The Phenomenology of Dementia: Time, Emotion, and Relationality in Life and Lifewriting

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This article will explore the subjective experience of time for people living with dementia, exploring the implications of the loss of the ability to expect, as well as to remember, and how this conditions lived experience. It will also look to intersubjective time as a condition of relationality and a structuring condition for reciprocal and empathic care. It uses an approach informed by neurobiology and phenomenology to analyze these forms of temporal experience, looking notably at features such as expectation and surprise, and their non-normative presentation in those living with dementia, following the methods of psychiatrist Eugene Minkowski, neurobiologist Francisco Varela, and philosopher Natalie Depraz. Finally, it will look to memoirs by those with dementia, as well those who live close to them, to add texture and emotional resonance to the scientific and philosophical accounts of time in dementia.

Introduction

The North American writer Thomas DeBaggio, writing of his own experience of Alzheimer's disease, describes the condition as an "eager beast in my brain gobbling time in both directions" (32). If DeBaggio feels the past in the form of lost memory to be 'eaten up,' this also affects his sense of the future. In fact, people living with dementia often retain long-term memories, but lose recollection of the previous day. And at the times when we struggle to remember in this short-term way, we also lose the ability to anticipate, an experience that can bring with it anxiety and distress. This article will explore the subjective experience of time for those living with dementia and for those who care for them, exploring the implications of losing one's grasp on time in relation to both past and future. It will, however, also demonstrate the way in which people with dementia continue to orient themselves in and organize time. Far from facing an impenetrable void, such individuals maintain an ethical and affective relationship with the future, however elusive it may feel, and also preserve connection with other people through a shared temporal framework. I will consider the ability—and the limitations—of phenomenology to convey such lived experience, foregrounding a neurobiological strand of this philosophical method that offers new insights into the subject's perception of the passing of time. Finally, I will also look to memoirs by those living with dementia and those close to them to add texture and emotional resonance to the philosophical account.

A Note on Method

I draw here on a combination of philosophy of psychiatry, qualitative health research and literary lifewriting in pursuit of a good description of the elusive character of lived time. I look first to the foundational account of lived time in psychiatry by Eugene Minkowski, informed by his encounter with the new philosophies of time in the early twentieth century. Building on the Minkowski's insights, the neurophenomenology of thinkers like Francisco Varela, Natalie Depraz, and Michela Summa undertaken in this century offers a way to understand the function and the conceptual structure of processes such as memory, expectation, and surprise—the *qualia* of consciousness—at a moment-by-moment level. As the cognitive and affective phenomena in question are subjective experiences undergone by individuals, first-person accounts of such experiences in interviews and ethnography (Clare et al.; J. Taylor) and memoirs (DeBaggio; Davis; Bayley) may also—self-evidently—offer some insight into their nature. Lastly, recent approaches informed by performance studies and theatre scholarship (Fuchs; Gibson; Moore) have furnished some particularly suggestive ways of thinking about the "now" of dementia. The thread running through these enquiries, despite their diverse approaches, is an interest in the temporal dimension of lived, first-person experience—what Minkowski calls the "me-here-now" (377). Such qualitative approaches, involving in some cases the testimony of those living with dementia, might help us, in the words of psychiatrist-philosopher Karl Jaspers, to understand as well as to explain this elusive condition (Jaspers 301).

The most contentious form of evidence among these sources might be the memoirs of intimates and carers, something which Thomas Couser has called surrogate lifewriting. These accounts can self-evidently be a rich source of insight—as well as in some cases works of great literary value. They can also, however, risk seeming speculative and even ethically compromised, on occasion, and especially so when they represent the experience of those who can no longer speak for themselves. And I might be seen to compound this risk by drawing principally on the controversial work of John Bayley. Bayley, the husband of novelist and philosopher Iris Murdoch, wrote several volumes of literary memoir which recalled their early life together but focused on Murdoch's last years, living with dementia, and the impact of the condition on Bayley himself, living with and caring for Murdoch. Bayley's first memoir, *Iris*—the work on which this discussion will draw—was seen to appear with indecent haste (Zimmerman 55): before its subject's death (but after the point where she was able to give consent). It was also felt by some that Bayley was exploiting Murdoch's vulnerability: diminishing her reputation and aggrandizing his own (Langan; see also Schilling). Murdoch—and, in principle, any subject of a carer's memoir—becomes doubly vulnerable, according to Couser (x): to harm or exploitation in her life and to misrepresentation in the writing that she can no longer read or refute.

It is beyond the scope of this article to mount a full defense of Bayley's work (even if I wished to do so) but it will offer some justification of the work's usefulness in this context. It is openly, as Carol Schilling (2017) has argued, an account of the effect of Murdoch's illness on Bayley, as much as it is one about the effects on Murdoch herself, giving a valuable insight—for our purposes here—into the way in which a partner or family member offering full-time care also finds their perception and experience of time to be changed and distorted. Bayley and Murdoch lived in relative seclusion and with relative affluence, meaning that they could adapt to Murdoch's pace and rhythm of life—something which, while not representative of many people's experience, can itself disclose certain new ways of living in time that dementia imposes (relatively) free of social or institutional routines and schedules. Linn Sandberg and Barbara Marshall's writing on queer approaches to dementia and time (Sandberg 2008; Sandberg and Marshall 2017) has posited an alignment between dementia and queer temporality: alternative conceptions of future that resist heteronormative narratives and their inscription of (re)productive futurity and age-related propriety. Building on this work, I want here to gesture towards more discrete, subjective and local ways in which an individual living with dementia might also enact non-normative temporalities in their improvisatory rhythms and routines. Murdoch is shown by Bayley to resist normative routine to live in more ludic and creative ways as she ages.

Bayley's memoir is also distinctive in attending to continuity as well as change in writing of a new life with dementia: noting the persistence of Murdoch's personality, values, concerns and philosophical disposition in the face of the disease, and repurposing metaphors first applied to their early life to describe her life in illness (see Zimmerman 53). Lastly, Bayley's eloquence on the nature of lived time for the couple is not simply an aspect of "writing well," as Michael Langan somewhat distastefully puts it, seeing in Bayley's style the potential for artifice. Literary memoir, and Bayley's philosophically acute writing in particular, can enact a kind of "practical counterpart to theoretical phenomenology" (24), in the words of Patricia Waugh. It can—in its attention to language, to the relation of abstract and concrete, to tone, and to mood—disclose both theoretical and affective aspects of this new temporality. The close fit between the characterizations of disordered time in the neurophenomenological writing, and its representations in first- and third-person accounts of living with dementia, mutually strengthen the credibility of these accounts. The reader must, however, decide for themselves if this approach and these sources bear fruit.

Time and dementia: knowing when

A plausible starting point for any qualitative investigation of lived time in dementia might be the systematic examination of this experience as it appears in clinical health research. A meta-analysis studies of the experience of lived time in dementia (Eriksen et al.) offers four key reasons why time is a salient concept for those with certain dementia diagnoses, and in so doing provides the clinical background for this discussion. Firstly, the condition can affect the hippocampus, the "core temporal device in the brain" (Dalla Barba and La Corte 104), and so those living with certain dementias have difficulty with time orientation and might, in the example of Eriksen and colleagues, get up in the middle of the night to have breakfast (436). They can struggle, to put it in the succinct formulation offered in relation to cognitive problems with time by Nygård and Johansson, with "knowing when." Secondly, such individuals can find it difficult to retain autobiographical memories, and so risk losing the chronological thread of their lives (Eriksen et al. 436)—that which Ronald Dworkin, following other moral philosophers on personhood, has called their "narrative self" (Dworkin; see also Summa and Fuchs 390; MacIntyre; C. Taylor). Thirdly, those living with dementia encounter the rigid, task-based, temporal regimes of health or care institutions, which can cause anxiety and remove autonomy when they cannot perform tasks to order or in the time available. Finally, dementia can disrupt the broader temporal lines of the lifecourse if it is seen to arrive ‘early’ (in middle age or young older age) or to progress rapidly (changes felt over months rather than years, for instance), being felt to rob an individual of the expected healthy retirement or hasten (and then truncate) their older age (see Eriksen et al.; Roach and Drummond).

This survey by Eriksen and colleagues of studies of the different facets of lived time in dementia might seem comprehensive in its treatment of the relationship between the two, and indeed represents a vital resource for anyone venturing on this topic. I want here to build on its findings, however, in drawing out how these experiences might *feel* to the individual living with a dementia diagnosis, as well as to those close to them, and to add a significant dimension to the coverage that Eriksen and her colleagues have given. A more fine-grained method than these authors employ might offer an account of the unfolding time in the present, the moment-by-moment experience of time that can seem to eclipse any perceptions of past or imaginings of future at an advanced stage of the disease. Furthermore, both the experience of time and the wide array of emotions intimately bound up with the temporal are intersubjective in nature, something arguably overlooked in Eriksen’s study but considered in greater depth here. Finally, Eriksen and colleagues focus on the disordered and aversive aspects of temporal experience, whilst a fuller account might also encompass the capacities that endure and the dynamic engagement with time that almost always remains. Bringing the intersubjectivity of time and these enduring capacities together, I will in the last part of what follows consider the ways in which those living with dementia, even in later stages of its progression, continue to organize time into conversational sequence and participate in social rituals, harnessing the “melody of speech,” in Elinor Fuchs’s terms, to preserve agency and social connection.

Towards a phenomenology of dementia

To give a moment-by-moment account of dementia experience, it seems appropriate to turn to the discipline that promises attentiveness at this granular temporal level. An account of embodied, first-person experience in time is the concern of phenomenological philosophy. A phenomenology of the later stages of dementia is an elusive goal, however. It is difficult or even impossible for many individuals living with this condition to give voice to their experience, and correspondingly difficult for those who speak with them to glean the fruits of their introspection.

Further, such a phenomenology, necessarily speculative, would need to attend not only to the altered texture of moment-by-moment experience, but also the threat to a normative sense of time *per se* that dementia represents. Subjective experience is underpinned by an ongoing interaction of past, present, and future states—states such as memory and anticipation—which might look quite different under the condition of a dementia diagnosis. Similarly, with the loss of one's memory for the past, the coordinates of one's home, one's current situation, and one's place in the world—in every sense—can feel similarly elusive. The phenomenology of dementia is, then, a challenging proposition—but one that is nonetheless vital to attempt in order to preserve empathy, recognize continued personhood and agency, and thereby improve dementia care.

Phenomenology is useful to us for being not only, as David Woodruff Smith terms it, "the study of structures of consciousness as experienced from the first-person point of view," but also a tradition that has—through the work of Husserl, Heidegger, and in particular Maurice Merleau-Ponty—emphasized embodied experience, the subject as 'lived body.' And this is the context in which we most often find phenomenology brought to bear on the condition of dementia. In an influential set of investigations of dementia, Pia Kontos has used Merleau-Ponty's 'body-subject' as the starting point for an exploration of the later stages of the condition (Kontos, "Ethnographic reflections", "Embodied selfhood"; Kontos and Naglie). The body is not, for Merleau-Ponty, simply (dumbly) material but also intentional. Bodily practices over many decades embed habits, tastes, and skills in an individual that amount to a "cultural and spiritual" world (Carman). Such social and cultural skills are "sediment[ed]" in the body over time, in Merleau-Ponty's description (149-50), consciously or unconsciously learned to begin with but later available in a habitual and pre-reflective form. These habits even include certain kinds of verbal utterance, complicating the distinction between mind and body, language and gesture. John Bayley described Iris Murdoch, for instance, answering the door and interacting politely, even gracefully, through a kind of buried "reflex" when language and willed propositional thinking were otherwise lost (76-77). In Kontos's reading of these ideas, laid-down values and dispositions are not simply automatic reflex, but a trace of our cumulative learning and experience—a bodily memory, in other words—that is a key element of selfhood and social identity.

In an influential 2005 paper, Kontos examined the behavior of a group of care home residents in the light of this idea. Movements such as taking a necklace from underneath the top of their apron, holding another's hand, or peeling a boiled egg are all intentional and expressive actions that circumvent the need for language or reflective cognition (560-1). Merleau-Ponty's focus is on the (innate) pre-reflective ability of the body to perform, but Kontos develops these ideas with reference to Pierre Bourdieu's theory of *habitus*, which builds on Merleau-Ponty's conception of the body as source of practical intentionality to focus on the "learned acquisition of sociocultural dispositions" (Kontos, "Embodied selfhood" 562). Kontos sees just such dispositions, including distinct ways of speaking or singing, walking, eating, or washing one's hands, as continuing to be displayed until very late stages of the disease. We are, as Kontos's article (and this special issue) contend, relational beings embedded in specific social worlds and cultures that continue to find expression until the very end of our lives.

This article will stand slightly to one side of the important work done to investigate the persistence of the 'body-subject' in dementia. In its focus on temporality, it will consider what can be seen as the more abstract concerns of phenomenology: the structures of experience represented by time, evidently, but also, insofar as this concept is necessarily related, space. Time is far from an abstract experience or neutral concept, however, in this context; it is integrally linked to emotion—and emotion to it. Emotions are constitutively temporal: the structures of anticipation, desire, regret, and surprise integrally oriented to past or future. We understand time through emotional experience, as St Augustine's famous meditations on the concept of time in the *Confessions* show us, framed by his experiences of loss, his shame towards past behavior, and his anticipation of God's forgiveness. Perhaps the most well-known line from this work shows the protagonist as a youth struggling to relinquish desire in the present and trading with his future self: "Give me the continence to live a chaste life, but *not yet*" (*Confessions* 8.7.17; my emphasis). And these temporal emotions are also very frequently intersubjective, as Augustine's are, bound up with desire, duty, embarrassment in the eyes of others, and regrets over losses or absences within key relationships. This enquiry sets out, then, to explore the particular cast that dementia gives to these temporal feelings and relationships using the tools of phenomenological psychiatry, tools turned explicitly to the task of attending to the structures of such psychological experience. It will also attend to the communal linguistic structures which determine the understanding and expression of perceptions of time—the language of days and weeks, of before and after, of since and until—which persist until the late stages of dementia, even when such language ceases to have purchase on the world and its referents fall away. The persistence of the language of time goes beyond a reflex, in Bayley's term, to represent a commitment to purposeful, social living, even when this becomes difficult to achieve.

Eugene Minkowski and the psychiatry of lived time

Psychiatrist Eugene Minkowski, in his formative 1933 work of psychiatric phenomenology *Lived Time*, made an early study of the experience of temporality in neurodivergent people and those living with mental health conditions. He takes dementia as one of his case studies in the chapters demonstrating the intimate and inextricable relationship between time and mental wellbeing (or distress). As he observes in this case-study, time, far from becoming unimportant to the individual living with dementia as they lose their hold on temporal sequence and duration, becomes ever more pressing a concern. This observation is reproduced in recent studies of dementia, where time as a theme and object of investigation can impose itself after the researchers' early analysis of interviews or recorded conversations, coming to be the focus of the work inductively even when researchers set out initially to investigate other facets of experience (see de Witt et al.). In his study, Minkowski reproduces excerpts of a set of interviews he made with a woman living in a care home and diagnosed with what he calls 'senile dementia.' She, far from relinquishing a sense of time, in fact demonstrates "*a marked tendency to constantly situate [herself] in time*" (Minkowski 377), as the following discussion will show.

What emerges from Minkowski's account of his patient is the significance for her not just of adhering to established temporal structures but of having these structures in common with others: it is important that they accommodate a shared history and a shared future. This patient, recognizing the doctor, is concerned to emphasize their historical connection, and in particular the amount of time they have known one another, repeating at two different moments, "I've known you [quite] a long time" (375), and the second time guessing at an acquaintance of "two years" (376). She also confabulates visits from her son, who has, in her account, "just left five minutes ago" and is returning soon, and who has—in the world that she constructs around herself—the habit of visiting her frequently. In the confabulated world of Minkowski's patient, if not always in the real one, her children sometimes come to visit; other people come to visit. This building of alternate realities with the abstract structures of time has epistemic benefits in allowing her to retain a coherent self-concept, and to participate in social interactions as a social being with social worth—with confidence and dignity, in other words (see Bortolotti and Sullivan-Bissett 263-64). Her life is still, even in this unfamiliar institution, integrated with that of other people over time.

It is also important to the patient that when she returns to her Paris apartment (as she believes she will do), she will have the same concierge. She says of her apartment and this future move:

> He said to me, 'You are going to be happy there.' I will be able to get all of my furniture back, which is in storage. I think I am going to be happy as a king.
> [. . .]
> My son told me, 'Everything is just the way you left it.' Then, too, I have the same concierge. She is also glad to see me again. (Minkowski 375)

She looks forward to future happiness in this apartment, but it is also important to her that both the apartment and the concierge in the building are currently there, waiting for her, and she refers to them in the continuous present. The perpetual "Now" that can sometimes characterize the life of those living with dementia, rendering past and future obscure, also infects the grammar of her locution in this instant: the concierge is (rather than the more correct "will be") glad to see her in a scene unfolding in this "Now." Living as she does "in the meantime" (Minkowski 375), her past life itself is also "in storage," suspended in this present tense and in an unspecified location. She remembers her previous dwelling on the rue de Rennes, and the apartment her son has newly found for her morphs into "precisely the same apartment" she lived in before, a composite space referred to more vaguely in this new present as "over there."

Minkowski relates the temporal and spatial language of these utterances to the "fundamental" phenomenological notion he identifies as "me-here-now" (377), an ability—in the absence of a clear memory or specific contextual knowledge—to feel located in a place and time, if only moment by moment. The rest of the world may disappear into a composite "over-there-before-or-after," in Minkowski's term, to which everything outside of the here and now is subordinated. But those with dementia do not lose the ability to anchor themselves in the present—something by contrast often disturbed in the condition of schizophrenia, when the individual may experience dissociation or in extreme cases imagine themselves to be in an otherworldly realm, or even dead. Minkowski says of those in the last stages of dementia that their world can be "empty of precise mnesic images" (378), which, while more categorical a statement than would be made today, points to the lack of autobiographical memory which might cause any of us, living with more advanced dementia, to find benefits in confabulation. If those in this condition confabulate, however, they do so with specifically *temporal* attachments and narratives: "they always invent in *time*" (330).

More than this, even when those living with dementia lose hold of the specific interests, plans and aspirations that might have structured their future, they are often no less committed to a future and do not let go of the desire to be purposeful, contribute or fulfil their responsibilities towards others. Studies have shown speech in those living with dementia to be peppered with modal verbs that express such a purposive stance towards the future ("I must," "I ought," "I should"): far from being shorn of intention, the self with dementia here is all intent. Trini Stickle, conducting a sociolinguistic study of people with dementia, writes of the "sheer number of modal verbs present" (27), and her participants show a far higher number of these than the control group (186).[1] This will to interact and discharge plans and duties without the context to do so can, of course, exacerbate anxiety and restlessness, making the condition of later stage dementia all the harder to bear. We might recall Oliver Sacks' account of the 'Lost Mariner,' his patient with Korsakoff's syndrome, a frontal lobe dementia related to alcoholism, as "fretful and restless." Sacks goes on: "Clearly, passionately, he wanted something to do: he wanted to do, to be, to feel—and could not; he wanted sense, he wanted purpose" (37). As Minkowski observes, those living with this condition need—and continue to need—to preserve a dynamic relationship with the world into the future.

The affective landscape of surprise

As the implied relations of duty and responsibility in these utterances attest, the way that we perceive time at all is a social process. Time is not—even for those who seem unmoored from many social relations—experienced in isolation, but through intersubjective interactions. Our perception of the world is always already colored by affect, the emotional valence of the moment, anchoring cognitive processes in the intersubjective fabric of our lifeworld.

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[1] The study participants with dementia used 143 modal verbs to the control group's 116 and recorded a higher number in relation to every individual verb, with eighteen instances of "should" as opposed to seven in the control group, and nine "musts" to seven respectively (Stickle 186).

Given this, the work of the late neuroscientist Francisco Varela and the philosopher Natalie Depraz, which has modelled the intricate relationship between time, emotion and intersubjectivity, might prove instructive in this context. Varela and Depraz bring together phenomenology and neurobiology (to create a method they call 'neurophenomenology') in a number of influential studies, demonstrating there the inextricability of emotion and cognition in everyday experience, and the way in which our experience of time underpins both. In a foundational paper from 2000, "At the Source of Time: Valence and the Constitutional Dynamics of Affect," the authors examine the interconnectedness of temporality and mood at the moment-by-moment level. And this, I want to suggest, is an approach which has the capacity to draw out the more elusive aspects of the experience of dementia.

Phenomenology might be expected to give a rich picture of the impact of losing memory on a subject, attentive as this method is to the processes of consciousness and self-awareness of which memory is such a central and constitutive part. As Michela Summa has argued, self-awareness involves "something more than the punctuated consciousness of now" (482). Philosopher Edmund Husserl—whose work underpins all the philosophical thinkers cited here—spoke to this richly temporal consciousness in his foundational works of phenomenology. In particular, he observed that even the 'now-moment' is obtained, in Summa's account, "*retrospectively* and through abstraction, for our experiences necessarily unfold themselves in time" (Summa 482; see also Husserl, *Phenomenology*). With a radical loss of memory, even such near-instantaneous retrospection can be affected, and time fail to appear to progress as it might usually do. This fundamental 'stuttering' of time creates both a wearying preoccupation with temporality and an inability to gain purchase on it: we cannot, in this condition, keep track of yesterday or tomorrow (or even today). It is not only the loss of the past which we are anxious about, however: anxiety by its nature also attends the future which is lost along with this past. Minkowski's patient herself, in my earlier example, describes living perpetually in the "meantime" (377) before some unspecified change or event.

In John Bayley's caregiver memoir about Iris Murdoch, the descriptions of Murdoch's daily life as her dementia progressed give some further flavor of the constant state of temporal anxiety which many people with dementia can experience. Time, Bayley writes, "constitutes an anxiety because its conventional shape and progression have gone, leaving only a perpetual query" (46). And later: "[h]er endless fidgets and queries begin to empty my mind" (165). Bayley offers a nuanced account of what happens to Murdoch's, and by extension his own, experience of time (so determined is his practical and emotional life by hers, in his own account at least). He describes the simultaneous necessity and futility of a change in their routine, a new situation bringing both of them momentary relief but almost immediately occasioning new worries: "change as a relief from anxiety and then more anxiety" (151).

The philosophy of expectation and the obverse, novelty—with its emotional correlate, surprise—may help to explain these ambivalent feelings towards change in those living with dementia. Natalie has explored the affective landscape of surprise, a striking instance of an emotion bound up entirely with temporality ("Rainbow" 250). And she reads this in relation to Edmund Husserl's idea of 'protention' (Husserl, *Phenomenology*): our ability to *expect*. As Depraz writes about surprise, so her colleague Francisco Varela writes about contingency and the unexpected (Varela, "Specious Present"): in both cases, these enquiries are a way of thinking about the 'microtemporality' of a lived consciousness. Surprise and the associated concept of novelty require that we can anticipate that the unexpected will occur, and be aware of the strong emotional quality of such an 'expectation,' without actually having any awareness of *what* that unexpected might be. The capacity to anticipate surprise is the paradoxical (yet entirely commonplace) condition that Depraz has called a kind of "expectation-consciousness": a "serene vigilance joined to an emotional quality of hope or expectation" ("Phenomenology of Surprise" 224). This is a "surprise that knows itself as such, a knowledge so intimate that it accepts no longer having purchase on (mastery of) itself" ("Phenomenology of Surprise" 224).

When we undergo memory loss in the course of dementia, however, this momentary loss of mastery over ourselves becomes constant and opens like a chasm within us; our vigilance is anything but serene. Those with dementia often display heightened watchfulness, made all the more troubling for not knowing what it is that they must watch for or be anxious about. These observations about surprise as the obverse of expectation thus relate to a fundamental issue for those with dementia. The loss of protention (the future) is a comparable source of terror for the person with dementia to the loss of retention (the past). As this article begins, Thomas DeBaggio writes in his memoir *Losing My Mind* of the way in which his condition was the "eager beast in my brain gobbling time *in both directions*" (32, my emphasis).

In the condition of advanced dementia, almost everything can be unexpected (as we have so little memory of what has come before), and the fact of this is itself unexpected; we have lost what philosopher Francoise Dastur, thinking along similar lines to Depraz, calls the "paradoxical capacity to await surprise" (cited in Depraz, "Rainbow" 253). The positive and negative affect of a surprise, as well as the serene vigilance that allows us to attend one, are replaced by a constant queasiness, a deeply felt unease that cannot name itself. The words of the participants in a qualitative study by Linda Clare and colleagues illustrate this predicament. Clare's participants, living with a moderate to severe dementia diagnosis in residential care, gave the following general characterizations of their situation in structured interviews:

> 'Well, I don't know what they're going to do with me in here, but er, they haven't said what they're doing, [and] I don't know why they've put me in here[.]' (BG06)
> 'I don't know whether I'm stuck here for the rest of me [my?] life or what's happening really[.]' (GR03)
> (Clare et al. 714)

The participants in Eriksen's study also described the dilemma of the *unknown*: "is it going to be worse than it is now? I do not know. No one can answer that one" (447). The participants' dislocation in space is paralleled by an alienation from the normal structures of time that affects their ability to predict a concrete future or imagine their place in it, despite their best will—and efforts—to do so.

There are situations where this lack of expectation (of either surprise or the known) can bestow a sort of neutral state of acceptance. Bayley describes asking Murdoch to take a bath in the middle of the day, observing: "Iris never objects to this; she seems in a curious way to accept it as both quite normal and wholly exceptional, as if the two concepts had become identified for her" (52). The loss of both protention (into the future) and retention of the past can allow one to relinquish certain habits without demur. More often, however, those with dementia and their carers describe a terrible restlessness. DeBaggio talks of "a convulsive time of stumbling and future loss" (200). According to Husserl, even a typical experience of temporality is in fact on a much more modest scale an experience of discontinuity or rupture: a perfect capacity to identify objects and lived experiences, a perfectly instant and complete perception, is never achieved (Husserl *Experience*; see Depraz, "Surprise of Non-Sense" 130-31). Perception is instead a broken dynamics of time comprising hesitation, doubt, and momentary pauses to weigh probability or potentiality—and so involves small moments of non-sense. Surprise is, then, in the argument of Natalie Depraz, linked fundamentally to this idea of non-sense: the suspension of meaning. These minimal openings of indeterminacy (moments of "non-assurance, hesitation . . . tiny vertigo") are, however, normally, "very quickly mapped into the reassurance of [one's] ongoing stable perception and cognition" (Depraz, "Surprise of Non-Sense" 130)—into our usually sense-oriented life. For those with dementia, however, that vertigo can and often does expand and extend and become their lived reality. Robert L. Davis, living with dementia, describes the aversion to surprise that the condition fosters in his memoir, *My Journey into Alzheimer's Disease*:

> Two years ago, I was able to handle sudden surprising situations on a routine basis. Now I am completely paralyzed mentally if I am thrown a question that demands an immediate decision on my part. I must protect myself from being thrust into an unexpected situation. (88)

Surprise stretches into a kind of paralysis that extends over time and is felt as disabling.

The constitution of these moments of non-sense in Depraz and Husserl's phenomenology are, then, consistent with the experience of enduring surprise—itself suspending the very structure of expectation—encountered in dementia. Depraz describes surprise in terms of "crisis" with respect to the "perceptive rupture" it occasions in temporality itself, what she calls a "an immediate bodily instant-rupture-shock" ("Surprise of Non-Sense" 132, 135). This surprise is habitually folded back into the continuum of stable perception, as Depraz describes above. In the experience of dementia, however, the rupture fails to be healed and can, as Robert Davis describes in his own case, be felt as paralyzing. Paul Ricœur's writing on what he calls the "quick judgement of novelty," in his discussion of the phenomenology and emotive aspects of attention, explores its bodily incarnation as "a diffuse inhibition, a certain stupor which stiffens the face" (254). In the context of Ricœur's writing this "shock [*choc*]" is a kind of rapture, not necessarily or even predominantly a traumatic experience, but it seems to hold within it the potential for a more traumatic incarnation in the prolonged experience of inhibition that dementia can entail. Thomas DeBaggio and Robert Davis speak in their memoirs of their own experience of permanent non-assurance in just those terms that philosophers such as Ricœur and Depraz use in relation to surprise (as a crisis, a paralysis, or a stupor) but emphasize its capacity to persist in a distressing way, rather than be absorbed into the continuum of perception. Davis, for instance, writes: "At the worst times, I cannot bring myself out of this state of stupor" (93-94).

This prolonged experience of non-assurance as to what the next few minutes or hours might hold threatens the stable continuity of selfhood itself. Linda Clare's interviewee, like many of those with late-stage dementia, looks to another to provide assurance of his continued place in his environment and engagement with future time: "Don't lose me, will you? Please don't lose me" (716). Another irony of the condition of dementia, then, is that although a couple lose at least some aspects of their "shared lifeworld" when one party develops dementia (Hughes et al.21-22; C. Taylor), intersubjective relationships are ever more crucial to the dementia sufferer in retaining the thread of the self. Bayley comments on Murdoch's terror of being alone, "cut off for even a few seconds from the familiar object": "If Iris could climb inside my skin now . . . she would do so" (78). As psychotherapist Alexandra Lemma once wrote of her role in listening to a patient with dementia, her interlocutor looked momentarily relieved when Lemma repeated back to her what she, the patient, had said to her the previous day: "*as if she felt held together*" (37, my emphasis). We all experience time intersubjectively to some degree; for those living with advanced dementia, finding it increasingly difficult to retain what has just happened or to anticipate the future, the role of the other in this process looms even larger.

‘Be Here Now’: a new appreciation of the moment

Theatre scholar Elinor Fuchs has reflected on the way in which living with dementia shares a lesson with dramatic art in this changed relation to past and future. In her article “What Theatre Has Taught Me About Alzheimer’s,” she cites the playwright Thornton Wilder’s famous dictum: “In the theatre it is always Now” (750). This, as has been seen, is the mode in which one exists perforce in living with advanced dementia. This aspect of dementia experience may seem to be another isolating factor: a suspension, a kind of perpetual stupor outside of the progressive time of past-present-future. In fact, as Janet Gibson’s groundbreaking work on dementia and performance has shown, the performative aspect of dementia is also a means by which the individual living with dementia connects with others, as a kind of audience, in the moment and can introduce all sorts of creative adaptations into their behavior and communication (Gibson 251-55). Furthermore, Fuchs’ enjoinment to “Be Here Now” contains a lesson for the carer as well as the individual living with the condition. If the actor “exudes spontaneity, yet hits all the markers of the stage blocking [planned and choreographed movements] at every performance” (750), the carer too can improvise a mood and a dynamic of communication moment-to-moment, at once spontaneous and incorporating elements of rhythm and repetition, and in both senses highly conscious of this changed relationship to time. “As a caretaker,” she writes, “I learned to exercise this double consciousness of the actor’s craft, being “here” and “now,” in both these senses” (“What the Theatre Taught” 750).[2] Both parties are working—and at the same time *playing*—together to maintain a certain momentum, to use

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[2] See also Gibson (258) on “double negativity”—simultaneously not oneself and not *not* oneself—and the performativity of dementia interactions on both sides.

the resources of the present in an ongoing, unfolding interaction over time.

Anthropologist Janelle Taylor describes her mother, diagnosed with dementia and losing more and more language, finding other ways to register togetherness amidst the turn-taking of conversations. She writes: "Mom and I are playing catch with expressions, including touches, smiles, and gestures as well as words, . . . It is a way of being together." (327)

These are happening in the 'Now,' but these are also a kind of conversational 'blocking,' or choreographed movement, a dynamic informed by decades of tacit rehearsal. Such touches, smiles and gestures are governed by social convention: she is, we assume, touching her daughter on the arm or the face rather than, say, the neck. She smiles at the appropriate times in the conversation, maintaining its rhythm; "lobbing [these gestures] back and forth in slow easy underhand arcs" (J. Taylor 327). Bridie Moore has written of the deployment of reciprocal gesture and touch in interacting with her father, even at a much later stage in the progression of his dementia than Taylor describes, to build a "circuit of care": "an improvisation, tenuous and breakable, but nevertheless a form of communication" (41). Returning to Pia Kontos's explorations of the "body-subject", we perceive that these are forms of social knowledge that those with dementia can retain and deploy in the moment. Linguistics scholars Boyd H. Davis and Margaret Maclagan note the retention of "pragmatic skills associated with being able to interact with others" (1) in their investigation of dementia and lived time.[3] Such bodily knowledge, sedimented over time, is not simply one's own expression of taste and social grace but a more fundamental understanding of oneself in relation to another that persists in the face of the loss of memory and language.

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[3] In their discussion of the way speakers use biographical details about themselves and others in order to "create common ground, establish relationships, handle impression management, and perhaps even maintain positive face" (Davis and McLagan 1).

Taylor recognizes the difficulty of appreciating the present and—by implication—transitory moments of value in these interactions in her own life, mortgaged as it can seem to be to the future: "so full of schedules, deadlines, plans and arrangements" (327). Yet it is necessary (as Taylor reflects) also to value these transient connections. She too can at least "sometimes . . . gain a new appreciation of the moment." Communication with those with dementia, like other activities they might engage in, is often perceived to happen in this "moment" and to find its value there.

One response to the loss of both retention and protention in those with dementia, as well as those who care for them, is to create around themselves as many ritual activities and routines as possible, in order to offer these repetitive practices as prosthetic aids to anticipation. To organize time at the microtemporal level—through music, through routine, through ritual—is to offer a kind of externalized expectation that can compensate to some degree for the loss of the internal structure of primal retention-impression-protention (Husserl, *Phenomenology* 29-31; see also Blaiklock 470). Robert Davis, living with dementia, describes how he "begin[s] to see the great value of establishing a routine within my limits" (87). He can also find structures within which to organize his daily life at a more microtemporal level: "At my own speed and in keeping with my individual body rhythms, I can still act with the skills and knowledge I have acquired over the years." His body has, as Bayley found Murdoch to have, the paradoxical phenomena that are "social reflexes" (Bayley 77): skills, habits and temporal rhythms that can offer order to his living.

Bayley and Murdoch kept a channel of communication open through shared, familiar lines of poetry or prosody—often phrases that had a special meaning for them in the context of the relationship, and so had already come untethered from their original source. Nikki Gerrard, similarly, describes the sharing of phrases, rhyming words, with her father, allusions to famous poems he enjoyed that now constituted, in her words, "little fragments of freedom and friendship and death" (144). As she writes, "the memory of words he had loved long ago still delicately chimed" and could open up "miraculous spaces of reciprocity" between them. Even when Iris Murdoch lost her ability to situate lines or phrases of poetry, she understood their status as allusion and their delivery as a kind of performance—and responded with a performance of her own. Bayley describes the scene as follows:

> 'The tyrant of the Chersonese was freedom's best and bravest friend', I assure her, giving her a solemnly meaningful look. At which she nods her head gravely, and seems to act a conspiring smile, as if the ringing confidence of Byron's line in 'The Isles of Greece' meant a lot to her too. (40)

He records the gradual loss of propositional language in Murdoch's speech, but they continue to communicate through this sort of play with tone and form that reawakens sedimented memories. These formulae—"snatches of doggerel, song, teasing nonsense rituals" (40)—build and maintain the rhythms of their shared temporality, organizing their exchanges and thereby the next few moments of time. As Bayley puts it, "[our] mode of communication seems like underwater sonar, each bouncing pulsations off the other, and listening for an echo" (41). Even when Murdoch ceases to use real words and just maintains a kind of conversational murmur, he feels he understands what she is saying, "apprehend[ing] it in a matrimonial way" (50). There is an intuitive understanding in a longstanding couple such as this akin to that which first emerges between a parent and child—what John Bowlby (1969) in the context of attachment theory and Daniel Stern (1985) in relation to communicative interactions, called mutual affect regulation. This time-freighted capacity to "anticipate the changes and dynamical affective contours" of an interaction (Ammaniti and Ferrari 11; see also Stern, *Forms of Vitality*) underpins our ability to turn-take and establish reciprocity—to communicate, in other words—throughout our life.

Finally, we might consider in closing a collective instance of the intersubjective other: an other more generalized than that in an individualized care relationship, but less generalized than the total social *habitus*, the milieu in which we learn our bodily habits and rhythms over the course of our lives. To return to "Jimmy," the Lost Mariner of Sacks's essay, we as readers are offered in this individual's story a picture of a Now in which the patient with profound memory loss may yet be "held," in Lemma's terms, and his self restored. This restoration takes place by a communal act of ritual: Sacks observes the way in which the man's agitation and fractured speech and thought resolve themselves in the course of an act of worship. He writes:

> [H]e was no longer at the mercy of a faulty and fallible mechanism—that of meaningless sequences and memory traces—but was absorbed in an act, an act of his whole being, which carried feeling and meaning in an organic continuity and unity, a continuity and unity so seamless it could not permit any break. . . . moral attention and action could hold him completely.
>
> But perhaps 'moral' was too narrow a word—for the aesthetic and dramatic were equally involved. . . . The same depth of absorption and attention was to be seen in relation to music and art. (37-38)

A key part of the service, and its restorative effect on "Jimmy," is its communal aspect. He is sustained by others: by the community that is present, but also the virtual community represented by the shared litany and practices over time, a history of repeated observances that is "laid down" in his body, rather than requiring autobiographical memory. In other words, a culture. This is a double consciousness in a different sense from that to which Fuchs points in performance: a participation that celebrates the present moment and its praxis, an absorption into the sensory experience of sound and rhythm, but one which also draws on this embedded communal knowledge. In another sense, however, this is very similar to what Fuchs describes, a ritual with pre-determined form (words, gestures, rhythms)—a form of "blocking" in theatrical terms—which must nonetheless be recreated anew each time in a perpetual Now.

Conclusion

A phenomenology of the latest stages of dementia must remain speculative to some degree, but this article offers some modest evidence for the way in which subjects moderately affected by the disease begin to experience time differently and feel destabilized as a result. Compelling subjective accounts of living with dementia bear out the intuition that losing the ability to remember affects the ability to expect, and with it the "serene vigilance," in Natalie Depraz's words, that underpins both normative anticipation and surprise. The queasy feeling of being at sea, the antipathy to unexpected events, the loss of an explicit sense of purpose (countered with an intense need to find a purposeful activity)—all encountered in first-person memoirs and qualitative studies involving those living with dementia—speak to this impairment of expectation and its ability to isolate and paralyze. If, on occasion, the converse is encountered—a dreamlike acceptance of any eventuality—it does not mitigate the background presence of generalized unease. As a pioneering exponent of phenomenological psychiatry, Eugene Minkowski observed a simultaneous preoccupation with time and challenge in measuring or managing it, aspects of the lived experience of dementia that are borne out in recent phenomenological studies. These experiences of time also give a particular affective charge to the memoirs and ethnographic accounts that explore the remaking of longstanding relationships in a new temporal landscape.

Despite our assumptions about dementia, this new landscape is not a barren or denuded one. Those in the advanced stages of dementia may confabulate, as

Minkowski's patient does, to structure and populate the expanses of time that have been emptied by their loss of memory, maintaining the thread of a narrative self and a coherent sense of themselves as social beings. In the moment, too, those living with dementia are able to participate in social interactions: structured rituals of greeting and leave-taking, rhythmic exchanges of familiar formulations or snatches of verse, the melodies of conversation and song. In this way, and in more fundamental forms of gesture and responsiveness, they can maintain and regulate an intersubjective form of affect that is meaningful and sustaining. An individual's own sedimented habits of speech and behavior recruit a moment-by-moment sense of time that does not desert them. The "me-here-now" that Minkowski finds intact in his patients with dementia is also the "Be Here Now" of Fuchs's theatrical present: an imperative to attend to and engage others in the present moment; a shared and co-created sense of being and being together. A phenomenology of dementia can in the right circumstances disclose in the individual, in answer to their losses of memory and expectation, a subtle and sustained attention to intersubjective time.

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