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Entering the grey zone of aging between health and disease: a critical phenomenological account

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Abstract

Phenomenological analyses of ageing and old age have examined themes such as alterity, finitude, and time, not seldom from the perspective of "healthy" aging. Phenomenologists have also offered detailed analyses of lived experiences of illness including lived experiences of dementia. This article offers a phenomenological account of what we label as entering the grey zone of aging between "healthy" aging and aging with a disease. This account is developed through a qualitative phenomenological philosophy analysis of elderly persons' lived experiences of being tested for dementia through primary care in Sweden, i.e., within a cultural context where dementia commonly is understood as a frightening a loss of self even though this understanding also is questioned. To enter this grey zone of aging, we argue, does not dissolve dynamic self-becoming but can involve an experience of oneself as being old. Further, in the grey zone, the self experiences itself as neither fully healthy nor as having a disease, and as needing to negotiate and live this ambiguity. To enter this grey zone is to enter an affectively charged, sociocultural and medicalized zone, and while the self can still act in different ways within it, staying in the grey zone can result in a re-orientation in the self's mode of being, in ways that are thoroughly beyond its control. To stay in the grey zone can have detrimental effects on the self, even though the self does not have a disease: the self can become "stuck" in a reflective mode of attending to embodiment, aging, health, and disease.

Keywords Ageing · Dementia · Critical phenomenology · Embodiment · Lived experience · Sweden

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1 Introduction

The aim of this article is to offer a critical phenomenological account of what we term as entering the grey zone of aging, between "healthy" aging and aging with a disease, such as dementia. We do this through a qualitative critical phenomenological philosophy analysis of lived experiences of being tested for dementia through primary care in Sweden, i.e., within a cultural context where dementia is commonly understood as a fearsome and sometimes frightening loss of self, even though the latter understanding has been questioned.[1]

Our starting point is the phenomenological understanding of the embodied self as being-in-the-world. From within this perspective, subjectivity or selfhood is understood as embodied and situated in relations with others and things in a sociocultural and historical world, and as a relation to the world. We follow the work of, for example, Maurice Merleau-Ponty in acknowledging the role of embodiment for subjectivity, for affecting and being affected by others and one's surroundings.[2] The lived body, in his reasoning, is sentient and sensed. It is ambiguously both the body I am and have. It is never decoupled from the world, but instead understood as oriented in, engaging with, and part of the world. As a lived body, the embodied self is dynamically shaped in relations with others, and affectivity – and different affective states – helps shape our very mode of being in the world, how the world and things in it appear and matter to us.[3] Further, the notion of intercorporeality has been used to further deepen the understanding of the lived body.[4] Intercorporeality is commonly understood as referring to a basic, tacit and constitutive connectedness between singular lived bodies and the world. In Lisa Käll's formulation, intercorporeality is understood as a dynamic formative structure or force that "designates the ways in which bodies are not only interconnected with one another but also formed and emerging as singular and separate bodies in their interconnection."[5] The embodied self is far from a self-enclosed entity, but instead understood as coming into being through "continuous differentiation and alteration" in relations with others and the shared world.[6] Further, phenomenological understandings of embodiment acknowledge both change and a certain stability: sensory-motor skills, ways of acting and interacting can sediment into the lived body through repetition and habituation and

[1] See Zeiler et al. (2022); Hydén and Antelius (2017); Örulv (2010; 2012). To age without a disease is sometimes referred to as "normal" aging, even though aging comes in different forms, and "normal" aging *qua* healthy aging – aging without a disease – has been part of discussions that contrast such aging with, for example, aging with dementia. As shown by scholars of the history of medicine, the understanding and conceptualisation of dementia shifted during the 20th century, from the idea of senile dementia as part of old age and Alzheimer's disease as a distinct condition for people in middle-age to "Dementia of the Alzheimer Type" as a disease set apart from "'normal' aging" even though age was its most important risk factor; see Holstein (2000, p. 158); Fox (2000). Within this article, we acknowledge that "healthy" aging understood as aging in health and without disease has normative and at times also idealised connotations.

[2] Merleau-Ponty (2013).

[3] E.g. Cataldi (2008); Fuchs (2015); Heidegger (2010).

[4] Weiss (1999); Merleau-Ponty (1968).

[5] Käll (2017a, pp. 363–364).

[6] Käll (2017a, pp. 364).

help shape the self's perception and experience of itself, others, and the world without this implying any determinism.[7]

In this article, we explore dynamic self-becoming with a focus on *aging*. In everyday language, aging might be understood in terms of "growing old" or "becoming elderly." It can, however, also mean "living through time."[8] According to this last understanding, aging need not refer to the successive decline of our body or a state that commences in the later phase of life. It can also be understood as the process of dynamic self-becoming that begins when we are born. To age is to continuously take shape – to alter and differentiate – as a subject, in and through intercorporeal relations with others and one's surroundings. At the same time, the experience of aging can encompass the experience of bodily decline and oneself as aged.[9] Thus, aging can encompass a simultaneous *becoming* and a *being*: a becoming in the sense of our continuous self-becoming, and an experience of being at a stage in life that we eventually (have) reach(ed).

Phenomenological literature on aging has thematized this simultaneous becoming and being as part of the lived embodied situation of the aging self.[10] However, while phenomenological accounts of aging have acknowledged that transformation is an integral part of embodied existence, emphasis has often been on aging in terms of alterity, namely, as the subject's experience of "the Other within" as "who is old," and the "revelations of our age" as typically coming "to us from outside – from others" and as something we do not accept willingly.[11] Formulations such as these acknowledge the experienced discrepancy, or ambiguity, that can occur between one's continuous dynamic self-*becoming* and one's experience of *being* old as a stage in life and as an insight that dawns upon the self in encounters with others.

Further, while some scholars have offered analyses of the role of temporality and embodiment in the experience of aging, without specifically attending to aging with a disease, others have engaged with the work of Merleau-Ponty, among others, in analysis of lived experiences of dementia.[12] A small but growing corpus of phenomenological literature also critically engages with normative assumptions of aging and how to age when aging "right" comes to be understood as a matter of one's lifestyle, and the responsibility for "healthy" aging or "aging well" becomes individualized. Such studies have also examined how norms about aging well, and related norms about how to act when "older," can help shape subjectivity.[13] This literature indicates how "aging well" can come to be medicalized: when such aging comes to be understood as partly falling within the realm of health care practices and requiring health care attention. Of relevance in this regard is also other medical humanities and critical gerontological work that has identified "successful" and active" aging discourses. Such studies not only show how these discourses can challenge the perception of old

[7] Merleau-Ponty (2013).

[8] Bavidge (2016, p. 207).

[9] See for example Hamilton (2016).

[10] See for example Wehrle (2020); Kruks (2010).

[11] Beauvoir (1996, p. 288); see also Fisher (2014); Stoller (2014).

[12] See for example Arp (2016); Kontos (2005); Zeiler (2014); Käll (2017b).

[13] Aho (2022); Wehrle (2020); Leder (2018).

age as implying loss and decline and offer a positive understanding of later parts of life, they explore at the same time, the homogenizing of "old age," a tendency feeding into anti-aging movements.[14] This literature underlines that the ways in which aging and old age are perceived, experienced and understood are fundamentally shaped by historical and socio-cultural processes. What it means to age and experience aging varies with time and from place to place. So too does the form and content of the grey zone of aging between "healthy" aging, which here refers to aging in health and without disease, and aging with disease, including a disease such as dementia – i.e., a disease for which old age is the most common risk factor.[15]

With the conceptualization of entering the grey zone of aging – that is, between "healthy" aging and aging with a disease – we intend to bring together on the one hand the simultaneous becoming and being as part of "normal" or "healthy" aging, *and* the experience of becoming and being when having reached a stage where one comes to perceive oneself as having a disease. A note on terminology is needed here: as shown in philosophy of medicine, several conceptualizations of health and disease co-exist, such that one can have a disease and experience health at the same time and health and disease need not be conceptualized in dualistic ways.[16] Further, the notion of illness is commonly used to refer to the experience of symptoms, pain, suffering, alienation or incapacitation, from a first-person subjective perspective, and, even if this is not the common case in health care, one can be diagnosed with a disease without experiencing illness.[17] When hereafter we refer to the experience of having reached a stage where one has come to perceive or experience oneself as having a disease, this may, but need not, include experiences of symptoms. Further, in everyday language, health is sometimes contrasted with having a disease, and this is a recurring feature in the interview material with which we will engage in this article.

We understand the grey zone of aging between health and disease as a temporal, intersubjective and social zone, where a diagnosis of disease is not (yet) given, but where nonetheless a disease looms as a real possibility for both the self and for others who witness changes in that person. In this grey zone, one's encounter with the other within as the one who is old (an experience both of becoming and being) implies an encounter with an other within that stands forth, to the self, as *at risk* for disease.[18] Thus, this is a grey zone between "healthy" aging and aging with a disease. To be clear, the experience of this grey zone is as distinct from the experience of aging without a specific disease as it is from aging with a disease. Further, in socio-cultural and historical contexts where aging and old age are to a growing extent associated with being "at risk" of disease, and thus understood as something of which the older self should be aware and to which it should attend, we can say that the existence of

[14] Grøn (2016); Lamb (2014); Baars (2012); Katz (2001/2002); Cole (1992); Rowe and Kahn (1998).

[15] World Health Organization (2019).

[16] For some examples of conceptual discussions of health and disease, see Nordenfelt (2014); Hofmann (2001); Sadegh-Zadeh (2000).

[17] See, for example, Carel (2008).

[18] Sometimes, as we will show, this takes place through others' ways of interacting or explicitly informing the self that one is.

this grey zone can be expected to grow in prominence. Which is to say, more and more people will experience themselves as having entered the grey zone.

The grey zone between "healthy" aging and aging with dementia – the disease we shall specifically focus on in this article – unfolds in socio-cultural contexts, such as in Sweden, where dementia is commonly understood as something to fear. We therefore situate our article in the context of past medical humanities research on lived experiences of dementia in Sweden, including phenomenological analyses. Such research has explored remaining capabilities when living with dementia and has offered alternatives to the conceptualization of dementia as a "loss of self."[19] It has shown that dementia can "bring to the fore deeply rooted existential fears" and that it is understood as something to be feared, and sometimes as a cultural taboo.[20] However, we believe that the account that we shall develop here has a bearing beyond Sweden – that is, in other contexts where dementia also tends to be understood in this way.[21]

The aim of this article can now be specified: our aim is to explore, identify and conceptualize central features of aging within a grey zone that exists between "healthy" aging and aging with a disease. We intertwine our phenomenological discussion with an analysis of three narrations from individuals who have undergone initial testing for dementia in Sweden. Further, phenomenological philosophy has branched out into several sub-strands including those of feminist or other critical phenomenology. We share the interest of critical phenomenology that, as Lisa Guenther puts it, seeks to shed light on "how contingent historical and social structures" shape our experience, and "not just empirically or in a piecemeal fashion" but in ways that "play a constitutive role in shaping the meaning and manner of our experience."[22] Guenther exemplifies these structures with patriarchy, white supremacy, and heteronormativity, and writes that these can "permeate, organize, and reproduce the natural attitude in ways that go beyond any particular object of thought" and help shape our very "*ways of seeing*, and even of *making the world* that go unnoticed without a sustained practice of critical reflection."[23] In the context, then, of the grey zone, on which this article centers, critical phenomenology becomes pertinent to discuss how contingent yet socio-culturally shared assumptions and norms surrounding old age as an "at risk" age that one needs to be cautious about – by being (i) particularly attentive to one's own body and (ii) alert to potential symptoms of diseases – can help structure and shape the very experience of the grey zone.

We see critical phenomenology as underlining the constitutive interrelation of embodiment and sociocultural and historical situatedness. To offer nuanced critical phenomenological accounts of aging or entering the grey zone of aging, we therefore content that phenomenologists have much to gain from acknowledging how assumptions and norms about aging vary across socio-cultural times and places and can help shape subjectivity. Differences between assumptions and norms about aging in,

[19] See for example Käll (2017a); Hydén and Antelius (2017); Örulv (2010; 2012).

[20] Örulv (2012, pp. 10, 30); Zeiler et al. (2022).

[21] See Van Gorp and Vergruysse (2012); Clarke (2006).

[22] Guenther (2020, p. 12).

[23] Guenther (2020, p. 12).

for example, Continental Europe, during the 1970s and Northern Europe during the 2020s, need to be accounted for in critical phenomenological inquiries that are concerned with how particular socio-cultural dominant, yet contingent assumptions and norms can help shape experience.

Our qualitative critical phenomenology analysis centers on and engages with patients' lived experiences of requesting or being asked to undergo tests for mild cognitive impairment, as part of a basic dementia assessment, in Sweden. In the following two sections, we therefore describe the routines for the basic dementia assessment in Sweden, along with a presentation of our research method.

2 Testing for dementia: the Swedish routine for basic dementia assessment

Dementia is a syndrome in which thinking, memory, and the ability to perform everyday activities deteriorate, and while dementia "is not a normal part of ageing," as stated by the World Health Organization, old age is its most common risk factor.[24] Further, according to the Swedish National Board of Health and Welfare, 130,000-150,000 persons live with dementia in the country. This number is expected to double by 2050, with presently 20,000–25,000 persons per year developing dementia in Sweden.[25] The National Board of Health and Welfare encourages early diagnosis.[26] Cognitive tests for dementia are primarily performed in primary care. Such tests can be part of the initial phase of a so called "basic dementia assessment," the purpose of which is to rule out or confirm a specific dementia diagnosis. The investigation is initiated when symptoms of cognitive impairment are reported by the patient or their kin or observed by their primary care physician or other health care professionals. If the suspicion remains after an initial anamnesis, a number of interventions follow, such as an ECG, blood tests, a CT scan, and, in the region of the country where our study took place, a referral to the "dementia investigation team" who, among other things, administers cognitive testing in combination with an assessment of activities of daily life. The dementia investigation team consists of nurses and occupational therapists, the latter of whom perform the cognitive tests, ordinarily in the patient's home.

Cognitive tests are one of the tools used in the initial phase of the dementia investigation in order to determine whether further examinations are warranted. Consequently, they are not in themselves diagnostic. Since they are performed in a primary care context, the tests are designed to be fairly quick and simple. The test instruments commonly used are the Mini Mental State Examination (MMSE) in combination with the Clock Drawing Test (CDT), which together take approximately 20 min to perform. The MMSE tests cognitive domains such as orientation, attention, language and memory, and the CDT tests language, executive function and visuospatial abilities. Both tests come with detailed, standardized instructions, but they only require the use of pen and paper. Further, for some primary care patients, supplementary

[24] WHO (2019).

[25] Socialstyrelsen (2019).

[26] Socialstyrelsen (2017).

brief testing of memory, executive function, and speed, still with paper and pen, can be added whenever deemed called for. Interviewees in our study had undergone these cognitive tests, via primary care, in Sweden.

3 Qualitative critical phenomenology: methods, material, research ethics

Qualitative phenomenological philosophy is a small but growing area of research, where qualitative research is combined with phenomenological philosophy analysis, and where the aim is philosophical and conceptual.[27] Qualitative critical phenomenology is a novel term that designates projects that specifically bring together qualitative research and critical phenomenology, with an eye for – among other things – how socio-cultural assumptions and norms about bodies can feed into and help shape subjectivity and function as contingent structures of perception and experience.[28] This project exemplifies qualitative critical phenomenology.

Within our project, interviewees who had been tested for cognitive function via primary care, but who had not gone through the whole basic dementia investigation nor (yet) received a dementia diagnosis, were invited to take part in an interview. While interviewees could choose to do the interview alone or together with a close relative or friend, all participants chose to be interviewed alone. The interviews were semi-structured and focused on the interviewees' experiences of being tested. The relatively small number of interviewees – three – included in the study is motivated by its theoretical orientation and overarching aim of conceptual development. The three narratives are examples of "possible human experience."[29]

The interviews were transcribed verbatim, and analyzed with an eye for the variation and the commonalities between the possible human experiences which the narratives exemplify, and the particular socio-cultural contexts with which they are intertwined. This made possible our inquiry into the phenomenon of aging in-between "healthy" aging and aging with a disease. Research ethics approval was obtained from the Swedish *etikprövningsmyndigheten* (Dnr 2018/28–31 and 2018/414 – 32). Written informed consent was obtained. All interviewees' have been anonymized and given pseudonyms (Barbro, Nils and Birgitta).

Together, KZ and MG developed the design of the article and performed the analysis. MG conducted the interviews, while KZ took the main responsibility for writing the article. AS was responsible for the selection of patients as possible interviewees and contributed to the description of the tests and the Swedish routine for dementia assessment. All authors have contributed to the manuscript.

[27] See for example Køster and Fernandez (2021).

[28] De Boer and Zeiler (2023).

[29] van Manen (2014, p. 63).

4 Entering the grey zone of aging

4.1 Paths toward cognitive testing: the other within and without

Barbro, Nils, and Birgitta's narrations show that the path toward cognitive testing for dementia can vary. In Barbro's case, it was her primary care physician who recommended testing. "[He] thought I was a little fuzzy or something," she says, adding "I realize that I am seventy, a bit more than seventy, and that one's memory and the whole person changes [as one ages]." Birgitta and Nils were, on the other hand, tested on their own initiative, though for different reasons. Nils was motivated by the fact that "dementia runs in the family." He had seen both of his grandmothers die with the disease, and his father suffered a cerebral haemorrhage that caused dementia-like symptoms. In addition, his younger sister underwent cognitive testing for dementia a couple of years back and was put on "some kind of inhibitor drug," he says. This prompted him to draw the conclusion that she "probably received a diagnosis that matched that [i.e., dementia]." All of this, together with his knowledge of the hereditary nature of dementia, motivated Nils to get tested. For Birgitta, it was her experience of a sudden deterioration of her short-term memory that led her to undergo the tests. During the autumn preceding our conversation, Birgitta felt that she kept forgetting the names of people and geographic locations. This she had not done before. In addition, she remarks that she had been experiencing difficulties with associative thinking for an extended period of time. However, she adds that "all of the examinations showed that there was no trace of dementia."

Despite the diverse ways in which Barbro, Nils, and Birgitta encountered cognitive testing for dementia, the tests have, in different ways, thrown them into or extended their stay within a grey zone of aging between health and disease. Judging from her story, Barbro has been told that the tests revealed some kind of abnormality. However, she explains that she feels that she has not received sufficient information about *what* they revealed and what, if anything, can be *done* about it. "What was it that I didn't remember, that I should've remembered and accounted for?" she wonders. In her mind, she manages her everyday life pretty well. "I think that I'm oriented in time and space, and I remembered my children's names [during the tests] and… and I find my way home," she says. She also emphasizes the fact that she is still able to do voluntary work at a secondhand store in the city, from which she always travels back home by bus. At the time of the interview, there is a lack of congruence between her experience of undergoing the tests and how she experiences her everyday life. This, then, is not so much an experience of the other within as old or ill, but rather an experience of an ambiguity regarding whether her aging is part of "healthy aging" or not – and how to make sense of this experience of herself as not having a disease, despite what others might think and what the tests indicate. She finds occupying such a grey zone both frustrating and worrying. Barbro repeatedly returns to the fact that if she only knew what the tests had detected she might be able to do something about it, go to a "memory school" or something, she suggests. She also describes how she felt "disappointed" with herself after the tests, and she reflects and says that at her age "one shouldn't feel ashamed if one no longer remembers everything."

For Birgitta, the incongruence between the test results and the experience she has of herself in her daily life is inverted. She experiences symptoms that she attributes to dementia, but performs flawlessly on the tests. Due to this incongruence, the reassuring effect that one might expect from the tests fails to appear. Instead, they help create a grey zone between health and a disease, which Birgitta, just like Barbro, finds frustrating: "I feel like they [the tests] aren't able to capture my problems." "And then, the other day," she continues, "someone asked me how I am mentally… because, you know, there is a mental side to dementia also. And then I realized that they hadn't asked me about that at all." "I have felt a little depressed during this fall," she says, "which isn't necessarily due to any incipient dementia […] but they didn't ask me about that at all." Due to the incongruence between the tests and her own experiences of herself, as well as her lack of confidence in the ability of the tests to capture her problems, Birgitta finds it difficult to dismiss her own worries, something her doctor has recommended her to do.

Nils' story shows that aging and the medicalization thereof – i.e., the process when non-medical conditions or problems come to be understood as medical – might create an experience of being in a grey zone between healthy aging and aging with a disease. For Nils, it is the combination of his awareness of the hereditary nature of dementia, the fact that the disease runs in his family, and his own coming of age, that throws him into a grey zone. On the one hand, he says he has always been somewhat "absent-minded and forgetful," which prompted his friends to give him the nickname "the professor" when they were in their teens. On the other hand, recently, he has asked himself if it has gotten worse, and whether his forgetfulness now should be seen as a sign of disease. And this is a question to which he has been unable to provide an unequivocal answer. Thus, it is to a large extent an already existing experienced grey zone between health and (possible symptoms of) disease that orients him toward cognitive testing. The tests themselves, however, cannot resolve this grey zone. Since the tests are not diagnostic, they can merely provide an indication of whether further testing is warranted, which they have in his case. As a trained behavioral scientist, having himself worked professionally with various forms of tests, he feels that he has a rather good grasp of how he performed. Yet, whether he is healthy or diseased is yet to be revealed.

Despite the variations in the narrations of Barbro, Nils and Birgitta, pathways toward cognitive testing for dementia seem to encompass a tension between an experience of being old – having reached a stage – where one's cognitive abilities may but do not need to be in decline (one may still be in health) *and* an experience of oneself as possibly having a disease that result in decline. Further, when entering the grey zone of aging between health and disease, the experience of being old and possibly also having a disease, seems to come to the self by way of others. In this way, it resonates with Sonia Kruks' formulation that the experience of being old comes "from the discovery that, without having chosen such an identity, we belong to the 'social category' of old persons."[30] Kruks analyses Beauvoir's account of old age, not what we term as the grey zone. However, the entrance into and staying within the grey zone, *even* when the initiative to get tested comes from the self, takes place through or after

[30] Kruks (2010, p. 271).

interactions with others who contribute to making the self attend, thematically and reflectively, to its own cognitive capacities as possibly failing.[31]

Further, while the experience of otherness within the grey zone might come from or be initiated from "without," i.e., through or in interactions with others, it does so in a different way than in descriptions of sudden revelations of age or disease as being stated by others. In the grey zone – as we conceptualize it – rather than an experience of suddenness, there is gradual and vague transitions that may or may not fall within "healthy" aging and yet not and possibly never qualify as aging with disease. This transition does not to result in a revelation of an either-or character, but rather in an experience of being both or in-between and fitting neatly into neither.

Characteristic of having entered the grey zone, we suggest, is an attention to oneself through a socio-cultural and medical lens where certain situations or ways of functioning come to be perceived and experienced as possible symptoms. The experience of uncertainty and ambiguity in the grey zone is, then, an experience within a socio-cultural and medicalized world where "fuzziness" or particular forms of absent-mindedness, at a certain age, can present themselves to the self and others as calling for investigation in the form of cognitive testing. Further, staying in the grey zone implies remaining within a scrutinizing mode of being where the self attends to itself as possibly other than before, and this in ways that may, through medical means, need to be tested.

The accounts of Barbro's, Birgitta's and Nils' paths toward and experiences of cognitive testing reveal two further dimensions of aging on which we shall focus in our further exploration: that of temporality, agency and responsibility, as well as affectivity, and being stuck in a reflective mode.

4.2 Temporality, agency, and responsibility

Following Beauvoir's lines of reasoning, encountering the aged other within can entail encountering oneself as a body in decline.[32] In a sociocultural context where aging is medicalized, this decline can come to be understood in terms of possible diseases, and explanations and interpretations of common experiences can be framed in the language of disease. As one of the interviewees, Birgitta, puts it: "People my age talk about diseases a lot these days, which I don't want to do and which my mother never did. It's a new culture."

If this "new culture" to which Birgitta refers also overlaps with a growing focus on the role of individual life-style factors for how to age and to "age well," then the responsibility for monitoring and acting on one's health may, to a growing extent, be experienced as shifting to, and falling on, the individual. If one has not engaged in health-promoting activities before, one might feel that it is time to do so when encountering one's aged other within. Further, if the self repeatedly makes sense of and talks about common experiences in terms of possible diseases, then this understanding – as a culturally shared understanding – may gradually and over time feed into and help shape the self's very way of being. This can occur tacitly: the self can

[31] Kruks (2010).

[32] Beauvoir (1996).

come to orient itself towards itself through the prism of disease, without necessarily noting that this has taken place.

A few things are noteworthy here. First, health and disease are complex categories, and both lay and biomedical understandings of what constitutes healthy bodily decline in old age and where to draw the line with respect to disease vary with time and place. Furthermore, for the individual undergoing, for example, tests for cognitive impairment, it can be unclear how to interpret the results of such tests that are developed to indicate early signs of such impairment – test that may need to be complemented with further investigation. However, the complexity and uncertainty that indeed are integral to the grey zone between health ageing and aging with disease, does not – in Barbro's, Nils', and Birgitta's narrations – appear as an ambiguous state that completely paralyzes them. It affects them; it makes them frustrated, sad, and anxious, but it does *not* divest them of their ability to reflect and act on their situation. This can be contrasted with Beauvoir's description of old people as suffering from a "frozen past," i.e., a situation which indeed, as she writes, "in many instances paralyses them."[33]

Beauvoir and more recent phenomenologists have examined the role of temporality and a growing awareness of finitude in the experience of aging, and how the "practico-inert" of "past activity" can congeal "in ways that mold present and future action."[34] The term practico-inert is Sartre's, which he uses to refer to entities that while being products of our own life together with others (be they objects, the built environment, social institutions or discourses or something else that result from our praxis, that we create through our activities) also delimit our freedom through the way they require maintenance or produce demands.[35] Here, however, we combine the insight that the concept of practico-inertia captures with the insights (for example in the work of Merleau-Ponty) that the past is never just a reified mass of our previous actions and experiences but a living matter that help shape the self's experience of the present and opens up the future in distinct ways, and that the experience of one's future (for example as finite) can help shape one's perception and experience of the present.[36]

On the one hand, the experience of old age can make the self acutely aware of finitude, and past activities can function as practico-inert, thereby delimiting what the self experiences as ways of acting that are "within reach." On the other hand, one's past, present, and future are not neatly set apart in experience, but co-constitute the self's temporal horizon. This is of help also when engaging with and seeking to understand the interviewees' narrations. Turning to one's past, reflecting on the past, can take place when people come up against their future as limited. Yet this need not foreclose one's future-oriented projects, necessarily and completely. Indeed, the past just as our future can be understood as being in a continuous state of becoming – open for re-interpretation – and both are part of the self's temporal horizon that helps structure experience. Further, the past and the present can stand forth as that *towards*

[33] Beauvoir (1996, p. 378).

[34] Kruks (2010, p. 275).

[35] Sartre (1960).

[36] Cf. Merleau-Ponty (2013); Beauvoir (1996).

which we direct ourselves in order to re-orient ourselves toward the future, from the point of view of our living present.[37] This can be understood, for example, as taking place when Nils (re)turns to his past in light of his present absent-mindedness, recalling how others in the past referred to him as the "professor," and how this was nothing he worried about. When in the grey zone of aging, however, absent-mindedness takes on different tonalities, and he starts to question his experience of absent-mindedness.

Neither Barbro's, Nils', and Birgitta's perceived pasts nor their perceived futures seem to appear as frozen, to them. Rather, their narrations indicate how they are directed toward a future that is experienced as finite and uncertain, and yet, even though their bodies may be in decline, they envision a future and try to create a future for themselves. And in the specific sociocultural contexts within which they operate, cognitive testing can be a part of and a means by which such a future is created.

Finally, Beauvoir offers a critique of the societies of her time and the way distinct practico-inert institutions weigh on and result in an embodied experience of old age as marked by alienation: such a society performs a "crime" against the elderly, she argues.[38] Remaining focused on how one's experience of aging is shaped within and through social encounters with others, including how such encounters can foreclose what one experiences as possibilities allows for a critical eye on how contingent yet culturally dominant norms about old age, at the present time and place, can help shape perception and experience.[39] Moreover, the very ambiguity of the grey zone can be understood to hold a latent subversive potentiality. Rather than orienting the self toward a univocally frozen past, the ambiguity and uncertainty characterizing the temporality of the grey zone creates the possibility for the self to grapple with and navigate within the temporal dimensions of his or her life.[40]

In the grey zone of healthy aging and aging with disease that we identify, fuzziness and difficulties in orienting oneself in other ways than toward the tests for cognitive functioning as tools, seem central – more so than frozenness. Coming of age today, then, can mean orienting oneself toward a future by, among other things, viewing oneself through the prism of health and disease and to a growing extent acting on and being expected to act on these categories.

5 Affectivity and being stuck in a reflective mode

Barbro's, Nils', and Birgitta's narrations need to be understood in relation to the larger socio-cultural context within which they live, as well as to understandings of dementia that circulate in this context. As seen in the introduction, Sweden encourages the early diagnosis of dementia, as do many other countries.[41] Furthermore, past

[37] This is the case since the experience of one's future can help shape one's perception and experience of the present and open up for a re-understanding of one's past, that in turn can help shape how one can re-orient toward the future.

[38] See for example Stoller (2016, p. 196).

[39] E.g., Weiss (2017).

[40] We thank the reviewer for this comment and for asking us to clarify this point.

[41] Socialstyrelsen (2017).

research among patients at a geriatric ward in Sweden has shown that dementia is, at least sometimes, understood as something that is feared.[42]

Severe dementia, Nils remarks, is "no fun perspective for one's future." Nils says that while he previously might have joked about "entering the dim" when approaching the age of 75, the joke is no longer funny. He comments on the role of time, in this regard, saying that what once felt distant – far away in the future – is now much closer, and while he states that he does not find this difficult to talk about, he also adds that it [the dim/dementia] is not something he takes lightly. Birgitta explains that Ahlzeimer's dementia is what she and "everyone" agonize over, and while she says she does not know much about dementia, "one has heard that it is terrible." Barbro, finally, narrates how a friend of hers reacted when she told her that she would be tested: "I told her, and she said 'Oh God! God, will they do that on you too?" The friend then told her about another friend, who had been tested for dementia, and for whom the experience had been devastating, particularly when she had been told that there were "some things in her brain that did not function."

Such narrations underline how the thoughts of being tested and needing to be tested, as well as the experience of undergoing testing, are affectively charged. Phenomenologically, affectivity has been understood as a mode through which the things, others, and the world appear and matter to us – as connecting the self to the world.[43] Here, Heidegger's understanding of fear as a mood situating the self and shaping the self's body-world relation through the disconcerting feeling of something threatening approaching us, can illustrate the experience of encountering dementia.[44] Thus, phenomenology invites attention to how fear connects the self to the world. If dementia is what is feared, this means that fear connects the self to the world in such a way that the disease stands forth as fearsome. The self can experience itself as filled with fear and the primary care personnel performing the test can manifest in perception and experience as bearers of potentially terrible news.[45] What is more, affectivity in this reasoning is not understood as something "internal" to the self, but can rather be understood as unfolding in shared space, in between persons, and as having the potential to draw people and things together or make them withdraw from each other.[46]

In Barbro's, Nils', and Birgitta's narrations, entering the grey zone of aging between "healthy" aging and aging with a disease such as dementia seems also to be affectively charged. The grey zone is not a neutral place, but one that is experienced as disconcerting. Being tested is likewise an affectively charged practice. Barbro, who narrated her friend's friends' experience as devastating, states that for this person everything became "wrong, wrong, wrong, because she was reminded of it [her difficulties]." Health care personnel doing the testing need to proceed with caution, Barbro states, and prepare the person being tested for what may come. Further, as

[42] Zeiler et al. (2022).

[43] E.g. Cataldi (2008).

[44] Heidegger (2010). See also Sara Ahmed's analysis of the intensity of fear as an anticipated suffering (e.g., Ahmed 2004a).

[45] Compare Zeiler (2020).

[46] Käll (2013); Ahmed (2004b).

seen in the narrations of Barbro, Nils and Birgitta, entering the grey zone can be ambiguously experienced: experienced as encompassing a tension between an experience of having reached a stage where one's cognitive abilities do not need to be in decline and experiencing themselves as possibly having a disease that result in such a decline. This ambiguity can now be further spelled out: entering the grey zone as a zone that is affectively charged implies certain ways of coming to be connected to the world, in *worrying* ways, and this without it being within the self's control.

However, at the same time, Barbro's, Nils', and Birgitta's narrations also allow for a focus on the self's ability to act on and interpret themselves as aged by means of the resources they have sedimented, habituated, and incorporated in and through their aging process, their dynamic self-becoming. In different ways, they make use of their experiences of the past to make sense of the present. This is the case when Barbro and Birgitta comments on what they see as troubling tendencies in society – what Birgitta refers to as "a new culture." Relatedly Barbro says that "not that long ago, when I was younger," an elderly relative who forgot things was perceived differently. She underlines that her point is not to downplay absent-mindedness, just that, at that time, "somehow, people were allowed to become old."

To sum up: the grey zone of aging, in our analysis, is affectively charged and intersubjectively and socially shaped. People that enter it will be affected by others and by being in it, and yet they can take a stand and act, even though some ways of acting, and some ways of orientating themselves, will be experienced as more within reach than other actions or orientations – because of how e.g., assumptions and norms about old age as an at risk age, according to which one should attend to one's body and possible symptoms can help structure one's very perception and experience of aging.

This reasoning can also be further developed: entering the grey zone does not dissolve the continuous dynamic of self-becoming that phenomenologists have shown as integral to selfhood, but it can involve a distinct experience of oneself as *being* old – including an experience of the other within as the one who is old.[47] More specifically, we suggest, to enter the grey zone is to find oneself in a mode of heightened awareness of the ambiguities of healthy aging and aging with a disease. In the grey zone, the self is neither fully healthy nor has a disease, but need to negotiate and live this ambiguity, often on reflective levels of existence.

As seen, subjectivity, in phenomenological reasoning, always already implies transformation and a dynamic becoming, and such becoming typically takes place on pre-reflective levels, i.e., without the self either reflectively and thematically attending to or noting this. Further, phenomenologists have suggested that when experiencing oneself as *being* old – i.e., in the experience of coming to see oneself as old – something has often happened that makes the self attend reflectively to itself as old. When entering the grey zone, however, the self cannot but reflectively attend to the ambiguities of healthy aging and aging with a disease, and such reflective attention can block seamless interaction with others and the world that they inhabit. Barbro's narration exemplifies this, when she describes how she repeatedly reflects on her memory after having done the test, and asks her sons and her friends if they have

[47] See for example Käll (2017a); Weiss (1999).

noticed any memory problems. "God, how am I? Senile or what?" she asks herself, adding "what if I can't continue doing things I really enjoy doing?"

The point we are making is not only or primarily that old age can be experienced as otherness within. Nor is the point only or primarily a critical eye for societies where the experience of old age is perceived as marginal, or that we need to open "ourselves up to the possibility that there are new ways of synthesizing space and time that a disabled or elderly person can enact" and that the very understandings of what "counts as a 'normal' existence" needs to be questioned.[48] While all of these are important insights, our point is this: to enter the grey zone of aging between "healthy" aging and aging with a disease such as dementia is to enter an affectively charged, intersubjective and socio-cultural zone, and to stay in the grey zone can have thorough and detrimental effects on the self, even though the self does not have a disease. When staying in the grey zone, the self can become stuck in a reflective mode of attending to one's aging as in between – neither as part of healthy aging nor as aging with a disease. And while staying in the grey zone does not imply that one's future "freezes" – agency is still possible – the grey zone is affectively charged and both socio-culturally and medically configured, such that remaining within it can shape the self's experience and perception of itself and what to do, in intricate ways.

6 Conclusion

The themes of whether the human subject "tend to profoundly disidentify on a subjective level with the ageing process that is occurring in and through our bodies," and what it feels like to "feel one's age" have been topics for phenomenological discussion.[49] Some such work also discusses what it means to "come to terms with old age" and how aging can be understood as underlining the "ethical meaning of human finitude" when "the process of ageing intensifies the experience of finitude," allowing "us to understand our own lives as the forming of singular totality, as really becoming-oneself."[50] To such past discussions, we add attention to aging within the grey zone between healthy ageing and ageing with a disease.

Aging and old age, in Sweden as one among many other Western countries, cannot be understood without acknowledging the role of medicalization. While people might still come to experience the other within as an old self, in encounters with others, this insight might not be sudden, but rather experienced as a gradual realization when entering the grey zone between healthy ageing and ageing with the disease. Moreover, the grey zone is affectively charged and can demand reflective attention to one's own embodiment including one's cognitive abilities. Entering and remaining in the grey zone allows for a dual experience: on the one hand, an experience of one's future as more explicitly finite than before, including an experience of one's body as declining, and oneself as being old, and, on the other hand, an experience of oneself as someone who is dynamically becoming and able to engage with and relate to one-

[48] Weiss (2017, pp. 214–215).

[49] Weiss (2014, p. 54); Bavidge (2016, p. 207); see also Arp (2016); Heinämaa (2014); Fischer (2014).

[50] Crowley (2016, p. 187); Rentsch (2016, pp. 355, 358).

self and the world, and with the capacity to act based on insights within this very grey zone. Aging within the grey zone between healthy aging and aging with disease thus involves a distinctly ambiguous experience of self-becoming and of being.

Finally, a critical phenomenological perspective and the qualitative critical phenomenology analysis adopted here has allowed us to discuss how aging as a sociocultural, biological and medicalized phenomenon can help shape the self's mode of being. It allowed us to show an account of aging within the grey zone, including how norms about aging can feed into the grey zone, that can serve as a basis for a critical reflection on these norms.

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