica», vol. CIV, n. 5, 2001, pp. 296-300; R. GIL, *Conscience de soi, conscience de l'autre et démences*, in: «Psychologie et neuropsychiatrie du vieillissement», vol. V, n. 2, 2007, pp. 87-99.

<sup>55</sup> See A. FONTANA, R. SMITH, *Alzheimer's Disease Victims*, cit.

<sup>56</sup> T. KITWOOD, K. BREDIN, *Towards a Theory of Dementia Care*, cit., p. 285.

<sup>57</sup> See S.R. SABAT, *Surviving Manifestations of Selfhood in Alzheimer's Disease. A Case Study*, in: «Dementia», vol. I, n. 1, 2002, pp. 25-36; S.R. SABAT, R. HARRÉ, *The Alzheimer's Disease Sufferer as a Semiotic Subject*, in: «Philosophy, Psychiatry & Psychology», vol. I, n. 3, 1995, pp. 145-160.

<sup>58</sup> Another case study reported by Sabat and Collins is that of a music teacher diagnosed with Alzheimer's disease. The authors particularly emphasize her experience of frustration, irritation, anger, and humor. Despite her memory and lexical impairments, the patient's emotional reactions and expressions testify for a kind of self-awareness that goes beyond the layer of the minimal and pre-reflective sense of mineness. S.R. SABAT, M. COLLINS, *Intact Social, Cognitive Ability, and Selfhood: A Case Study of Alzheimer's Disease*, in: «American Journal of Alzheimer's Disease and Other Dementias», vol. XIV, n. 1, 1999, pp. 11-19. For further discussion of these cases, see M. SUMMA, *The Disoriented Self*, cit.

<sup>59</sup> See T. KITWOOD, *Dementia Reconsidered*, cit.; A. TATOSSIAN, *Phénoménologie des états démentiels*, cit.

<sup>60</sup> See J.C. HUGHES, S.J. LOUW, S.R. SABAT, *Seeing Whole*, in: J.C. HUGHES, S.J. LOUW, S.R. SABAT (eds.), *Dementia*, cit., pp. 1-39; J. MCMILLAN, *Identity, Self, and Dementia*, in: J.C. HUGHES, S.J. LOUW, S.R. SABAT (eds.), *Dementia*, cit., pp. 63-70; J. RADDEN, J.M. FORDYCE, *Into the Darkness: Losing Identity with Dementia*, in: J.C. HUGHES, S.J. LOUW, S.R. SABAT (eds.), *Dementia*, cit., pp. 71-87.

<sup>61</sup> See J. RADDEN, J. M. FORDYCE, *Into the darkness*, cit.

<sup>62</sup> See J. MCMILLAN, *Identity, Self, and Dementia*, cit.

<sup>63</sup> See G. HUBBARD, A. COOK, S. TESTER, M. DOWNS,

*Beyond Words*, cit.; P.A. SAUNDERS, "My Brain's on Strike" - *The Construction of Identity through Memory Accounts by Dementia Patients*, in: «Research on Aging», vol. XIV, n. 1, 1998, pp. 65-90.

<sup>64</sup> See J.A. SMALL, K. GELDART, G. GUTMAN, M.A.

CLARKE SCOTT, *The Discourse of Self in Dementia*, cit.

<sup>65</sup> See G. HUBBARD, A. COOK, S. TESTER, M. DOWNS, *Beyond Words*, cit.

<sup>66</sup> See T. FUCHS, *Das Leibgedächtnis in der Demenz*, cit.