

Trusting the permanence of self for people with Alzheimer's disease

Gloria Frisone

Abstract: Although informed consent is rooted in the growing affirmation of the subject's autonomy, medical anthropology has highlighted the inherent limits of this procedural notion. My ethnographic research in neurological and geriatric clinics between France and Italy showed the triangular (dis)trust relationship—between older people with Alzheimer's disease (AD), their doctor, and their caregiver. Following their cognitive decline and loss of autonomy, people with Alzheimer's disease (AD) could be victims of epistemic injustice in two specific moments of the illness: the diagnostic disclosure and the institution of legal protection. If the diagnostic information diminishes the patient's credibility, the institution of legal protection undermines the patient's social identity and legal status. However, when caregivers preserve an unconditional trust in the permanence of the patient's subjective identity, this trust may be conveyed to clinical teams, significantly improving the therapeutic relationship, the course of the disease, and the quality of life for all the actors involved.

Keywords: informed consent, Alzheimer's Disease (AD), cognitive decline, loss of autonomy, diagnostic disclosure, legal protection, (dis)trust relationship, epistemic injustice, social identity, subjective identity.

Note on the author: Gloria Frisone is a Cultural and Medical Anthropology professor at the University of Milano-Bicocca, the University of Udine, and the University of Milan. Through ethnographic fieldwork between French and Italy, she highlighted the contemporary definition of aging and dementia, primarily Alzheimer's disease, in diagnostic and common sense. Her last research, funded by the 'Foundation Croix-rouge française', focused on the social and medical inequalities of elderly immigrants in Seine-Saint-Denis.

<https://orcid.org/0000-0003-1924-8092>

gloria.frisone@unimib.it

Introduction

Informed consent has become an integral part of contemporary medical practice, reflecting an ethical and political commitment that defines the doctor–patient relationship and upholds the growing recognition of individual autonomy. Article 5 of the Convention on Human Rights and Biomedicine (Oviedo, 4 April 1997) asserts the necessity for medical treatments to be administered based on patients’ voluntary and informed consent. Simultaneously, Article 35 of the Code of Medical Ethics (2005) emphasises the responsibility of clinicians to ensure patient comprehension. The patient’s entitlement to understand the therapeutic process is safeguarded by legal systems in numerous European countries, including laws like the Italian Law of 22 December 2017, and the French Kouchner Law of 4 March 2002 (art. L. 1111-2). Generally, informed consent stands as a fundamental principle in safeguarding patients’ well-being. Its unshakable foundation must rest upon the voluntary and conscious decision of the individual undergoing the treatment (Derouesné 2005, Quagliariello & Finn 2016).

Nevertheless, medical anthropologist Sylvie Fainzang (2010) has underscored the inherent limitations of this procedural concept. Drawing from my ethnographic research conducted in neurological and geriatric clinics across France (Frisone 2022) and Italy (Frisone 2017), this article delves into the intricate and ambiguous nature of informed consent for older adults grappling with neurodegenerative conditions, including Alzheimer’s disease (AD). According to the Alzheimer’s Disease Association (2001), the involvement of family members in the consent process carries significant ethical weight, even when devoid of legal validation (Petrini 2008: 27). Immediate family members are often seen as the most attuned interpreters of the patient’s best interests. Nonetheless, in numerous European nations, the consent of family members cannot supplant that of the individual patients (Canavacci 2006).

Background

Interpersonal trust serves as a cognitive framework that exerts influence over human social interactions and economic conduct. Contemporary trust theories draw from behavioural economics and social psychology (McGeer & Pettit 2017). In opposition to neoclassical economic theory (Von Neumann & Morgenstern 1944), which deems trust as irrational due to its non-selfish nature (Camerer 2003), psychological viewpoints examine trust as a product of reciprocal interaction between individual attitudes and societal contexts (Krueger 2009, Lewin 1936).

Consequently, personal credibility becomes pivotal for the acknowledgment of an individual as an autonomous human entity.

My ethnographic study spanning neurological and geriatric clinics in France and Italy elucidated the adverse impact of AD on patients' credibility. In essence, medical practitioners and caregivers encounter difficulty in confiding in AD patients. When cognitive decline challenges the patient's social identity and legal standing, the absence of trustful interactions erodes the fundamental perception of the patient's humanity (Hirsch 2012).

This situation could embody an instance of epistemic injustice. Broadly defined, epistemic injustice occurs whenever an individual's trustworthiness is undermined solely due to their specific identity or social attributes (Fricker 2007). Epistemic injustice involving individuals with dementia and Alzheimer's disease becomes conspicuously evident during two stages of the therapeutic process: the diagnostic disclosure and the establishment of legal guardianship.

In terms of the diagnostic disclosure, the doctor–patient relationship becomes imperilled, jeopardising the patient's credibility. Even in the absence of clinical evidence, AD patients are implicitly perceived as incapable of comprehending medical information (Lechevalier-Hurard 2016). Consequently, medical professionals tend to convey all medical information to the caregiver instead (Weber 2012).

Regarding legal protection, designating the primary caregiver as the legal guardian of the afflicted individual establishes a dependency dynamic (Blum *et al.* 2015, Capuano & Weber 2015). While chronic illnesses already impede legal status, AD notably erodes cognitive capacities and independence in daily activities (Lechowski *et al.* 2005), undermining self-concept and relational abilities (Davis 2004).

During both stages, medical practitioners exhibit minimal trust, if not outright distrust, in the patient's account, which often necessitates validation or supplementation by the caregiver's narrative. Consequently, it is more fitting to characterise the narrative of AD as a collaborative endeavour (Frisone 2022).

In advanced stages, AD can induce cognitive confusion, including episodic memory loss (Ballard *et al.* 2011, Lyketsos *et al.* 2011), alteration of autobiographical memories (El Haj *et al.* 2017), and at times, significant spatiotemporal disorientation, hallucinations, and paranoid delusions that can lead to personality shifts and severe behavioural disruption (Kim *et al.* 2021). This situation initiates a cascade of issues within families, affecting psycho-social equilibrium (Bercot 2003).

Nevertheless, ethnographic research (Frisone 2017) also underscores that, when caregivers maintain unwavering trust in the enduring essence of the patient's

identity, this confidence can be conveyed to clinical teams, substantially enhancing the therapeutic relationship and the overall quality of life for all parties involved.

Method

In this article, my aim is to explore the impact of AD on the dynamics of trust and mistrust among the doctor, patient, and caregiver. The arguments presented herein stem from two distinct medical anthropology research projects.

The first ethnographic study encompassed patients, family members, and healthcare personnel across five geriatric clinics situated in Paris and its suburbs. Employing a multi-sited ethnographic approach (Hannerz 2003, Marcus 1986, 1995)¹ I conducted research within a diverse array of healthcare settings, including: 1) the neurology department of an outlying academic hospital; 2) a smaller-scale geriatric hospital within one of the more economically challenged and densely populated northern suburbs of Paris; 3) a geriatric facility located within a privileged district of the city centre; 4) an internationally renowned institute specialising in neurodegenerative disease diagnosis; and 5) an association comprised of neurologists, neuropsychologists, and nurses delivering private diagnoses and treatments across urban and peri-urban domains.² This investigation encompassed varying socio-economic and ethnic backgrounds. On one hand, it involved the working-class, heavily industrialised, and culturally diverse neighbourhoods of the Parisian outskirts. Conversely, it concentrated on the affluent urban populace with elevated socio-economic status and French heritage. By integrating with diverse hospital teams, I observed the activities of physicians, geriatricians, neurologists, neuropsychologists, nurses, and other professionals dedicated to neurodegenerative disease care. Through in-depth, semi-structured interviews, I elicited their experiences and reflections. Moreover, occasional interactions with patients and their families transpired amidst clinical sessions. This ethnography explores the

¹Muti-sited ethnographies marked the transition from a traditional anthropology based on intensive 'single-site' studies, to a contemporary ethnography, settled in cross-cultural and cross-national contexts to highlight the complex relationships and interconnections between the local and the global (Marcus 1995). According to Ulf Hannerz (2003), the univocal but still hierarchical relations between local and global can locate both along transnational routes and within narrower national and local contexts. In the present case, the socio-cultural, economic, and ethnic characteristics of each of the sites considered delineate radically diverse clinical settings in terms of the demographic composition of staff and users, health services, diagnostic devices, local prevention and care policies, treatment practices, and power relations between patients and therapists.

²The description of the locations is deliberately imprecise to respect the privacy and ensure the anonymity of health professionals and their patients.

historical, cultural, and political underpinnings of discourses that frame AD within the context of de-subjectification and self-loss (Kontos 2006).

The second ethnographic study was conducted within a nursing home in northern Italy. This investigation centred on the interplay among a woman exhibiting a logopaedic variant of AD (referred to as 'Manuela'), her psychotherapist ('Lorella'), and her daughter ('Elena'). Despite its relatively brief duration of six months, this fieldwork exhibited a high level of immersion, focusing on the construction of subjectivities, personal perceptions of illness, and an extensive collection of life narratives. To achieve this, I engaged with the three women twice a week, opting for unstructured and extended interviews that were intentionally not recorded to foster a natural, spontaneous dialogue with my interlocutors. Lorella shared the challenges she encountered in working with this patient due to her language deficits; Elena openly discussed her personal experiences and relationship with her mother; ultimately, interactions with Manuela occurred predominantly through non-verbal communication. Additionally, I conducted participatory observations of clinical interactions and periodic sessions involving an innovative cognitive stimulation technique known as 'window therapy'.

Findings and discussion

Diagnostic disclosure

The initiation of any therapeutic relationship is invariably marked by the disclosure of a diagnosis. During my participant observation within clinical settings, I had the opportunity to delve into diagnostic meetings among the multidisciplinary team members of the hospital, encompassing neurologists, geriatricians, psychologists, nurses, and social workers. My research unveiled that each professional employs specific approaches to collect clinical data, which are then synthesised to formulate a multidisciplinary diagnosis. Neuropsychologists administer memory tests to differentiate between normal and pathological cognitive aging, neurologists scrutinise brain imaging scans to detect the presence of lesions like amyloid plaques and neurofibrillary tangles around the hippocampus—the organ responsible for memory storage—and geriatricians evaluate whether the patient's physical and psychological vulnerabilities can be attributed to physiological aging or neurodegenerative disease. This concise overview demonstrates how memory-related issues enable clinicians to differentiate between physiological aging and conditions such as AD and other neurodegenerative disorders (Jahn 2013, McKhann *et al.* 2011).

According to medical anthropology research (Lock 2013), diagnosing AD is a multifaceted process involving an array of clinical data. Nevertheless, conveying such a diagnosis can be an even more intricate endeavour. Research from the United States has indicated that AD is communicated to patients in only around 40% of cases (Johnson *et al.* 2000, Pinner 2000). Studies in the United Kingdom have previously revealed that the diagnosis of AD is communicated less transparently compared to other grave illnesses like cancer (Vassilas & Donaldson 1998) or schizophrenia (Clafferty *et al.* 1998). Generally, it is easier to inform family members than the patients themselves. In line with a British study conducted among general practitioners, only 55% of patients are informed concurrently with their families (Downs *et al.* 2002), while the figure stands at 53% on a European scale. How can we explain doctors' reluctance to disclose AD diagnoses to patients? On one hand, this hesitance might stem from the chronic and irreversible nature of the disease. On the other hand, there is a distinct peculiarity in the context of AD.

All individuals grappling with chronic conditions inevitably undergo a transformation from their previous social roles to the perpetual status of the ill³ (Weisz 2003). However, this phenomenon is particularly pronounced in AD cases (Weber 2012). Indeed, the diagnosis of AD accentuates intellectual capabilities and relational competencies, which have long been viewed as fundamental components of human identity since the days of John Locke (Douglas 1992, Hacking 1995). Cognitive deficits can severely impede the faculties upon which this notion of personhood is founded. These faculties constitute the bedrock of a concept of humanity anchored in autonomy, self-awareness, and liberty (Derouesné 2005: 119). Therefore, family members often become the primary interpreters of the patient's condition. As a neurologist at a suburban academic hospital aptly put it: *'The family frequently interprets and conveys the complaints as the patient may struggle to articulate or describe their difficulties'* (ethnographic interview, 8 August 2017).

According to professionals, patients are often incapable of recognising their own disorders and may even reject the diagnostic disclosure. Neurologists categorise this attitude as one of the symptoms of AD, a phenomenon referred to as 'anosognosia'. A geriatric neurologist, discussing most of her patients, explained, *'It's often others who notice memory problems'* (ethnographic interview, 2 June

³The American sociologist Talcott Parsons (1951) was the first to define the 'role of the sick' in modern society. The role of the sick allows the individual not to be delegitimised in society and not to be considered deviant or antisocial. From the social point of view, sickness is perceived as an alteration of the person's social status: it marks a suspension of the patient's social life, functions, and obligations. The diagnosis removes responsibility from the sick person, who is called upon to be a passive subject into a society of active individuals (Friedson 1970).

2017). Simultaneously, patients are often prone to paranoia: *'They sometimes believe that others are plotting against them'*, shared a neuropsychologist from a reputable Paris hospital (ethnographic interview, 5 December 2017).

The erosion of trustworthiness envelops patients due to their cognitive and memory impairments, which in turn fosters scepticism among medical professionals regarding their accounts of illness. Consequently, patients' voices are marginalised, and caregivers are given more weight in discussions. This is despite legislative and ethical frameworks urging healthcare practitioners to communicate patients' health conditions to the patients themselves. For certain practitioners, the 'right to know' is deemed as crucial as the right 'not to know' (Derouesné 2005: 121). The task of disclosing 'the truth' about the disease often makes doctors uncomfortable. When faced with this legal and ethical obligation, a geriatrician acknowledged that early in his career, he found this responsibility particularly challenging: *'I found it difficult to convey things because it led to many conflicts'* (ethnographic interview, 1 August 2017).

The physician tasked with conveying the progressive decline of these cognitive faculties finds themselves in a paradoxical position: they must respect the patient's dignity even as they deliver a diagnosis that will inevitably disrupt that very dignity. Unfortunately, legislative guidance seldom resolves these ethical quandaries. Consequently, announcing the diagnosis of AD remains an especially complex and delicate undertaking.

The institute of legal protection

As seen, the AD patient embodies the quintessential depiction of a chronic patient (Attias-Donfut 1997). Diagnosed with a condition that debilitates cognitive functions, language, reasoning, and memory, those with AD find themselves relegated to the passive role of dependent individuals (Capuano & Weber 2015).

Typically, a dependent person loses the capacity to make decisions and assess potential hazards for themselves and others (Trabut & Weber 2009). When older individuals are deemed non-autonomous due to their deteriorating health, legal protective measures are enacted. These measures often involve assigning a legal guardian, commonly a family member. French legislation equates the legal status of older adults with dementia to that of individuals with disabilities (Capuano & Weber 2015).⁴ In both scenarios, the establishment of a formal dependency

⁴Law 11 February 2005: 'For the purposes of the present law, a disability is any limitation of activity or restriction of participation in society experienced by a person in his or her environment due to a substantial, lasting or definitive impairment of one or more physical, sensory, mental, cognitive or psychological functions, a multiple disability or a disabling health disorder' (author's translation).

relationship between the person unable to cater to their own needs and their legal guardian becomes necessary (Capuano 2014).⁵ On the other hand, Italian legislation maintains a clear distinction between these two situations while extending legal protection to all those incapables of self-sufficiency, including those with AD.⁶

Although families frequently receive assistance from a variety of medical, social, and legal professionals (Blum *et al.* 2015), transitioning from autonomy to dependence is challenging for both patients and their relatives. For the younger population, lack of autonomy is a constant state, while for older individuals, entering a state of dependence is marked by the gradual loss of the capacity to act (Le Borgne-Uguen & Penneec 2004: 70). Consequently, dependent older adults forfeit their legal status as citizens.

The judiciary typically relies on a medical certificate to institute legal guardianship for AD patients. From this point forward, the individual with the illness forms two care relationships: an official one with the doctor and an informal one with the caregiver. This division between formal and informal care relationships aligns with Joan Tronto's (1993) conceptualisation. The care relationship involves the caregiver taking on responsibility for the person in their care while also exerting influence over them. This dynamic establishes a dichotomy between an active and a passive subject.

This relationship of dependence and care between patients and caregivers is a significant consideration for medical professionals. My research unveiled that doctors are only occasionally willing to place trust in AD patients. The erosion of AD patients' credibility, often due to memory loss, prompts doctors to supplement their illness narratives with information from the caregiver. Consequently, accounts of AD rarely reflect the patient's subjective viewpoint. Instead, they emerge as co-interpretations of symptoms, engaging in the negotiation of meanings (Frisone 2002). The perspective of illness in this context does not solely emerge as a personal account; rather, it embodies multiple viewpoints that converge in an intersubjective co-narration. Furthermore, the caregiver subtly morphs into a co-narrator of the patient's story. This co-narration underscores how illness narratives evolve into a collective narrative of intersubjective illness that shapes and is shaped by familial caregiving.

⁵Law 5 March 5 2007: persons requiring legal protection are 'unable to look after their own interests due to a medically diagnosed impairment of either their mental faculties or their physical faculties such as to prevent them from expressing their wishes' (author's translation).

⁶Law 9 January 2004 'aims to protect, with the least possible limitation of the capacity to act, people deprived in whole or in part of autonomy in the performance of the functions of daily life, through temporary or permanent support interventions' (author's translation).

Take the case of Mr Leroy⁷ an 85-year-old man admitted to a geriatric psychiatry department following a two-year history of AD prompted by a stroke. He consistently references his wife's opinions. This infusion of the caregiver's perspective aligns with the behaviour of most patients and reflects their mistrust of their own viewpoint. The recent memory loss distresses the patient, leading him to contemplate a future where his autonomy fades and he becomes a burden to his family. This sensation of being burdensome can either translate into guilt toward others or invoke a rejection of the dependence, often manifested as aggressive reactions.

The possibility of memory loss deeply concerns both patients and caregivers. Patients convey that their memory problems extend beyond recent memory to encompass older memories. Simultaneously, family caregivers dread memory lapses affecting daily life that might jeopardise the patient's safety or their own. Consequently, mutual trust in their love becomes precarious for both the caregiver and the patient.

This co-narration of illness brings to light the 'moral economy' of AD, or more specifically, the interplay between contemporary moral norms and the societal concept of AD. As described by Didier Fassin (2009), 'moral economy' refers to the exchange of values, emotions, and affections within the realm of daily relationships. The nexus between memory and value is implicit in the moral economy of familial caregiving relationships. Elements of crucial value and profound meaning need to be retained and remembered. From this perspective, the most distressing prospect for caregivers is the loss of memories that constitute shared histories with their afflicted family members.

However, the power of the diagnostic pronouncement ostensibly absolves the AD patient of responsibility for forgetting. In exchange, their credibility is undermined, and they become innocent victims of their ailment. Conversely, caregivers are cast in the role of sacrificial victims who dedicate themselves to caregiving duties. Thus, within this localised 'moral world' (Kleinman & Van Der Geest 2009), patients grapple with the sense of losing their autonomy and becoming burdens, while caregivers embrace the role of dedicated caretakers.

Simultaneously, this perspective leads caregivers to perceive the afflicted person as someone who is no longer their former self—a person who has vanished. A sense of pre-emptive mourning pervades caregivers. Nonetheless, as the subsequent paragraph will delve into, caregivers may continue to recognise the patient's subjectivity and maintain trust in the continuity of self.

⁷The last name of the patient is fictive to guarantee his anonymity.

The permanence of subjective identity

In another ethnographic study conducted (Frisone 2017), the focus shifted to a private residence in northern Italy catering to older adults with AD or other neurodegenerative conditions. This research specifically examined the triadic relationship between a patient named Manuela, her daughter Elena, and the psychotherapist (Lorella).⁸ The facility operated with a dual clinical and supportive approach, offering medical and psychological care for chronic aging-related disorders.

Emphasis was placed on non-pharmacological treatments, with a focus on cognitive and mnemonic stimulation techniques that extensively utilised autobiographical prompts. This context highlighted the unique mother–daughter relationship where mutual recognition bolstered the memory of their shared history. Furthermore, the growing emphasis on patient-centred care prompted an exploration of the patient’s relational and social dimensions. Lorella, the clinical psychologist at the residence, exemplified this approach through her professional practice.

Lorella’s initial interaction with Manuela was somewhat superficial. Initially tasked with administering neuro-cognitive tests, Lorella struggled to establish rapport with Manuela, who had a compromised ability for verbal expression due to her logopedic variant of AD. This deficiency in verbal language hindered the early therapeutic relationship. However, upon the intervention of Manuela’s daughter Elena, Lorella’s perspective gradually evolved. Elena accompanied her mother to group sessions and engaged with her, assisting in answering questions and solving basic exercises. Although significant improvements in correct answers were not achieved, Elena maintained a steadfast belief in her mother’s ability to comprehend her surroundings. With time, Lorella recommended an individualised therapy for Manuela, integrating autobiographical psychotherapies and motor–cognitive stimulation. This marked the turning point where Lorella became a central figure for both Manuela and Elena, ultimately leading to the formation of a ‘therapeutic triad’.

Elena’s unwavering presence and commitment to her mother’s care were notable. Despite her mother’s verbal limitations, Elena continued to visit regularly, driven not by guilt or duty but by an innate need. Elena refused to perceive her mother as completely changed, recognising that while their relationship had evolved due to the illness, it remained profound and essential. ‘*I stay her daughter; she stays my mother, and this really cannot change*’ (ethnographic interview, 4 May 2018), she said. This acceptance allowed Elena to adapt to their new dynamic, finding significance in her role as both a daughter and a caregiver. This shift in perspective nurtured a unique and meaningful bond between them.

⁸ Once again, fictitious names are chosen to guarantee people’s anonymity.

From an anthropological point of view, believing does not necessarily concern objective reality (Needham 1972: 69). This steadfast trust in the continuity of Manuela's sense of self by Elena mirrored a type of 'faith'. This isn't an irrational belief but rather a 'truth of reason', which doesn't require empirical validation. Instead, it is reinforced daily through repeated behaviours that confirm its validity (Frisone 2017: 108). Elena's trust in her mother's constancy did not arise from empirical observations but presupposed those observations, reaffirming her trust over time.

Conclusion

As highlighted in this article, the contrast between the politics of informed consent and clinical practice becomes apparent when dealing with Alzheimer's disease (AD). Healthcare professionals, including neurologists, geriatricians, and neuropsychologists, often choose to communicate and interact with the family members of AD patients rather than the patients themselves. This tendency stems from the erosion of credibility that AD patients experience due to cognitive deficits and memory loss, leading to a strained therapeutic relationship built on trust. This situation gives rise to an epistemic injustice, where doctors implicitly distrust AD patients due to presumed mental deficits, thereby focusing their attention primarily on caregivers.

This epistemic injustice manifests prominently during two critical moments: the diagnostic disclosure and the legal protection process for AD patients under the guardianship of caregivers. The former moment involves the medical diagnosis, which relegates the patient's complaints to pathological symptoms, such as anosognosia, thereby diminishing the patient's autonomy. The latter involves the legal transfer of the patient's illness narrative to a family member, resulting in an illness co-narration. Both instances signify a transformation of roles—the patient from a free and autonomous citizen to a dependent individual, and the caregiver into a dedicated caretaker.

This transition disrupts mutual recognition and the moral economy surrounding AD, absolving both patients and caregivers from guilt. The new moral economy often revolves around the familial relationship between patients and caregivers, accentuating their roles as victims, one innocent and dependent, the other sacrificial and devoted.

However, the story of Manuela and Elena presents an alternative representation of the AD patient. Their narrative unveils a unique moral economy. Elena's approach to caregiving defies the traditional roles—she cares for her mother with-

out seeing her as solely passive and dependent. She embraces her new role as a ‘daughter–mother’ without exploiting her mother’s vulnerability. Elena’s refusal to be cast as a sacrificial victim prevents the mother’s characterisation as an innocent victim. Despite AD’s challenges, Manuela’s subjectivity remains intact, and all perceive her presence in its fullness.

In conclusion, Elena’s unwavering trust in Manuela’s subjective identity is intricately woven into their relationship. This trust forms a circular and narrative loop where Manuela’s recognition of herself relies on her daughter’s recognition and vice versa. As a shared experience, memory reinforces their bond, making the mother–daughter relationship resilient to the effects of AD. Their mutual story remains open-ended and continually evolving.

Acknowledgments

This work was accomplished with the consent of the health managers of clinical structures and hospitals where I conducted my ethnographic work. I want to thank all the healthcare professionals, doctors, psychologists, social workers, and all involved in the complex and daily work of providing professional care and emotional support to people with neurodegenerative diseases and their families. I want to thank all those who wished to share their experience of illness or their testimonies, always full of intimate memories and suffering.

I thank the many colleagues who wished to cultivate a relationship of exchange and dialogue with me that has been stimulating and enriching for developing this work. I want to mention Martina Laganà, Francesco Diodati, Luca Rimoldi, Marta Scaglioni, Barbara Pieta, Virginia Moratti, and Magnifique Neza.

Moreover, I would like to thank the eminent anthropologist Richard Recthman, my mentor and thinking voice, who accompanied me during my PhD.

Finally, I would like to give special thanks to my friend Eloisa Franchi, an indefatigable doctor and social scientist capable of looking with an eye as surgical as it is open to the dilemmas and contradictions of the contemporary world. I thank her for carefully revising, correcting, and reformulating entire paragraphs. Thanks to her contribution, my thoughts, often silenced by clumsy rhetoric, could find their voice here.

References

- Alzheimer's Disease Association, (2001), 'Ethical issues in Alzheimer's disease', Alzheimer's Disease Association, Chicago, IL.
- Attias-Donfut, C. (1997), 'La construction sociale de la dépendance', *Droit sanitaire et social*, special issue, *La dépendance des personnes âgées*, 15–24.
- Ballard, C., Gauthier, S., Corbett, A., Brayne, C., Aarsland, D. & Jones, E. (2011), 'Alzheimer's disease', *The Lancet*, 19(377): 1019–31. [https://doi.org/10.1016/S0140-6736\(10\)61349-9](https://doi.org/10.1016/S0140-6736(10)61349-9)
- Bercot, R. (2003), *Maladie d'Alzheimer. Le vécu du conjoint* (Ramonville, Éditions Érès). <https://doi.org/10.3917/eres.berco.2003.01>
- Blum, P., Minoc, J. & Weber, F. (2015), 'Familles en danger ? Psychiatrie, hébergement familial et vulnérabilité', *Informations sociales*, 2(188): 68–75. <https://doi.org/10.3917/inso.188.0068>
- Camerer, C.F. (2003), *Behavioral Game Theory: Experiments in Strategic Interaction*. (Princeton, NJ, Russell Sage Foundation).
- Canavacci, L. (2006), 'Il consenso informato', in *Guida all'esercizio professionale per i medici-chirurghi e gli odontoiatri* Eds by M. Greco, A. Pagni, A. & Panti (Torino, Edizioni Medico Scientifiche) 16–37.
- Capuano, C. (2014), 'Faire l'histoire de la dépendance contemporaine. Le cas des solidarités familiales en France dans la seconde moitié du vingtième siècle', in *La protection sociale en Europe au XXe siècle*, Eds A. Brodiez-Dolino & B. Dumons (Rennes, Presses Universitaires de Rennes), 147–64. <https://doi.org/10.4000/books.pur.50222>
- Capuano, C. & Weber F. (2015), 'La tierce personne : une figure introuvable? L'Incohérence des politiques françaises de l'invalidité et de la perte d'autonomie (1905–2015)', *Revue d'histoire de la protection sociale*, 8(1): 106–30. <https://doi.org/10.3917/rhps.008.0106>
- Clafferty, R.A., Brouwn, K.W. & McCabe, E. (1998), 'Under half of the psychiatrists tell patients their diagnosis of Alzheimer's disease', *British Medical Journal*, 317: 603. <https://doi.org/10.1136/bmj.317.7158.603b>
- Davis, D. (2004), 'Dementia: sociological and philosophical construction', *Social Science and Medicine*, 58(2) 369–78. [https://doi.org/10.1016/S0277-9536\(03\)00202-8](https://doi.org/10.1016/S0277-9536(03)00202-8)
- Derouesné, C. (2005), 'La communication du diagnostic de maladie d'Alzheimer', *Gérontologie et Société*, 28(115): 117–33. <https://doi.org/10.3917/g.s.115.011>
- Douglas, M. (1992), 'The Person in an Enterprise Culture', in *Understanding Enterprise Culture: Theme in the Work of Mary Douglas*. Eds S.H. Heap & A. Ross. (Edinburgh, Edinburgh University Press), 41–62.
- Downs M., Clibbens R., Rae C., Cook A. & Woods R. (2002), 'What do general practitioners tell people with dementia about their condition?', *Dementia*, 1: 47–58. <https://doi.org/10.1177/147130120200100106>
- El Haj, M., Roche, J., Gallouj, K. & Gandolphe, M.C. (2017), 'Autobiographical memory compromise in Alzheimer's disease: a cognitive and clinical overview', *Gériatrie et Psychologie Neuropsychiatrie du Vieillessement*, 15(4): 443–51. <https://doi.org/10.1684/pnv.2017.0704>
- Fainzang, S. (2010), 'Patient information between public space and anthropology: ethnography's contribution to the debate', *Etnográfica*, 14(1)97–114. <http://journals.openedition.org/etnografica/166>, <https://doi.org/10.4000/etnografica.166>
- Fassin, D. (2009), 'Les économies morales revisitées', *Annales Histories Sciences Sociales*, 6: 1237–66. <https://doi.org/10.1017/S0395264900027499>
- Fricker, M. (2007), *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford, Oxford Academic). <https://doi.org/10.1093/acprof:oso/9780198237907.001.0001>
- Friedson, E. (1970), *Profession of Medicine: A Study of the Sociology of Applied Knowledge* (New York, Harper & Row).

- Frisone, G. (2017), 'Guardar-si alla finestra, Una terapia narrativo-autobiografica per la stimolazione cognitiva di una paziente Alzheimer', *AM, Rivista della Società Italiana di Antropologia Medica*, 19(43–6): 89–132. <https://www.amantropologiamedica.unipg.it/index.php/am/article/view/409/392>
- Frisone, G. (2022), 'La Malattia Di Alzheimer in Prospettiva Tridimensionale: Alterazione Sociale, Patologia Clinica e Malessere Intersoggettivo', *Antropologia medica e invecchiamento. Esperienze e prospettive di un dialogo interdisciplinare*, 9(1): 53–73.
- Hacking, I. (1995), *Rewriting the Soul. Multiple Personality and the Sciences of Memory*. (Princeton, NJ, Princeton University Press). <https://doi.org/10.1515/9781400821686>
- Hannerz, U. (2003), 'Being there ... and there ... and there! Reflections on multi-site ethnography', *Ethnography*, 4(2): 201–16. <https://doi.org/10.1177/14661381030042003>
- Hirsch, E. (2012), 'Inventer d'autres expressions de la sollicitudes', in *Alzheimer, éthique et société*. Eds F. Gzil & E. Hirsch (Toulouse, Éditions Érès), 72–86.
- Jahn, H. (2013), 'Memory loss in Alzheimer's disease', *Dialogues Clin Neurosci*, 15(4): 445–54. <https://doi.org/10.31887/DCNS.2013.15.4/hjahn>
- Johnson, H., Bouman, W.P. & Pinner, G. (2000), 'On telling the truth in Alzheimer's Disease: a pilot study of current practice and attitudes', *International Psychogeriatrics, International Psychogeriatrics Association*, 12(2): 221–9. <https://doi.org/10.1017/S1041610200006347>
- Kim, B., Noh, G.O. & Kim, K. (2021), 'Behavioural and psychological symptoms of dementia in patients with Alzheimer's disease and family caregiver burden: a path analysis', *BMC Geriatrics*, 21: 160. <https://doi.org/10.1186/s12877-021-02109-w>
- Kleinman, A. & Van Der Geest, S. (2009), 'Care' in health care. They are remaking the moral world of medicine, *Medische Antropologie*, 21(1): 159–68.
- Kontos, P. (2006), 'Embodied selfhood. an ethnographic exploration of Alzheimer's disease', in *Thinking About Dementia: Culture, Loss, and the Anthropology of Senility*. Eds A. Leibing & L. Cohen (New Brunswick, NJ, Rutgers University Press), 195–217. <https://doi.org/10.2307/j.ctt5hjhbhp.13>
- Krueger, J.W. (2009), 'Empathy and the extended mind', *Zigon*, 44: 675–98. <https://doi.org/10.1111/j.1467-9744.2009.01024.x>
- Le Borgne-Uguen, F. & Penneç S. (2004), 'Les stratégies des personnes âgées', in *Prévenir l'isolement des personnes âgées. Voisiner au grand âge*, Ed. D. Argourd (Paris, Dunod).
- Lechevalier-Hurard, L. (2016), 'Être présent auprès des absents: repenser la relation de soin en établissements d'hébergement pour personnes âgées', *Sociologies*, Dossier, <http://journals.openedition.org/sociologies/5441>, <https://doi.org/10.4000/sociologies.5441>
- Lechowski, L., De Stampa, M., Tortrat, D., Teillet, L., Benoit, M., Robert, P.H. & Vellas, B. (2005), 'Predictive factors of rate of loss of autonomy in Alzheimer's disease patients. A prospective study of the REAL.FR Cohort', *The Journal of Nutrition, Health and Aging*, 9(2): 100–4.
- Lewin, K. (1936), *Principles of Topological Psychology* (New York, McGraw-Hill). <https://doi.org/10.1037/10019-000>
- Lock, M. (2013), *The Alzheimer Conundrum. Entanglements of Dementia and Aging* (Princeton, NJ, Princeton University Press). <https://doi.org/10.23943/princeton/9780691149783.001.0001>
- Lyketsos, C.G. et al. (2011), 'Neuropsychiatric symptoms in Alzheimer's disease', *Alzheimer's Dementia*, 7(5): 532–9. <https://doi.org/10.1016/j.jalz.2011.05.2410>
- Marcus, G.E. (1986), 'Contemporary problems of ethnography in the modern world system', in *Writing Culture*, Eds J.Clifford & G.E. Marcus (Berkeley, CA University of California Press), 165–93. <https://doi.org/10.1525/9780520946286-010>
- Marcus, G.E. (1995), 'Ethnography in/of the world system: the emergence of multi-sited ethnography', *Annual Review of Anthropology*, 24: 95–117. <https://doi.org/10.1146/annurev.an.24.100195.000523>
- McGeer, V. & Pettit, P. (2017), 'The empowering theory of trust', *The Philosophy of Trust*, Eds P. Faulkner & T. Simpson (Oxford, Oxford Academic), 14–34. <https://doi.org/10.1093/acprof:oso/9780198732549.003.0002>

- McKhann, G.M. *et al.* (2011), 'The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging–Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease', *Alzheimer's Dementia*, 7(3): 263–9.
- Needham, R. (1972) *Belief, Language, and Experience* (Oxford, Blackwell).
- Parsons, T. (1951), *The Social System* (London: Routledge & Kegan Paul).
- Petrini, C. (Ed.) (2008), 'Il consenso informato al trattamento dei soggetti affetti da demenza: aspetti etici, deontologici e giuridici', Rapporto ISTISAN 08/3. Unità di Bioetica, Presidenza dell'Istituto Superiore di Sanità, Roma.
- Pinner, G. (2000), 'Truth telling and diagnosis of dementia', *British Journal of Psychiatry*, 177: 514–15. <https://doi.org/10.1192/bjp.176.6.514>
- Quagliariello, C. & Finn, C. (2016), *Il consenso informato in ambito medico. Un'indagine antropologica e giuridica* (Bologna, Il Mulino).
- Trabut, L. & Weber, F. (2009), 'Comment rendre visible le travail des aidants? Le cas des politiques de la dépendance en France', *Idées économiques et sociales*, 158: 13–22. <https://doi.org/10.3917/idee.158.0013>
- Tronto, J. (1993), *Moral Boundaries. A Political Argument for an Ethic of Care* (London, Routledge, Chapman, and Hall).
- Vassillas, C.A. & Donaldson, J. (1998) 'Telling the truth. What do general practitioners tell patients of their diagnosis of Alzheimer's disease', *British Journal General Practice*, 48: 1081–2.
- Von Neumann, J. & Morgenstern, O. (1944) *Theory of Games and Economic Behavior* (Princeton, NJ, Princeton University Press).
- Weber, F. (2012), 'Relation d'aide et décision pour autrui, une approche ethnographique', in *Alzheimer, éthique et société*, Eds by F. Gzil & E. Hirsch (Toulouse: Éditions Érès), 142–53.
- Weisz, G. (2013), *Chronic Disease in the Twentieth Century. A History*. (Baltimore, MD, Johns Hopkins University Press).

To cite the article: Frisone, G. (2023), 'Trusting the permanence of self for people with Alzheimer's disease', *Journal of the British Academy*, 11(s6): 103–117. <https://doi.org/10.5871/jba/011s6.103>

Journal of the British Academy (ISSN 2052–7217) is published by
The British Academy, 10–11 Carlton House Terrace, London, SW1Y 5AH
www.thebritishacademy.ac.uk

