

Autopathographical Life Writing as Distributed Subjectivity, Cognition, and Prostheses for People Living with Dementia

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Abstract

Malafouris suggested that cognition does not exist in the brain but in the interaction with the material world and different forms of material culture enabled these cognitive capacities and processes or changed them over different periods. This study explores how narrative acts as a medium of embodied subjectivity, remembering, disremembering, and prostheses for a disoriented self. Further, it explains the importance of material things as a cognizer in the life of the narrator and the distributed subjectivity of a woman living with Dementia drawing its insights from autobiographical theories and the Material Engagement approach.

Keywords: forgetting, material engagement, cognition, prostheses, memory, disremembering

1. Introduction

Life writing is predominantly a work of memory, and it is full of recollection. The term *Life writing* is used in its overarching way throughout this paper. This very definition is reassessed when people living with dementia writes their life where more emphasis is on the process of recollection. Dementia life narratives such as *The Long Hello*, *Where the Light Gets in*, *The seasons of my mother*, and *The Theft of mother* dealt with the life of people living with dementia and are written by their caregivers, not the people themselves but *Somebody I used to Know* is a collaborative autobiography written by Wendy Mitchell and Anna Wharton. People diagnosed with Alzheimer's Dementia have difficulty recollection and cued recall, but it differs from aging-related memory loss where the cued recall decline is slower than a free recall. They have difficulty tracking time, place, days, months, news, finances, TV shows, or any other familial settings. Also, Verbal deficits are profound in them. They display occasional moments of clarity and logical structure in recounting events. Although this sounds paradoxical in understanding the life of a woman living with dementia through her autobiography, the life experiences of Wendy Mitchell in understanding Dementia are non-negligible.

Somebody I used to Know is a narrative journey of an illness progression and its effects on the life of the narrator. It helps to understand Dementia in terms of a lived experience. It falls under more than one genre of life writing; it is a collaborative work by Wendy Mitchell and Anna Wharton. In this sense, it becomes *heterobiography* and, exhibits the quality of a diary entry by talking about the daily-ness of life. G. Thomas Couser (2012) coined the term *Autopathography* to categorize personal narratives about illness or disability which contests the cultural stigmatization associated with it. According to him, such narratives are *antipathological* because the very act of writing depathologizes the condition. *Somebody I used to Know* is essentially a work of *Autopathography* where Wendy provides a counter-narrative to the social construction of the illness by offering hope, an alternate way of life, and empowerment in the narrative.

The author experimented with two major forms of narratives in this single work: linearly written narratives and letters. This kind of split narrative explicates the difference between the narrating 'I', Wendy after her diagnosis, and the narrated 'I' in the letters, Wendy before Alzheimer's. These two different identities are in alternation in the narrative. Alzheimer's Dementia holds the dynamic tension between the two identities in Wendy's life. The choice of the form represents the interruption in recollection for people living with Dementia and the author's yearning for her memories. Life writing is mostly associated with the act of remembrance and is usually examined for the episodic memories of the remembered, whereas this account of Wendy Mitchell employs the act of remembrance to describe the evolution of the illness associated with forgetting. The act of remembering has become a significant theme in the narrative but the narrator "I" brings attention to the forgetting associated with the illness. The narrator uses multiple modalities for remembrance such as a memory room full of photographs, albums, and digital photos in sustaining her life.

Every remembered event is an outcome of the synchronous action of remembering and forgetting from a memory recall. Temporality and Spatiality are the two major aspects of it that enable the remembered to form a coherent narrative of their life story. People living with Dementia are not able to make sense of time and space, but the author defied this conception by writing her life experiences in the period of dementia progression. The interplay of temporality and spatiality also contributes to disremembering in the life of the narrator and the struggles in forming a coherent life narrative. This paper aims to explain the importance of material things as a cognizer in the life of the narrator which in turn asserts the importance of material engagement and the cognitive life of things in sustaining human life and explains how the iPad, recipe book, Computer, photographs, and post-it notes used by Wendy act as enactive cognitive prostheses and

co-constitutes the Women, Wendy. At the outset, it tries to substantiate the claims of material Engagement theory that is, 'the human cognitive system is the constitutive intertwining of brains, bodies, and things in a specific cultural-historical setting' (Malafouris 2016, 102).

2. Material Engagement Theory

Material Engagement theory extends the argument of New Materialists and Cognitive archaeologists which is, 'human intelligence "Spreads out" beyond the skin into the culture and material world' (Malafouris 2016, 15). It proposes and substantiates Edward Hutchins's argument by acknowledging the manifold cognitive ecologies that are part of human cognition. Malafouris says that Minds and things are continuous and interdefinable processes rather than isolated and independent entities. 'Cognitive life of things recognize that all these different domains (social, bodily, cultural, or material) are essentially inseparable parts of the ontological compound we call the human mind' (Malafouris 2016, p.29). Embodied and Extended cognitive paradigms acknowledge the presence of the mind beyond the brain by including the role of the body and other material objects in the constitution of the human mind. Different forms of material culture played an active role in bringing about the cognitive processes and capabilities in humans.

Material Engagement theory proposes that material things, bodies, and objects do not represent or replace cognition but as enacted spaces of cognition. Malafouris suggests that human understanding of the world and intelligence comes in the form of material culture. The more humans tend to use things, the more they are being driven or co-constituted by them which can also be clearly understood from the evolution history of our species. He claims that thinking happens in the interaction between the brain, bodies, and things. 'Human intelligence is not situated simply in a basic interactive sense but in a deeper intra-active and temporally structured sense' (Malafouris 2016, 57). This means that our interactions not only affect our cognitive abilities but shape future interactions with the world. Space and the environment also acquire agentic qualities in the creation of human cognitive capability. This is when relationality comes in and all the major disciplines offer several ways to articulate the idea of the relationality of mind. The relationality does not end with the relations among human agents but with non-human agents and materials of different sorts and it does account for spatiality and the temporality of the environment. This paper aims to explain material things not only as evocative objects but as prostheses for people suffering from Dementia.

3. Analysis

Somebody I used to Know is ghost-written by Anna Wharton on behalf of Wendy Mitchell. Memories work through encoding, processing, consolidation, and retrieval as well as absence and interruptions. The retrospective and anticipatory quality of the brain accounts for continuity in human life. Any cognitive impairment in the brain disrupts this process and alters the order of things. Any autobiographical narrative is a work of memory written with the goals and contexts of the present. For life narrators, their memories are the primary archival source. They rely on other sources such as letters, journals, conversations, and photographs to support their autobiographical work. "Memories are not objective images of past perceptions, even less of a past reality. They are subjective, highly selective reconstructions, dependent on the situation in which they are recalled" (Erlil 2016, 8). Any life narrative has to be interpreted in such a way that it is a highly selective reconstruction of the past with the goals and directions implicated in writing the narrative. This narrative is written after Wendy is diagnosed with Alzheimer's Dementia. Therefore, the phenomenological understanding of the life narrative of Wendy Mitchell has the affectivity of the illness entering the affect economy of its interpretation.

Theorists of automediality such as Jorg Dunne and Christian Moser suggest that the choice of the medium, and materiality of the medium are constitutive of the subjectivity rendered in any narrative. Wendy's subjectivity is constructed through writing in different media. Two months after her diagnosis, Wendy starts to record her memories in the digital space every day. Though this seems to reduce the gap in recollection, it is still a re-construction. This is the primary archival source for Anna Wharton in writing Wendy's life narrative. Anna Wharton and Wendy Mitchell communicated primarily through email and WhatsApp for collaborative life writing. Sarah's diary and hospital notes are the other sources used for writing the narrative. Therefore, Wendy's memories are mediated by multiple digital mediums before it gets shaped into a narrative. Any life narrative has the affectivity of earlier writing practices, medium, spatial-temporal dimension of the narrative's present, and the present goals and contexts of writing. Since it is ghost-written and the narrator is diagnosed with Alzheimer's Dementia, the role played by multiple media technologies is also non-negligible in interpreting the narrative. Anna Wharton mentioned that Wendy used to give two or more variations of the same event and it was appropriated to fit into the narrative. This alerts us to the fictionalization of certain life events. Hence the materiality of different mediums, the reader's affectivity, Anna Wharton's subjectivity, and memory loss equally constituted the life narrative of Wendy Mitchell.

Life writing, "as the narrative genre most associated with remembrance, is an ideal starting point, as it also allows us an insight into the processes and transactions at work when writers take on narrative form and remembering/forgetting" (Gudmundsdottir 2016, p.27). Wendy and Wharton overcome Wendy's limitations in recollections and justify the genre of life writing where the readers can understand Dementia as a lived experience rather than in medical terms. They tried to provide a linear narrative from the day she was diagnosed with Alzheimer's Dementia to the day the book was published. The very structure of the book exemplifies the workings of the memory of an aging woman living with Dementia. The book has two forms of narrative where the linear flow of the narrative has interruptions when the narrator addresses her older self. This flashback quality of the narrative reflects the intrusion of involuntary memories in the life of the narrator. Flashback is a type of memory that you experience as markedly different from those memories of the event that you can retrieve at will' (Hellawell and Brewin 2002, p. 48).

Kline and Rausch described that flashback memories are so vivid that are experienced as reliving the past in the present. (1985) The narrator's address to the older self in the narrative which was presented as triggered by the narrative present transports the reader to the narrator's past. "The involuntary mode of episodic memory does this by providing an automatic mechanism for maintaining and re-evaluating memories of the past and adjusting future goals in the light of a constantly shifting present reality" (Berntsen 2012, 198). The narrative is structured in such a way that the present narrative Situation act as a cue to her memories and explicates the memory's contingent quality of connecting the past, present, and future. Though the form of the narrative can be interpreted as mimicking the cognitive capacity of a person living with Dementia, the narrative is full of remembrance and attempts to recollection.

Wendy Mitchell was a non-clinical NHS health worker leading teams of nurses and practitioners at a hospital in the UK. She remained an active marathon runner till she was diagnosed with early onset of Alzheimer's. She realized her first dis-orientation in her morning jog and this is the point of departure from her normal otherwise active life where the narrative takes a turn towards the delineation of the progression of the illness. Space remains both a metaphor and distributed cognitive artifact in the life of Wendy Mitchell. The hospital space which was once used to be a space for empowerment and propagated economic independence for Wendy becomes an enclosure once her role changes as a patient. The materiality of the space that affects the narrator's feelings is influenced by the relationship between the role of the actors and the corresponding social formations in the grand assemblage of a hospital in the narrator's life. It affirms the materialist's stand against the notion of pre-existing definitions of space. "Social entities are not made up of bipolar oppositions" (Guattari 2009,26). The complex arrangement of parameters like social class, roles, sex, illness, care, etc., suggests the indeterminacy and instability of space against its fixed capacity and capability affect. Space is an important cognitive artifact in the life of people living with dementia in two aspects that is familiarisation and defamiliarisation co-exist in their lives and correspond to remembering and forgetting. This suggests the mutability of the material world such as office space, home, and rooms and provokes thinking on its affective quality in shaping the cognitive process of remembering and dis-remembering. The space becomes an important material object for Wendy wherein the brain of people living with dementia relies on it to make sense of their environment. Any disruption in the things that inhabit the space and the change of space put great strain on them and leads to confusion. "Space is not simply the passive background against which the activity unfolds; it is something that can be used as a cognitive artifact" (Malafouris 2016, 88).

Dementia is a condition that affects the cognitive capacity of an individual in which the person is unable to exercise coordination between brain and body. Any act of cognition is the "property of a hybrid assemblage of brains, bodies, and things" (Malafouris 2016, 30). When the brain is unable to communicate with the body in Damasio's terms for instance, the narrator's inability to turn right in her car and bicycle on her own explicates the constitutive quality of brain, body, and things more than anything. "It is not just that conscious and nonconscious processes coexist but rather that nonconscious processes that are relevant to maintaining life can exist without their conscious partners" (Damasio 2011, 31). Even the more automatic procedural memory tasks or the nonconscious processes become difficult for Wendy as the illness progresses. "My feet not talking to my brain, the car over-revving, my hand fumbling with the gears. It's happening again. Only one process can filter through at a time. There's not enough time to think about how to turn right. A different me clutches the wheel; hands clammy; it slips beneath my grasp" (Mitchell, W 2019, 31). A disconnect between the brain and the body is evident in her narrative. "The brain maps the world around it and maps its doings. Those maps are experienced as images in our minds, and the term image refers not just to the visual kind but images of any sense origin such as auditory, visceral, tactile, and so forth" (Damasio 2011, 18). This profound disconnect between the brain and body and the inability of the brain to form mental images concerning the body emphasizes the enactive constitutive intertwining between the brain, body, and material culture.

After a period of reconciliation and agencement with the illness, the narrator started to rely on material things to lead an independent life. The narrator used post-it notes at the beginning stage of the illness to remember the events and tasks to do. As the illness progresses, the cognitive life of things like post-it notes becomes obsolete and new things such as iPad, phone reminders, memory room, etc., emerge to acquire the status of constitutive entities in Wendy's life. "The cognitive life of things is not exhausted by their possible causal role in shaping some aspect of human intelligent behavior; the cognitive life of things also embodies a crucial enactive and constitutive role" (Malafouris 2016, 63). Encoding and decoding are the simultaneous and recurring process of memory however the cognitive distortion in people living with dementia render encoding and retrieval difficult and they couldn't create new memories. The same material objects which constituted the life of the narrator lead to her confusion in the foggy days of her memory. "The traditional boundaries of the unit of analysis for cognition must be extended beyond the individual to accommodate broader cognitive events that include interactions among people, artifacts, space, and time" (Malafouris 2016, 88). In the case of people living with Dementia, the unit of analysis for cognition remains more with the material artifacts. The degree to which the cognitive artifacts become part of life and their affectivity as a result of their interactions with brains, bodies, and other social formations are affected by the memories of the human actor and the materiality of the brain in relation. It repositions the self or the subjectivity in the interaction between brains, bodies memories, and social formations by exposing itself to endless connections, new demands, and possibilities.

For a cognitive process to be effective, every participating entity including the brain, ideas, bodies, social institutions, values, material, and immaterial objects becomes important thus exhibiting an equal agentic capacity to affect the life of an individual. The impairment or distortion in the brain renders the cognitive process incomplete hence memory. "Even though Malafouris claims that cognition does not rest inside the body, but it is constitutive of the material world, the impairment in the brain does have an impact on the cognitive process and it disrupts encoding and retrieval. Nonetheless, the mere stimulating quality of the material world in sustaining human life is also

non-negligible in the case of people suffering from a cognitive impairment like Dementia” (Niranjana, Bhuvanewari 2021). The transgressive and distributive potential of the material world, things and spaces, and the distributed agency invigorates a rethinking in the ethics of life and the cognitive life of things. “From the perspective of distributed cognition, our mental machinery is essentially an extended functional system that does not simply involve internal representational states but also involves the transformation and propagation of such states across external media” (Malafouris 2016, 88). In the case of people living with Dementia, the mental machinery which was supposed to be involved in internal representations and changes upon interaction with the external world is impaired. Therefore, the role of the material world (things) changes and it ceases to become constitutive but acts as prosthesis of the human mind.

In this narrative, the material objects are both evocative and act as prostheses for the impairment in the brain. As the narrative progresses, it is clearly evident that Alzheimer's has consumed her memories of driving and cooking for which the author is more passionate. “Embodied cognitive science has made a strong case for the fundamental role of bodily sensorimotor experiences in the structure of our thinking” (Malafouris 2016, 88). The failure of her brain to make sense of her bodily sensorimotor experience emphasizes the importance of neural structures of the brain for an effective cognitive process. Once the post-it notes become unusable, Wendy turns to the iPad for reminders, alarms, and to-do lists to lead her life independently. Another interesting perspective from the account of Wendy Mitchell is the power of technology in sustaining her life. Wendy used online blogs for encoding new experiences and recording disconnected episodes of her life. The narrator subverts the normative experiences associated with Alzheimer's by making a whole new life out of it. She actively contributed as a volunteer to Dementia research, participated in Dementia conferences, and recorded her life for the movie *still Alice*. She defies the conventional image of a woman living with Dementia as slowly deteriorating and tied to a bed.

New Materialism propounds that bodies, things, and social formations gain their capabilities and capacities only through their relationship to other similarly contingent and ephemeral bodies, things, and ideas (Deleuze, 1988: 123; Haraway, 1991: 201). The maps, photographs, signboards, post-it notes, iPad, and mobile phones were exploited and assisted more than their defined roles in the technological order thereby confirming Deleuze and Guattarian's hypothesis where the objects and entities do not have properties associated with it before their existence but they acquire it only through interaction. Actions and Events are called *assemblages* ((Deleuze, 1988: 123; Haraway, 1991: 201) of these relations between objects, bodies, ideas, and social formations. The capacity and capabilities of material objects to affect and be affected are determined by their interactions in the relational assemblages. Post-it notes, iPad, maps, and mobile phones serve a different purpose or in other words de-territorialized to make sense of the world for Wendy. This affirms the tangibility of material things and objects and substantiates the Posthuman (Braidotti 2013) turn to matter.

Wendy's life narrative is an altered perspective of the clinical discourse on Dementia Which mostly dealt with the progression of the illness and its effect on the people living with it. Through her life experience, she exposes the possibilities of living an independent life with Dementia, the challenges faced, and the possible alternatives for life. Wendy's life experience is counter-narrative to the traditional conception of people living with Dementia. This text contributes to social production by providing a post-anthropocentric perspective on Alzheimer's Dementia and the discourse on Medical Humanities and Disability studies. Memory is intersubjective and it is a practice of recollection by a subject for other subjects. In the case of Wendy Mitchell, it is already a collaborative effort by both Wendy and Anna Wharton. “Memory is a means of “passing on,” of sharing a social past that may have been obscured, thereby activating its potential for reshaping a future of and for other subjects. In sum, acts of personal remembering are fundamentally social and collective” (Smith, Watson 26). It is a recollection that is both personal and collective thereby prefiguring the future life narratives of people living with dementia.

4. Conclusion

This study explored the vitality and constitutive quality of material things in shaping the memory and the enactive role played by the material things in the epiphanic memory narrative of Wendy Mitchell. Extended Mind Hypotheses (Clark and Chamber 1998) challenges the conception of Mind inside the body by signifying the constitutional qualities of the extended environment and the Material Engagement Theory proposes that Material engagement is a “synergistic process by which, out of brains, bodies, and things, mind emerges” (Malafouris 2016, 32). The material world acts both as a cognizer and a disruptive force in the life of people living with Dementia as it is understood from the life of Wendy Mitchell. “Memory and narrative are inextricably linked, as the only way we have access to another's memory, and in some sense, our own is through narrative” (Gudmundsdottir 2016, 27). The narrative thus acts as a medium for rendering subjectivity to the disoriented self and prostheses in the life of Wendy Mitchell. The self is not only reported in the life narrative, but it is performed by Wendy, Wharton, and the readers.

More than empirical evidence and a contestation ground for Material Engagement theory (Malafouris 2016) and Extended Mind Hypotheses, Wendy's narrative proved to be an exemplar for people living with Dementia by offering hope for a normal life after the diagnosis and qualifies as an *Autopathography*. Wendy's life narrative is thus an act of cognition, explication of the extended self in Damasio's terms, de-pathologization of Alzheimer's Dementia, and prostheses for Wendy's memories. Also, this narrative offers hope for a new life, it implicates the transformation needed in society to accommodate people living with dementia and invigorate for more inclusive public spaces. *Somebody I used to know* is empirical evidence for the deconstruction of the human and matter divide, it provides for the embedded and embodied quality of the material things and affirms the materiality of remembering. It is reflective of the post anthropocentric view of the world which deconstructs the primacy of humans on the earth. This text also contributes to the social production as a cultural memorial under the discourse of dementia.

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