Technologies of Ascription: How Does a Dementia Diagnosis Acquire its Symbolic Power of Exclusion in Later Life?

Sébastien Libert
s.libert@ucl.ac.uk
Division of Psychiatry, University College London

Paul Higgs
p.higgs@ucl.ac.uk
Division of Psychiatry, University College London

Abstract

Amidst the widespread stigma and exclusion attached to dementia in dominant narratives of successful ageing, this article addresses a gap in the scientific literature concerning our understanding of the medicalization of cognitive decline as a natural phenomenon. To this end, it explores how a dementia diagnosis acquires its symbolic power of exclusion in later life through an ethnography of cognitive rehabilitation therapy in two memory clinics in a southern European nation. It argues that this symbolic power of exclusion is locally produced through the meaning making practices of therapists and researchers administering regular cognitive training therapy and exercises to support autonomy. It shows how the different steps involved in rehabilitation play a role in dividing later life by defining and reifying a category of abnormal ageing during the cognitive assessment, and by applying a confrontational approach exposing decline. It shows how this approach generates the position of older adults who can be rehabilitated against those who cannot; the latter representing a “failed” ageing in the narrative of successful ageing. This article proposes the adoption of the concept of “technologies of ascription” to characterize this process of exclusion through reification and confrontation of “abnormal cognitive decline.” The paper argues that such practices are central to the local production of the symbolic power attached to a dementia diagnosis as well as its capacity to fragment later life. Finally, it argues for the utility of this concept in offering new opportunities for anthropology to characterize exclusion in later life through medicalization.

Keywords: Dementia; Exclusion; Ascription; Successful Ageing; Failed Ageing; Technology
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Sébastien Libert  Paul Higgs
s.libert@ucl.ac.uk  p.higgs@ucl.ac.uk
Division of Psychiatry, University College London
London

Introduction

As dominant public health narratives across the world present dementia as a “global priority” (World Health Organization and Alzheimer’s Disease International 2012), dementia further strengthens its status as a medical problem isolated from a so-called normal ageing (World Health Organization 2017). Scarcely challenged, despite its numerous incoherencies (Lock 2013), the medical conception of dementia continues to expand and diversify. It is constantly adding new diagnostic labels including schema to categorize a predementia phase (e.g., Mild Cognitive Impairment (MCI), or prodromal dementia), as well as the identification of new risky causal behaviours occurring earlier in the life course (e.g., Livingston et al. 2017). This is in addition to proposals for a more systematic screening of the older population for the condition (Kitanaka 2020, 121). This expansion is also happening in the post-diagnostic phase attracting the attention of more and more clinical professionals and researchers, resulting in various attempts to develop pharmaceutical and psychosocial interventions (Booth et al. 2018; Clare and Woods 2003; Yates et al. 2019). Overall, these transformations represent the reinforcement of an earlier trend that Adelman (1995) called the “alzheimerization of ageing,” an extension of new regimes of health encouraging surveillance and screening for risk and preclinical signs of health conditions (Armstrong 1995), further expanding the medicalization of human conditions into treatable disorders (Conrad 2007; Zola 1972). While some people still dispute a clear separation of dementia from the ordinary ageing process (Cohen 1998, 70; Lock 2013, 41), this expansion demonstrates a general trend to further medicalize cognitive decline (Beard and Neary 2013; Lock 2013), maintaining the status of dementia as a threat to either prevent or cure (Livingston et al. 2017; Lock 2013; Orrell and Brayne 2015).

Much of this medicalization takes place in a general context marked by successful ageing as a dominant cultural narrative giving meaning to ageing today (Andrews 2009). This successful ageing narrative essentially attempts to separate decline from a so-called “normal ageing” process (Lamb 2017), impacting the meaning attributed to dementia (McParland, Kelly, and Innes 2017). Studies of the role of localized practices of medicalization of cognitive decline and their impact for an ageing population in this context have remained limited. Looking at the consequences of medicalization in dementia within existing social science scholarship, researchers studied the impact of a diagnosis on emotions (Aminzadeh et al. 2007) on the possibilities it offers to understand and manage one’s own decline (Beard and Fox 2008) or on the stigma experienced by older adults (Milne 2010). They also looked at the consequences of a predementia diagnosis or MCI (Aminzadeh et al. 2007; Beard and Fox 2008; Beard and Neary 2013), the attribution of dementia risk (Milne et al. 2018), or the impact of different clinical cultures on the diagnostic process (Graham 2006). They explored the benefits of diagnosis in term of symptom management and access to therapy (Aminzadeh et al. 2007), issues with self-esteem and social
participation, accessing networks of support, and promoting an active citizenship with dementia (Birt et al. 2017, 208). Finally, they looked at issues with population-wide screening and the promotion of diagnosis in the absence of post-diagnostic support (Fox et al. 2013). While considering localized processes to some extent, these studies do not consider the symbolism attached to the medicalization of cognitive decline within dominant cultural narratives of successful ageing. Borrowing the words of anthropologist Eriksen (2001), they do not locate these “small places” as constituting “large issues.” Using ethnography, this article first aims at addressing these limitations in contextualization.

Meanwhile, cultural studies on ageing and health essentially proposed a macro-analysis of the medicalization of cognitive decline and its social significance, or ethnographies of people’s experience of cognitive decline in later life. These discussions considered the cultural origin of the boundary between normal ageing and (cognitive) pathology through narrative and historical analysis (Ballenger 2006; Pickard 2011). They also explored the current reconfiguration of health expectations under the dominance of cultures of active, “successful” ageing (Williams, Katz, and Martin 2011) and their impact on how older adults give meaning to (cognitive) decline (Kitanaka 2020; Lamb 2017; 2014). While this corpus of research on the cultural aspects of health in later life helps to understand some of the impacts of the broader context of successful ageing on the symbolic value of diagnosis, or the experience of older adults in this context, they do not consider how localized processes of medicalization give a dementia diagnosis its capacity to substantially transform the identity of people in later life, or what forces give symbolic significance to a diagnosis within narratives of successful ageing.

As we can see therefore, current research on the diagnosis of dementia either considers its effects in a decontextualised manner or explores the symbolic value of diagnosis in cultures of ageing while having limited concern for the local processes producing this symbolic power of exclusion. Inevitably, these approaches miss the capacity of a dementia diagnosis to divide later life. To address this gap, this article will explore the following question: how does a diagnosis acquire its symbolic power of exclusion in later life?

To answer this question, we present an ethnography of the daily practices of clinicians and researchers in two memory clinics implementing cognitive rehabilitation for people with dementia in a southern European country. This ethnography enables us to propose a detailed analysis of the local processes contributing to the symbolic power attached to a dementia diagnosis. The ethnography lasted for three months from October to December 2018 and was part of a broader 18-month multi-sited fieldwork exploring processes involved in the social exclusion of people with dementia across Europe and the UK. This article results from a collaboration and joint analysis produced by Sébastien Libert and Paul Higgs (referred as “we” or third person in the text). Both the ethnography and the fieldwork were conducted by Sébastien Libert (referred as “I” in the text and within the ethnographic vignettes).

Memory clinics are the most specialized facilities to provide a diagnosis of dementia in biomedicine and provide therapy for individuals diagnosed with the condition (Jolley, Benbow, and Grizzell 2006). They represent pertinent locations to observe the processes contributing to the symbolic power of a dementia diagnosis and the manufacture of medicalized identities. The southern European region in which this ethnography took place has a small younger population caused by rural depopulation and economic difficulties. The exodus of working age people meant that this region had a disproportionate population of older people, making it one of the most important centres of ageing in Europe. In this rural context, the memory clinics function as proximal forms of care supporting ageing communities.

During the three months of research, I followed the activities of clinicians and researchers on cognitive rehabilitation interventions through participant observation, exploring the meaning that they produced about dementia, as well as their objective in the implementation of cognitive rehabilitation.
documented in detail the different steps leading to the separation of people with dementia from those with “normal” cognitive ageing in the diagnostic and rehabilitation process. I also considered how they conceived potential challenges associated with the implementation of the cognitive rehabilitation and how they understood the problems that they were trying to address. Finally, I explored how the clinicians and researchers dealt with the progressive decline associated with dementia.

The role and status of the individuals I encountered within the memory clinics varied. Some were psychologists and neuropsychologists while also being PhD and MSc students. Others were senior psychologists and neuropsychologists. Some played a managerial role in the clinic, while others assisted in providing the therapies and research activities.

As few of my informants spoke English in this region, I actively learned their language for a year and a half prior to the actual fieldwork, enabling me to participate in day-to-day interactions and research activities. Being experienced to learning new languages, I could rapidly reach a level of competency necessary to understand the meaning conveyed in conversations. I also spent time discussing my observations with participants to ensure that I properly understood them. Additionally, many discussions occurred in lay language because clinicians tried to avoid using technical language in their explanations to the patients.

In this article, we will present the active role that researchers and clinicians play through discourse and practice in defining the problem of dementia in certain ways; in addition, the impact that it has on the identity and social position of people reaching memory clinics for symptoms of cognitive decline. We will explain how the symbolic manufacture of the meaning attached to a diagnosis in cognitive rehabilitation operates, indexing identity in later life as a result. We will review three different positions resulting from this indexation: active agers, people with dementia who can be rehabilitated, and those who cannot be rehabilitated. We will then present the cultural significance of these positions. Finally, we will introduce the concept of technology of ascription to qualify the role of cognitive rehabilitation in the local production of the symbolic power attached to a dementia diagnosis. We will then present how the analytical lens of technologies of ascription can support studies of processes behind this symbolic power of diagnosis in other localities. This endeavour should support a better understanding of social exclusion in later life today.

This research followed ethical guidelines from the American Anthropological Association (AAA) Statement on Ethics (n.d.). It received approval from University College London Research Ethics Committee and an institutional research ethics committee in the Southern European country where the research took place. Informed consent was first recorded in writing. It was however continuously reassessed in dialogue with the participants so to accommodate their preferences in particular circumstances. Participants were approached individually through the intermediary of a collaboration with a local mental health foundation. Their agreement was kept confidential, and measures to maintain anonymity were established.

The Referral and First Encounter Defining the Parameters of Abnormal Cognitive Ageing

Where does the symbolic manufacture of medicalized identities start? To understand this, we need to look at the first contact that an older adult with cognitive concerns has with a memory clinic. It normally starts with a referral leading to a first encounter with the memory clinic. In this southern European country, a referral to a memory clinic is usually made by a physician, such as a general practitioner or a neurologist in a hospital. This referral leads to a first encounter with a neuropsychologist at the
memory clinic. As I observed during fieldwork, and present in the following ethnographic vignette, this first encounter delineates important meaning-making processes around identity and announces more profound transformative processes for the older adult with cognitive concerns.

13th December 2018, inside the memory clinic: We sit together with the therapist and a couple who took a first appointment with the memory clinic to consider the possibility of a cognitive rehabilitation therapy. We are in a small room of the memory clinic, arranged like a restful living room. The couple comfortably sits on one side of the room while I am introduced by the therapist. The encounter starts and the neuropsychologist carefully explains the process involved in starting a cognitive rehabilitation programme with the memory clinic. She introduces herself to them and explains her role as a neuropsychologist in the centre, as well as what the centre does for whom in terms of therapy. She tries to reassure the person potentially receiving the therapy that there are many different causes capable of affecting memory. She also points out that there can be multiple causes behind memory problems. For instance, she describes traffic accidents or seizures. She also explains that memory problems can be diagnosed if the kind of memory issues encountered differs from the trajectory of “normal ageing.” She then presents the rehabilitation process and the voluntary nature of participation. This process starts with a cognitive assessment to understand the specificities of the memory problems encountered.

The first encounter represents an important step initiating the process of rehabilitation and its capacity to shape the identity and social position of older adults with cognitive issues. Through the intimate environment of the comfortable meeting room, the neuropsychologist progressively sets the scene for the life-changing processes that the potential patient will eventually experience in the memory clinic. Indeed, this first encounter establishes the nature of the problem identified by the therapist and enables the medical professional to communicate a new system of meaning attached to a cognitively declining identity to the potential patient. Hence, in this encounter, we notice how the neuropsychologist distinguishes the identity of someone experiencing a cognitive disorder substantial enough to be qualified as “abnormal” from a so-called “normal ageing.” Through this exchange we perceive how the act of defining decline as abnormal inevitably announces the possibility that this adjective becomes attached to a person’s identity and prepares the potential patient for this transformation. This first encounter introduces to the potential patient the prospect of a first boundary-crossing exercise between normal ageing and pathology. This boundary-crossing will continue in the ensuing steps of the rehabilitation.

The Assessment Reifying Abnormal Cognitive Ageing

The cognitive assessment represents a logical step ensuing from this referral and precedes the cognitive rehabilitation. Baseline assessments are sporadic events as they generally happen once at the start of the care trajectory of the patient. During my period at the memory clinics, I observed two assessments with two different neuropsychologists. Assessments I observed lasted for approximately an hour to an hour and a half. These assessments were based on “paper and pencil” exercises graded with standardized scales such as the Wechsler Adult Intelligence Scale and the Mini-mental state examination which are common practice in memory clinics (Tariq et al. 2006, 901). They can also be combined with brain scans or blood tests often earlier in the diagnostic process or in combination with it to rule out conditions that differ from dementia and assist diagnosis for instance (Karas, Scheltens, and Barkhof 2008; National Health Service 2020; Speechly, Bridges-Webb, and Passmore 2008). Assessments play an important role in shaping the identity of older adults as we will see in this vignette:

18th December 2018, consultation room: A therapist invites me to observe how she conducts a cognitive assessment. I meet her in the consultation room. The therapist introduces me to the patient as a researcher observing the therapist’s activities and asks if I can attend the assessment. I am then granted authorization by the
patience to stay next to her to observe her work. The assessment will last for over an hour and a half, involving a series of standardized cognitive tests. She strictly controls the conditions of the assessment and carries a stopwatch with her to precisely keep track of time. She starts the assessment with the two usual questions part of the procedure of cognitive rehabilitation consultations, namely on temporal and spatial orientation. “What date is it?” and “where are we?” she asks the person being assessed. Naively forgetting that these simple queries are part of the test, I try to help the person. While listening to the participant, the therapist interrupts me immediately with a fast and discreet gesture before I start intervening, concerned by the importance to maintain standardized conditions for the assessment. I stay quiet and the test goes on. I find the questions she asks to the patient challenging to answer, and I find myself unable to answer some of them. The atmosphere is tense, and the patient seems focused. The test is composed of various standardized scales of measurement based on questions displaying unique answers, either right or wrong. While the patient replies, the therapist does not provide any clues about the answer’s accuracy. Only the time she spends scribbling on the paper with her pencil can eventually give a hint about this accuracy. The assessment ends and we spend time together with the therapist to discuss my observations. She shares her first thoughts on the dysfunctions the assessment probably indicated. She then explains to me how each singular test works while drawing a parallel between the objectives of these tests and a complex cartography of the brain, the functions associated with each of its areas, and how the tests aim to locate issues in them. In her explanation, a test result becomes the indicator of “neuro-localized” zones of cognitive success and failure, a numerical coordinate enabling to draw a map of the (dys)functional brain.

The assessment I describe in this vignette is a key event and necessary step in the trajectory of care proposed by the memory clinic. It represents the crystallisation of previous assumptions made during the referral. It plays an important role in directing the future trajectory of care constituting the rehabilitation. This assessment presents a holistic picture based on a vast array of phenomena and their associated metrics defined by neuroscience disciplines. Remarkably, the consequence of a test is the reification of the previously evanescent and eminently complicated phenomenon found in cognitive decline into a single label of dementia or Alzheimer’s disease.

This symbolic power of labels is central to social positioning in later life and marks the transition toward a new status for the older adult. Rose and Abi-Rached aptly describe the symbolism of the encounter of a patient with what they call the neuro-disciplines (neuropsychology, neurology, neuroscience, etc.) within the novel means deployed by the neurosciences to assess the operation of the mind:

When it comes to seeing the brain, seeking to discover within its fleshy volume the traces of the pathological or normal mental processes that the brain might embody, it involves the designation of those who have the authority to see: doctors, neurologists, researchers, psychopharmacologists, geneticists, and now, of course, the imagers. It also involves the subjectification of those who are spoken about—subjectification in the sense that living creatures become subjects of these visualizing technologies only as a consequence of certain technical interventions, and subjectification in another sense, in the case of humans, whose sense of themselves may well be transformed as a result of the images of their brains with which they are presented. (2013, 55)

Rose and Abi-Rached’s (2013, 55) explanation over the operation of the neurosciences and their impact on subjectivity suggests how the symbolic power of a diagnosis in dementia partly results from the authority of the neuroscientist and the particular images that they produce to legitimate it.

The controlled environment of the cognitive assessment I describe in the vignette above presents similar parameters constituting the symbolic power of the encounter. The subjectivity of the patient in this encounter for instance becomes redefined through the constitution of a controlled environment.
composed of standardized metrics, acceptance of the medical gaze, standardization of the temporality of the encounter through the use of a stopwatch, and isolation of the consultation room from the outside world in the detached environment of the memory clinic. All these elements play an important role in crafting the social reality of this new identity, the reification of complex mechanisms and deficiencies in the brain into a coherent whole grading cognitive capacity. While this research essentially focused on the definitional practices and discourses of clinicians, other research (e.g., Tolhurst 2015) suggests how clinical encounters in memory clinics can transform the patients’ “sense of themselves” alluded to by Rose and Abi-Rached (2013, 55). The power of the images evoked by Rose and Abi-Rached (2013, 55) is found here in the numerical coordinates of the (dys)functional brain emerging from the application of these standardized measures corresponding to particular zones of the brain. These numerical coordinates give a tangible materiality to the evasiveness of cognitive decline.

Overall, the assessment classifies individuals following a culturally informed definition of normality or abnormality in ageing. The assessment is an important reformulation of identity through medical tools—a sort of “rite of passage” and an initial triaging of individuals into different groups in later life. Those who are not diagnosed as having dementia will be temporally assured as belonging to the most culturally desired position of normal ageing defined by third age cultures. For now, they will not be affected by the symbolic power of diagnosis on identity in later life. Others whose cognitive ageing is now classified as abnormal will be prescribed cognitive rehabilitation, initiating a trajectory of care with variable consequences on identity.

**Cognitive Rehabilitation Supporting People with Dementia Who Can Be Rehabilitated**

This second position corresponds to the desired outcome for the memory clinic and to the success of the rehabilitation (the first position simply being the one of individuals whose diagnosis is negative for dementia). Individuals in this position are valued according to the norms established by the neuropsychologists I met, who take great care of creating a supportive atmosphere when implementing the rehabilitation. The objectives of the memory clinics and the nature of rehabilitation are determinant to align the identity of people diagnosed along the norms defined by the active cognitive ageing narrative. This narrative according to Libert, Charlesworth, and Higgs (2020) represents the current inclusion of brain health into active ageing. Hence, the responsibility to stave off the impact of decline in ageing now includes the brain as a locus of prevention and risk management. In the following vignette I describe the nature of the rehabilitation itself to illustrate this correspondence:

12th December 2018, inside the memory clinic: I met with two clinicians to attend the cognitive rehabilitation session. The room is a casual classroom setting with two round tables and a series of computers on the side. I enter the room with the patients. We sit together at the table, two patients, the clinician, and me. The length of the consultation and the level of the challenges set for the patients are important, as I will discover during the next hour and a half that the session will last. The session for one of the patients starts with thirty minutes of cognitive exercises through the traditional “paper and pencil” rehabilitation—a contrast with the novel use of computers—followed by another thirty minutes of computer-based rehabilitation. The computer-based session requires the patient to sit in front of the computer and carefully answer the prompts and exercises that the cognitive rehabilitation software automatically generates. Then the person comes back for thirty minutes of the same “paper and pencil” cognitive rehabilitation exercises. While sitting at the table, the clinician alternatively spends time with each patient, quickly shifting from one patient to the other in order to set up the exercises and monitor each of them. Each “paper and pencil” exercise follows the same pattern: the clinician lays square-shaped cards down on the table with images of objects of different kind printed on them: a shirt, a bowl of soup, a train, keys and so forth. The patient then tries to remember this sequence of objects represented on the cardboard figures by creating
a narrative based on these objects. Here could be a typical example: I put my shirt on, drank some soup and left the house, closing the door with the key, and took the train. Cards would then be put face down and the patient would attempt to recall the shirt, the soup, the house, the keys, and the train printed on the cards in a sequential order by visualizing the story in their head. Some patients experience more difficulties than others in fulfilling these exercises as I observed during this consultation and on other occasions. Indeed, the challenging nature of these exercises has the apparent capacity to expose different levels of deficits in patients. Although patients can find the exercises challenging, they usually fulfil them successfully according to the standards of rehabilitation. The atmosphere of the consultation is supportive. I notice how therapists take great care to create an enjoyable environment where patients feel valued. When exercises appear too complicated for patients, therapists help patients to complete them, therefore supporting their sense of achievement and wellbeing.

This vignette shows how cognitive rehabilitation implies an ethos of engagement, of “not giving up” in front of the challenges generated by dementia. In the cognitive rehabilitation, such an ethos is encouraged, and decline becomes a phenomenon that one should confront through self-discipline and self-management. Sometimes, under the request of therapists, patients are expected to complete some homework in addition to taking part in the consultations. These are “pencil and paper” exercises to complete at home, ones that will be reviewed by the therapist at the start of the following session. Significantly, this set of expectations regarding cognitive health in later life strongly echoes key aspects of the model of “successful” or active ageing developed by Rowe and Kahn (1997) which states that successful ageing is defined by three components: “low probability of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life” (1997, 433). Indeed, fostering autonomous living through the development of “alternative cognitive pathways” represents a central objective of rehabilitation echoing this definition.

Accordingly, a successful cognitive rehabilitation represents the maintenance of norms of capacity and independence in later life valued as part of active cognitive ageing. It therefore demonstrates the engagement of the individual to maintain an identity which remains connected to the one they had before the diagnosis. This engagement embodies the will to fight against the inevitability of decline valorised by successful ageing in later life. The demonstration of this will symbolizes remaining connections between the person with dementia and those who normally age according to the ideal of active cognitive ageing. For those individuals diagnosed with early-onset dementia, it also enables them to distance themselves from what Gilleard and Higgs (2010) call the “fourth age”—the most negative aspects of dementia which are often associated with the dreaded imaginary of a non-agentic later life. A successful rehabilitation is therefore a means to maintain parts of the individuals diagnosed with dementia away from the gravitational pull of a culturally devalued non-agentic life.

**Active Cognitive Ageing and its Periphery—People Who Cannot Be Rehabilitated**

However, this ethnographic vignette above also shows the complex relationship that such a form of therapy establishes with decline and altered capacities. This impression stemmed from the peculiar approach of rehabilitation practitioners relying on challenging exercises as a bedrock for therapy. These challenges that were meant to encourage the development of “alternative cognitive pathways” in people with dementia also render cognitive decline apparent. Choosing the right answer, remembering a series of words sequentially, locating oneself temporally or spatially, etc. All these represent cognitive puzzles which are artificially created for the purpose of therapy. Confronting decline becomes instrumental to supporting autonomous living through the maintenance of an idea of “optimal functioning.” Therefore, the nature of this therapy inevitably results in situations where cognitive exercises become obstacles rather than enablers. They may either demonstrate the remaining capacities of the person and eventually support them, or they may lead to a situation where these obstacles become
increasingly difficult to fulfil, giving a symbolic weight and a more tangible reality to the deficit fostering an encounter with the tangible reality of their own decline. The decision to proactively engage in a struggle against decline, to confront it through regimes of self-care and management, is a definitional characteristic of active cognitive ageing. When locating it in a more global cultural perspective, this confrontational approach represents a peculiar cultural conception of decline in ageing and the life-course (Lamb 2017). Indeed, Lamb (2017) presents different ethnographic insights into various cultural spaces defining ageing around the world, showing that numerous other ways of perceiving and portraying decline exist beyond the Western binary understanding of active ageing and its aversion for decline.

The possibility of losing one’s agency remains a shadow persistently attached to the positive aspiration of cognitive rehabilitation. This double-edged nature of cognitive rehabilitation—of being both an obstacle and an enabler—represents an important challenge that cognitive rehabilitation therapists inevitably confront in their attempt to support people with dementia. While in the memory clinics, I interviewed a neuropsychologist who describes her perspective on rehabilitation and the issue of decline. This encounter specifies this important challenge of rehabilitation:

*I will first do an evaluation. I will do an evaluation which is more or less intensive. The objective is to determine which [capacity] is conserved and which one is altered. I don’t know whether the one which is altered we are going to get it back. Because if the person lost her capacity to write, she will not get it back, like for someone who developed an aphasia [impairment of language affecting speech and writing]. She will not get it back. (…) But you will strive to maintain [the capacities] that you have kept. (…) And also, a struggle to work on the ones which are altered. If we speak of a cerebral damage, we are going to work on the ones which are altered. But for a neurodegenerative disease, we will try to work on [the altered capacities] but we know we are not going to recover. (…) Because a degenerative disease, well, degenerates. So, the objective is, when you come to see me, I evaluate you. If we have here the conserved capacities, and there the altered ones, we will try to maintain the ones that remain for the time you are here (…) until you lose these capacities.* [Interview translated by the first author]

In this vignette, we perceive how cognitive rehabilitation applied to dementia constitutes a struggle against its neurodegenerative nature, a complex balance between loss and stability. The role of the therapist is to localize these territories of alteration and stability and to specifically train the altered capacities—until they are lost.

In this interview, the neuropsychologist makes an important distinction between stable and neurodegenerative conditions (such as dementia), evoking the complexity of treating progressive decline in this manner. This complexity in rehabilitation has only recently emerged as it became applied to dementia. Indeed, the original purpose of cognitive rehabilitation was to treat brain injuries, it developed after the Second World War to treat soldiers affected by cerebral damage on the European battlefields (Prigatano 2005, 5). With the expansion of motorized transportation throughout the twentieth century, ensuing applications of rehabilitation involved the treatments of individuals affected by brain injuries resulting from car accidents. Brain injuries are often relatively stable and do not lead to progressive decline. Indeed, as another therapist pointed out during my fieldwork, individuals with such brain injuries are often able to benefit from rehabilitation for many years, therefore echoing the distinction with dementia made by the neuropsychologist I interviewed. This stability contrasts with the application of cognitive rehabilitation to a progressive condition. Capacities sustained through hard work one month may be lost the next, and so can exercises completed by the patient in one month appear irrelevant or even frustrating in the next. As evoked in the interview above, the therapist needs to engage in a constant process of revaluation to reorient the therapy amidst this progressive loss of capacity. This caution is also raised by some supporters of cognitive rehabilitation in the scientific
literature. Prigatano (2005, 6), a neuropsychologist and prominent figure in the development of cognitive rehabilitation, recognizes this confrontational nature of cognitive rehabilitation with decline. Prigatano (2005, 6) warns us that the level of difficulty of exercises should be progressively adapted and managed to avoid feelings of failure and frustration.

While the subjective and psychological impact of this confrontation is considered by therapists who are particularly careful to ensure the wellbeing of patients throughout the rehabilitation, its social significance for identity in later life remains unexplored. The following quotes will help shed light on this matter. As a therapist told me, when a patient with dementia becomes too advanced to benefit from rehabilitation, when exercises become too difficult to adapt to the declining capacities of this patient, there needs to be a consultation with the family to decide whether to institutionalize the patient or not. The ultimate powerlessness of rehabilitation therefore signifies the rupture of a bond of the person with dementia with active cognitive ageing and her entry into a third position marked by a dreaded non-agentic state. This third position is distinct from the first most desired position of active ager and the second more culturally valued, although excluded, position of people with dementia who can be rehabilitated. In characterizing the operation of memory clinics, Jolley and colleagues (2006) explain that “Any clinics restrict their involvement to the assessment and treatment of patients early in their careers with dementia. Longer term follow up falls to community mental health teams or primary care. If patients move into an independent sector nursing home, it is not unusual for them to be lost to follow up all together” (203).

This explanation, together with the one of psychologists I encountered, alludes to the position of those existing in the cultural space beyond therapy, in the shadow of rehabilitation. Hence, we argue that cognitive rehabilitation’s classificatory capacity reaches its peak as soon as it becomes unable to address neurodegeneration. Cognitive rehabilitation in dementia, a strategy essentially directed toward the treatment of early-stage dementia, stands in this ambiguous space between its therapeutic objectives and the subsequent ascription of people on the path leading to the loss of agency encompassed by “unsuccessful ageing” (Gilleard and Higgs 2010). This is a feared cultural location that Hazan (2011, 1129) also describes as “deep old age, which lies beyond the corrective power of therapy.” Through the operation of its apparatus of detection, classification and monitoring, cognitive rehabilitation participates in the construction of this social space by implicitly filtering out the existence of those individuals beyond the reach of therapy. Paradoxically, by elevating the status of those who can be rehabilitated, it inherently demarcates the social position of those who cannot, further reinforcing the symbolic power of exclusion of their diagnosis—a dementia beyond rehabilitation.

Technologies of Ascription Fracturing Later Life

This ethnography of cognitive rehabilitation progressively unveils three significant positions in our treatment of cognitive ageing through the lens of the Western “successful” or “active ageing” project (Lamb 2017, xii) and its expansion in brain health through active cognitive ageing (Libert, Charlesworth, and Higgs 2020). It presents how this practice inherently classifies people in three different social positions: the one of active agers without a label of dementia, the one of individuals diagnosed with dementia who can benefit from rehabilitation, the one of individuals diagnosed with dementia who cannot be rehabilitated. How do these three positions illustrate the capacity of rehabilitation to give its symbolic power to a dementia diagnosis in cultures of “successful ageing”?

The first position is inhabited by “active agers,” those without a label of cognitive decline who often engage in prevention practices such as brain training (Libert, Charlesworth, and Higgs 2020). Although the life of these older adults representing an important segment of the population in later life is not
directly described in this ethnography, it has been widely documented within ethnographic accounts and narrative analyses, often referring to this cultural field as “the third age” (Baltes and Smith 2003; Lamb 2014; Laslett 1989). The success of technologies such as brain training devices used to prevent dementia and other regimes of prevention, “brain health” and “cognitive fitness” in ageing populations characterize how the third age approaches cognitive ageing (Libert, Charlesworth, and Higgs 2020). Libert, Charlesworth, and Higgs (2020) explain how they are used as important instruments to maintain a social standing valued by cultures of the third age, as modes of distinction from individuals who embody the decline, abjection, and loss of agency symbolizing an “unsuccessful ageing.” This attitude toward decline in successful ageing often leads to the othering and exclusion of people with dementia (Higgs and Gilleard 2014; Libert, Charlesworth, and Higgs 2020) whose existence echoes the widespread fear of “losing” oneself (Degnen 2012, 9).

This ethnography shows a complementarity between memory clinics and technologies of distinction in supporting the social position of the third age. The cognitive assessments and monitoring that they promote play an important role in “guarding the frontiers” of successful (or active) cognitive ageing. They closely monitor belonging to this ideal of later life by comforting some about their normalcy while relegating those whose cognitive ageing is perceived as abnormal outside of the third age paradigm. Medical expertise, the establishment of strict procedures and controlled environments in memory clinics, as well as their legitimacy in healthcare play an important role in the reification and stabilization of this frontier between active ageing and dementia. This process of filtering is symbolically powerful in sustaining and affirming the triumph of third agers over cognitive decline. It celebrates their dedication to self-care and prevention in the field of later life.

For those receiving a diagnosis of dementia, cognitive rehabilitation plays a different role from the one of distinction, yet intrinsically linked to it. The diagnosis marks a separation from active cognitive ageing and only initiates a more extensive process ascribing people with dementia in a trajectory of decline. What cognitive rehabilitation essentially does is to ascribe a medicalized identity upon people experiencing cognitive decline. Previous studies showed that this label of dementia is intensely related to stigma (Ballenger 2006; Beard and Fox 2008; Fletcher 2021). Ballenger (2006) argues that the biomedicalization of senility operating since the end of the Second World War “has been at best ambiguous in lessening the stigma of old age” as it is central to the reinforcement of a boundary between normality and pathology (113). In this regard, Fletcher (2021) points out that a diagnosis can reinforce “felt” stigma in the person diagnosed; “felt” stigma being the subjective anticipation of a hypothetical “enacted” stigma afflicted by others. Although the patient can still choose disclosure or not, once being diagnosed there is often no turning back (unless a new medical authority counters the first one and indicates a misdiagnosis). Current trends toward medicalization in the clinics show how this logic is likely to expand due to the routinization of large-scale screening and monitoring it enables.

The steps that follow the classificatory event of the assessment continue this transformational process of identity in later life through the action of cognitive rehabilitation and its involuntary classification of people in later life into those who can and those who cannot be rehabilitated.

This post-diagnostic process is however ambivalent. Indeed, cognitive rehabilitation can be beneficial by potentially reducing the othering of those with a diagnosis of dementia. A successful rehabilitation raises their symbolic worth in the light of successful ageing when they can be rehabilitated. At a symbolic level, and leaving considerations of efficacy aside, the positive positional benefit of rehabilitation relates to its cultural desirability. It corresponds to a valued imaginary of individuals triumphing over their cognitive decline through active engagement and dedication to regimes of
rehabilitation. This successful rehabilitation represents the primary objective of the neuropsychologists I encountered which is to mitigate the capacity of the diagnosis to create exclusion.

However, this first benefit of reducing stigma through the cultural desirability of rehabilitation also foregrounds the tensions found in the position of those who cannot be rehabilitated. First because it essentially relies on diagnosis as a *sine qua non* entry point implying issues of stigma listed above. Moreover, this strategy aspires to the expansion of this diagnostic process—for instance through digital population level screening (Kitanaka 2020, 121) and forms of early diagnosis such as MCI or prodromal dementia—therefore encouraging further labelling. Labelling remains a challenge in a general context in which stigma against dementia is prevalent, and in which attempts to further medicalize dementia and separate it from previous categories of senility have proved limited in alleviating this stigma (Ballenger 2008; 2006; Kitanaka 2020).

Another issue beyond labelling is that rehabilitation confronts individuals diagnosed to the norms of capacity desired by active ageing. This confrontational approach to decline is illustrated through the challenging exercises imposed during the rehabilitation, which often need the reassurance from therapists that it is fine to fail and that participants should continue to try. This confrontational logic inevitable exposes their impairment as a result. The position of individuals who can be rehabilitated is therefore not without tensions. Despite its therapeutic benefits, it reifies and exposes the existence of decline, therefore rendering it amenable to potential exclusion or “felt” stigma among patients (Fletcher 2021). This exposition of decline through labelling and challenging exercises is an additional process leading cognitive rehabilitation to locally contribute to the symbolic power that society attaches to a diagnosis of dementia.

Finally, the more tacit, yet no less present, position of people with dementia who cannot be rehabilitated illustrates the ultimate process by which rehabilitation contributes to the symbolic power of a diagnosis. It exposes the existence of individuals whose decline is irreversible and separates them from the active ageing population. As I observed during this fieldwork, this third position is rarely discussed among key actors in the field of dementia, be it in memory clinics, influential institutions such as the WHO, or patient associations. Its existence evokes fear and powerlessness in the face of irreversible decline. This narrative clashes with the hopeful discourse that these institutions wish to promote. However, this promotion of hopeful discourses is an important source of othering for people with dementia falling beyond the reach of therapy. Rehabilitation, through its process of diagnosis ascribing label, and the filtering process it inherently operates by applying a selective therapy prioritizing early and moderate dementia therefore contributes to affirming and crystallizing the fear attached to individuals who cannot be rehabilitated. It further ascribes them in a culturally significant position symbolising a failed ageing.

Overall, when considering the relation of memory clinics with the broader context of successful ageing, we see how memory clinics play a specific social role in ascribing a pathological identity separated from ageing upon older adults experiencing cognitive decline. Their definition of abnormality, standardized assessment reifying decline through metrics, and confrontational approach to decline locally produce the powerful symbolism attached to the dementia diagnosis and its capacity to separate individuals from a so-called normal ageing. We propose to conceptualize this peculiar symbolic role of cognitive rehabilitation in the dominant narrative of successful ageing as a technology of ascription.

While the contribution of technologies of ascription to processes of social exclusion is difficult to perceive locally within the clinics, it becomes significant when the processes they deploy is relocated within dominant cultures of successful ageing. Technologies of ascription help to understand how
localized processes and day-to-day interactions—such as the ones taking place in rehabilitation within the memory clinics—are essential in generating the symbolic power of a dementia diagnosis to fracture later life. Exclusion is not solely the by-product of large-scale dementia strategies and public health campaigns, but also results from the combined action of various sites and mundane practices materializing the aspirations of these discourses.

Other studies explore the social impact of diagnostic practices for other conditions (e.g., Armstrong, Michie, and Marteau 1998; Strong 1979). Even though these practices can be transformative for identity, we argue that they do not possess the same symbolic intensity in evoking existential fear in later life as those found in cognitive assessment and rehabilitation.

Amidst the widespread expansion of medicalization in dementia, we propose that technologies of ascription are not limited to cognitive rehabilitation alone. Technologies of ascription can help us analyse other pharmaceutical and psychosocial interventions and therapies playing a similar social role of separating decline from normality in later life and determine their capacity of exclusion. By pointing to the importance of studying technologies of ascription, we also wish to delineate a field of research which remains relatively understudied in anthropology. It could offer many promising avenues for future ethnography to study social exclusion in later life.

Importantly, what we point out is not an outright rejection of the medicalization of cognitive decline in later life. Rather, in introducing the analytical concept of technologies of ascription, we call for the importance to more critically appraise the symbolic role that interventions can play in shaping identity and the benefits of medicalization for older adults. While medicalization can be beneficial for some—the ones whose decline remains “manageable” through rehabilitation—it also delineates a position associated with more exclusion for others.

**Conclusion**

This ethnography starts from the observation that little empirical research has been conducted on the localized processes of medicalization of cognitive decline contributing to the symbolic power of exclusion of a dementia diagnosis. Most psychosocial or gerontological research considered the diagnosis as an isolated entity requiring an intervention to facilitate its acceptance, underline its benefit, and promote it as an example of neurodiversity to prevent stigma and exclusion. Research in this domain often involved either exploring experiences of people with dementia as if being detached from the dominant cultural narrative of “successful,” active cognitive ageing, or problematizing this narrative while paying little attention to documenting the localized processes reinforcing the symbolic power of a dementia diagnosis to divide later life. This ethnography observing the actions and meaning-making practices of neuropsychologists and researchers implementing a cognitive rehabilitation therapy in two memory clinics in southern Europe aimed at addressing this gap in the literature. In this study, we considered the various steps followed by individuals experiencing cognitive decline. We presented an account of how the referral and the assessment represent an important transformation of identity as separated from “normal ageing” enacted through the reification of cognitive decline into dementia through standardized tests and metrics. We then presented how the confrontational therapeutic approach to decline found in the cognitive rehabilitation implicitly divides people with dementia into those who can benefit from rehabilitation, thereby demonstrating a desired ethos of active cognitive ageing in dementia and separating them from those who cannot be rehabilitated. We explained how this implicit process of filtering in rehabilitation is constitutive of an excluded category of people whose identity increasingly represents a “failed” ageing marked by the loss of agency in therapy. Based on this ethnography, we proposed the term of technologies of ascription to qualify this
process defining and reifying abnormal cognitive ageing, and involuntarily filtering individuals experiencing cognitive decline. We explained that technologies of ascription exemplify how the symbolic power of exclusion of a diagnosis of dementia is locally produced, therefore materializing discourses of successful cognitive ageing. Finally, we presented how technologies of ascription can be used as an analytical concept to explore how the symbolic power of division of a dementia diagnosis is locally produced in other therapeutic interventions for dementia. We explained how anthropology could play a key role in this exploration and improve our understanding of processes leading to social exclusion in later life.

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References


Birt, Linda, Fiona Poland, Emese Csipke, and Georgina Charlesworth. 2017. “Shifting Dementia Discourses from


