Affective, Interpersonal, and Subjective Aspects of Denial in Anosognosia for Hemiplegia: Neuroscientific and Psychoanalytic Perspectives

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Declaration

I, Arturo Kerbel-Shein, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: *Date:*

Abstract

Some patients customarily deny left hand hemiplegia as a consequence of a right hemispheric stroke. Denial is a key aspect in Anosognosia for Hemiplegia, and is also an essential concept in the development and structure of psychoanalytic theory. In research on AHP, denial is approached from neuroscientific perspectives, which include empirical research on several aspects that are relevant in the presentation of the syndrome (e.g. senso-perception, cognition, neuroanatomy, etc.). Psychoanalysis has emphasised intrapsychic, developmental, and defensive aspects based upon clinical observation of mainly non-neurological patients. However, the Cognitive Arrest Hypothesis (a model stemming from psychoanalytic theory) has proposed a view of denial that is in accordance with, or does not contradict empirical evidence on AHP. Both fields have recognised the importance of affective, motivational, interpersonal, and subjective aspects in the presentation of denial. The Cognitive Arrest Hypothesis allows discussing evidences on denial in AHP research, and in psychoanalytic theory, under a common framework of reference. The present thesis aims at opening a debate between these two fields with the goal of demonstrating how can their arguments be of mutual assistance in further comprehending denial. Three research proposals are presented to illustrate practical ways to consider contributions from both fields in future research and clinical directions.

Impact statement

The main importance of the present work lies in the disposition to put to debate the fields of neuroscience and psychoanalysis in order to advance the discussion on areas that have been relegated or not satisfactorily attended by both fields. The currently dominant biomedical attention system tends to be limited to physiological care, leading to underdiagnosis of symptoms or syndromes just because they are seemingly not life threatening. In that way, several cognitive, psychiatric, and neurological issues that patients present in hospital wards are

left largely unattended. Such is the case with Anosognosia for Hemiplegia, the central topic of this dissertation. This syndrome ensues most commonly following right hemispheric strokes and usually remits in a short time, which leads to the belief, or unconscious practice, of not paying attention to the deficit, which does not always present overtly. The problem with this issue, is that if unawareness of hemiplegia is left unattended, quality of life, and disposition for treatment would decrease, whilst exposure to risky behaviours could increase.

The syndrome is generally reviewed from empirical, neuropsychological perspectives. Some accounts of the syndrome exist in psychodynamic approaches, however, the strength of psychoanalytic theory in this topic lies in the diversity and depth of points of view that developed, more so after Freud. None of the fields has been able to put forward proposals or hypothesis that are generalisable for all cases or instances of the syndrome.

A debate involving evidence and observations from both fields can contribute to their mutual progress in many ways, including the possibility to design bolder experiments, and individually tailored and effective treatments for rare neurological disorders like AHP.

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CHAPTER 1

Anosognosia for Hemiplegia Following Right Hemispheric Stroke in the Context of the Mind – Body Debate

Introduction

From the earliest days of civilisation, humans have shown an archaic and pervasive interest in understanding the body: the one thing that allows us to be materialised, and biologically capable of engaging in any experience of the world. The world is not limited to an external surrounding environment that presents us with events to which we swiftly react with the ultimate goal of adaptation. There is also the body, everything that happens in it, and the experience of that body.

Throughout history human beings have progressively expanded their knowledge about the body, its' composition, and function. As a necessary effect of this expansion of knowledge a vast array of hypotheses, theories and methods have been developed continuously extending the reach of inquiry, shifting paradigms as new experience gives way to updated accounts. Methods have been mastered and ground-breaking techniques developed to manipulate the world aiming at conceiving and curing our bodies from illness in an on-going quest to grasp the flesh, the bones, muscles, articulations, biochemical, and electrical processes that deem our bodies, that is *ourselves*, existent.

Nevertheless, the very nature of how some of the manifestations of our existence present to ourselves is elusive to tangibility and henceforth impedes straightforward conclusions to be drawn from material evidence, which in turn complicates the task of confirming or favouring some knowledge over another. Common experience, for example, leads to a seemingly unavoidable assertion that phenomena such as *thought*, *judgement*, other aspects or derivatives of cognition *somehow* exist; these processes often at least *seem* to include different distinguishable factors or even phases that allow the representation and,

ultimately, the responses to these stimuli belonging to the world we are exposed to as bodies with agency. Only some aspects or clues of what has been thought as *immaterial* will be albeit revealed under microscopes or through any of the different imaging or surgical techniques available to us, at least not as scientific establishment often expects. Philosophers, artists, social and –increasingly – natural scientists have eagerly strived to understand consciousness, perception and self-awareness, consequently contributing to the development of approximations to do so from different cultural and disciplinary backgrounds.

This introduces us to what is often referred to as the *mind-body problem*, which is a philosophical debate regarding the relationship between mind (i.e. thought, consciousness) and the physical body, or brain (Bunge, 2014). A plethora of theories, paradigms, and propositions have yielded evidence in entire fields of research that find their origin in this antique debate.

Historical background

Accounts of the mind-body debate often part from propositions stemming from classic Greek philosophy, and sometimes present a fairly lineal narrative centred in the technological and scientific advances of Western thought. Only those intending to present comprehensive historical, anthropological and/or conceptual revisions of the topic (perhaps more often in book format) invest more consideration of a greater number of contributions from different cultures and latitudes. As can be summarised thus far, humans *seem* to posses both physical and 'mental' properties. Skin tone, temperature, weight, the molecular composition of a chemical compound, or a brain area activated by some task are at least to some extent measurable by visual inspection assisted (if need be and if available) by proper technological tools and expertise. That is however not the case with desires, dreams, emotions or creativity just to name a few examples. These examples may only be inferred, simulated or conveyed by indirect means that differ greatly from person to person, and so does the understanding of these

means by others. The mind-body debate finds a comfortably fertile position for its' development comprehended within the gap of knowledge that extends between what is observable and measurable and what is not, between what has been defined as physical states and as mental states. That intellectual gap has provided ground to establish the questions that reflect the essential issues and intentions of this debate, mainly: Are mental and physical states distinct? Do they exist? If they do, can one influence the other? When? And in light of the aforementioned: What are self, consciousness, and awareness? Are they related to the body? How? The variety of answers and approaches put forward exert a meaningful influence upon the beliefs and practices of the society that generates them in a specific historical context.

Some ancient views on the questions determining what we understand as a debate grounded upon a *presumed* mind-body dichotomy, do not question the capacity of different systems, agencies or even of *other* dichotomies to closely interact and act upon each other. The Aztec civilisation for example conceived the human body as being able to function when an optimal balance between three different forces, which concentrate in a set of vital organs (head, heart and liver), is given. Furthermore, in their system of beliefs every living thing possesses a *tonacayotl* (lit. *'Spiritual flesh-hood*'), and on that note referred to the body as *tonacayo* (lit. *'the whole of our flesh'*) precisely because they did not conceive the 'biological' body as fragmented or separated from its' spirit, socio-cultural or ecological environments, or as ultimately different to *any* other living organism (López Austin, 1997). As may be inferred, their division of *physical* and *spiritual* illnesses is a blurry one since they considered them to be mutually involved in the manifestation of disease. This allowed them to conceive that personal experiences affect not only *the soul*, but the body as well (Fernández, 2012; Álvarez Heydenreich, 1987) and, of course, in light of the *spiritual flesh-hood* materialised in any and all living beings. It is this context of conceptions and beliefs that allowed the medical practice in this society not to be limited to 'correcting' what the medic diagnosed, but also what the patient expressed regarding his/her pain and suffering. Health disciplines and the substances and

procedures they employed for treatment were dedicated to the *whole* person, that is, taking into account the socio-cultural context. In other words, the body was not conceived as opposing the spirit, the individual or society (Villaseñor Bayardo, *et al.*, 2002).

In other latitudes, the ideas within Western thought that argue that there is a single reality not divisible or representable by a mind-body dichotomy, are grouped under what is termed *monism*. On the other hand *dualism* and, more specifically *substance dualism,* stems from the tenet that none of the realities (i.e. mind and/or body) may be denied and they are not to be incorporated into each other mainly because the mind is a distinct substance that is not subjugated to the laws of physics. Such views –or at least their interpretations by subsequent researchers –have had a very deep impact upon how the field of medical science consequently developed theories and research methodologies, inclusive of accompanying advantages and drawbacks. The field has concentrated its efforts in the understanding and care of the 'material', the physical body and, in doing so, has labelled 'immaterial' factors as mere emergent properties that play no role in the aetiology and/or manifestation of symptoms upon clinical examination and are hence relegated or ignored, a situation which in turn has led to biologically reductionist views that have prevailed in the field (Yaffe, 2016; Demertzi, *et* al., 2009; Balint, 2002). The 'sharp' focus of these views has led to continuous scientific breakthroughs, it has nonetheless been criticised for its' emphasis in the *individual* and in technology, which have led to a biomedical model that discourages focusing on the patient as a whole, inclusive of psychosocial factors (Switankowksy, 2000; Engel, 1977). This comes mainly as a consequence of the model's dominant concern with the anatomical, physiological aspects of the person, and its' strong reliance upon pharmacological treatment as means of healing (Brown, *et al.,* 1994). It discounts the role that mental states may play in facilitating or impeding health by preferring objective signs versus patients' (subjective) reports of the disease (Sullivan, 1986).

Other views stemming from some of the criticisms of current dominant approaches mentioned, have albeit emerged within the Western tradition in the last decades. Empirical evidence accumulated in fields often referred to as *mind-body medicine*, *mind-brain medicine*, and the like, shows many aspects of how negative emotional states such as stress and depression may exert a damaging effect on physical health (Lane & Wager, 2009). This serves as ground for the increasing interest in researching techniques of relaxation, meditation, or 'mindfulness' (Shapiro & Carlson, 2017; Kabat-Zinn, 1995). Some of their applications have proved effective or beneficial in a number of situations of a clinical nature within health care. For example, a systematic review and meta-analysis of randomised controlled trials of mindfulness-based interventions for patients with vascular disease (Abbott, *et al*., 2014) which recruited participants suffering from different conditions (e.g. hypertension, diabetes, heart disease, and stroke) for the trials, showed a decrease in stress ($p = .01$), depression ($p = .003$) and anxiety ($p < .001$). However, results of the effect on physical outcomes (e.g. blood pressure, stress hormones) were mixed and no conclusions could be drawn. Another recent work which investigated whether a mindfulness-based pilot intervention for cancer patients and their carers (26 dyads; mean age: patients, 53.5 ± 10.4; carers, 51.5 ± 14.6 years) improves psychological and physical health, quality of life, and levels of metabolic markers of stress (cortisol and IL-6) (Lengacher, *et al*., 2012). It was found that after a 6 weeks programme stress and anxiety levels were improved ($p < .05$), and so was quality of life (the latter not significantly, though); additionally levels of cortisol and salivary IL-6 were overall lower during the 6th week. Another line of research into what was coined as *psychoimmunology* (Solomon & Moos, 1964) has proven to be a key for the understanding of how mental states may influence the body and vice-versa. A large amount of literature yielding important findings that have contributed to the research and practise of health disciplines has been produced on the topic since its' popularisation. For instance, evidence has been provided showing correspondence between psychological processes and inflammation in reviews and meta-analyses (Marsland, *et al.*, 2017; Bauer & Irwin, 2016; Steptoe,

et al., 2007). Moreover there is at least modest evidence showing that interventions of a psychological nature may modulate certain facets of immune responses (Miller & Cohen, 2001).

The studies mentioned above use empirical approaches and point to the direction of taking into account psychological and social factors as well, which have been long considered by many as capital for the comprehension of manifestations of illness and health (Eisenberger, 2013). A comprehensive analysis of the multiple ways in which the epistemological and philosophical approaches to the so-called 'mind-body debate' characterise current medical and mental health practises and research lies beyond the reach of this work. It is of interest however to delve into the specific implications for stroke and disorders of self-awareness.

Stroke and self-awareness in context

Stroke and conditions causing degrees of brain damage provide unique windows into the mind and the body. The measurable and localised nature of strokes provides optimal ground for understanding tangible aspects of the body in light of changes presented in the mind, and vice versa. Inquiry into the causes and effects of such disorders lead us towards a crossroads of philosophical and epistemological issues; each position taken derives in particular methodological or technical approaches preferred by different researchers. The consequences of stroke are moreover highly heterogeneous and they include both 'physical' (e.g. movement disorders) and 'mental' (e.g. changes in cognition, perception, emotion) effects. These issues deem brain damage as optimal to analyse not only what lies at the extremes of the supposed mind-body dichotomy, but also in between.

The importance of studying stroke is not limited to philosophical or research purposes. World organisations and governments have categorised it as a leading cause of death and disability and warn about an increase incidence in our ageing

societies (WHO; 2012). For instance, according to the UK Stroke Association (2018), there are over 100,000 yearly strokes in the UK –which is equivalent to a stroke every five minutes. Strokes are moreover the fourth leading cause of death in England and Wales, and the third in Scotland and Northern Ireland. There are 1.2 million stroke survivors: about two thirds leave hospital with some type of disability, and a third experience depression. It is furthermore calculated that stroke costs £26 billion a year. This brings this particular ailment to the forefront of the attention of academics, scientists, clinicians of different fields and disciplines, as well as the wider public.

The striking outcomes of a stroke may have extensive implications in the patient and the system at many levels and optimal recovery requires a variety of strategies that go from the immediate, medical treatment to those that may be developed over less immediate periods of time. There are several cognitive, mental and psychological consequences that are characterised as 'immaterial' nature (i.e. mental, social, subjective), and are consequently relegated to other professionals specialising in psychosocial factors. In other words, the emphasis of rehabilitation has been traditionally placed mainly on the normalisation or containment of the physiological effects and the physical outcomes with less regard to psychological and social factors. These latter factors are also important in subsequent phases of rehabilitation that often take place back home, where clinicians or researchers are not present. This significantly decreased contact with professionals makes it even more unlikely to get attention for psychological and social factors during recovery (Teasell, *et al.*, 2002; Burton, 2000). It is hence not surprising that it has been asserted that currently *"no rigorous evidence-based study can ignore psychosocial variables"* (Gupta & Upshur, 2012).

Beyond approaches used towards the treatment of stroke, victims perceive gains from rehabilitation programmes whilst finding challenging limitations in their recovery. Some of these challenges (such as the care provided in home post-discharge from hospital as mentioned above) develop out of the reach of professionals and are henceforth excluded from clinical or academic scrutiny.

There is however a set of challenges or experiences by patients that may be overlooked within the primary care context as well, in the presence of professionals. Overlooking symptoms may in turn lead to a lack of detection of neurological syndromes. It may thus happen that an under-diagnosed patient progresses to subsequent phases of care terminating in discharge once an acceptable degree of biological homeostasis is re-established. The subtlety of the manifestations (such as changes in components of senso-perception and self-awareness) of some syndromes are often not to be found upon overt examination. Specific tasks or questionnaires are henceforth needed to address elements such as degrees of change in components of senso-perception and self-awareness. Additionally, impairments remaining from symptoms in the acute phase of stroke may persist after discharge and become residual, posing challenges to the patient, family and health care staff.

Anosognosia for Hemiplegia (AHP), namely the lack of knowledge or awareness of left hand hemiplegia (Babinski, 1914), involves impairment in self-awareness following strokes in the right hemisphere of the brain and produces the type of manifestations that are difficult to find upon overt examination. The complexity of the possible aetiologies and the overall presentation of the syndrome, make it a good parting point to revise and question what we know about the mind and the body, and how does unawareness impact stroke patients.

The following section will introduce some issues on the background, taxonomy, incidence, and presentation of AHP. Some associated disorders like Disturbed Sense of Ownership (DSO), whereby patients disown the limb affected by hemiplegia shall also be considered as the phenomenon often presents itself in addition to AHP and after right hemispheric strokes. AHP and DSO are optimal examples of the type of phenomena that may remain unattended in the currently dominant biomedical and health care models and that may best illustrate all aspects of the clinical, theoretical, empirical and philosophical implications of the approaches taken to answer the questions posed by the ‘mind-body debate’.

Anosognosia for Hemiplegia

A stroke brings about a set of developments in the patient that commonly evolve into an array of sensory, cognitive, emotional and body awareness disturbances. The vascular event does not only implicate localised damage of cells in the brain, it creates a 'glitch' (sic.) in the multilevel networking systems of information processing in the patient (Laidler, 2000) and the effects are greatly influenced by its' type (e.g. ischaemia, haemorrhage), size, and location (i.e. structures and networks compromised) (see review by Azouvi and Peskine, 2007). The effects may include difficulties in motor awareness, as illustrated over the last century by patients that are customarily convinced that their limb can be moved properly despite paralysis and deny having any weakness (Cutting, 1978; Karnath and Baier, 2010). It was since the end of the 19th century that a symptom of 'nonrealisation of disease' (sic.) – consisting in a patient's denial of visual impairment (i.e. cortical blindness) –was described (von Monakow, 1885). It was not until the works of J. Babinski that the topic attracted more significant interest from the scientific community. He was studying two cases of left cerebral hemiplegia following a vascular event when he coined the term 'anosognosia' (1914), a novel concept in the history of neurology conformed by the Latin prefix 'a' (absence), and the Greek words νόσος ('nosos'=disease) and γνῶσις ('gnosis'=knowledge) in order to refer to a general lack or absence of knowledge in the patient regarding his/her impairment.

False claims are central features presented by patients with AHP after stroke (as reviewed by McKay and Kinsbourne, 2010), which are customarily convinced that their paralysed limb can be moved properly and deny having any weakness (Cutting J, 1978; Baier and Karnath, 2010). These persist even after contrary evidence presented by caregivers and doctors point to a clearly visible impairment. Nonetheless, anosognosia shows multivaried degrees of pathogenic causes that go from uncritical underestimation of deficit to complete denial (Azouvi & Peskine, 2013; Orfei, *et al.*, 2010). Moreover, AHP cannot be

approached as a fixed set of deficits; it rather arises from combining impairments that display varied severity across stroke patients (Vuilleumier, 2004). 'Anosodiaphoria', for example, is a failure to 'fully appreciate' and emotionally respond to the relevance of a deficit (Babinski, 1914), and its implications for everyday life (Mendoza, 2011).

Literature reveals that anosognosia ensues significantly more often after right than left hemisphere stroke (Cocchini, *et al*., 2009). For instance, a meta-analysis of all published studies on the topic between 1930 and 2001 found that only 9.2% of the total stroke patients showed it after left hemisphere stroke, whilst 54.1% of the sample presented it after right lateralised lesions (Pia, *et al.*, 2004). Furthermore, researchers have recommended assessing symptoms of self-awareness in patients after right-hemispheric stroke due to their clinical relevance (Noe, *et al*., 2005) and to commence appropriate rehabilitative treatment (Vossel, *et al.,* 2013). Untreated unawareness after stroke predicts negative prognosis (Orfei, *et al.*, 2007), lack of treatment compliance (Patel & Prince, 2001), greater probability of exposure to dangerous behaviours (Starkstein, *et al.*, 2007), negative influence on rehabilitation outcome, increased length of hospitalisation (Gialanella, *et al.,* 2005) and less likelihood of returning to independent living (Pedersen, *et al.*, 1996).

Vocat, *et al.* (2010) argue the importance of viewing AHP as a multi-faceted disorder. They performed a voxel-by-voxel lesion symptom mapping (VLSM) method (Bates, *et al.*, 2003) of 58 right hemisphere stroke patients that examined the different degrees of anosognosia across subjects and its progression throughout post-stroke stages. During the hyper-acute phase the areas that are more commonly damaged were the anterior insula, anterior claustrum and putamen, anterior internal capsule, head of caudate and anterior paraventricular white matter within the right hemisphere. Patients with sustained AHP (after 1 week from onset), showed additional regions in the right hemisphere that were selectively damaged (i.e. premotor cortex, temporo-parietal junction, frontal white matter in anterior internal capsule, hippocampus and amygdala). A dynamic progression of the phenomenon that changes in its clinical and anatomical

presentations over time was revealed. The authors concluded that AHP may reflect a 'multi-component disorder' with underlying distributed lesions in a specific group of brain regions, which can lead to a high comorbidity of deficits in sensation, interoceptive bodily representations, motor programming, among other processes.

The aetiology and pathological presentation of AHP has been researched with great interest in the last 100 years from different disciplinary backgrounds and it is clear that *denial* is considered a central issue for the understanding of the syndrome. However, reviews of the literature on *denial* and similar and related concepts, have found that the terms and notions are often used interchangeably as will be later explained. It could therefore be assumed that the lack of consensus on what is denial broadens the gap of knowledge within which the mind-body debate develops. A deeper revision of the term *denial* will henceforth be offered later in this work.

Critchley (1953) notes that the term *anosognosia* was originally employed to refer specifically to denial of hemiplegia, but it has however been recognised that anosognosia can occur for other motor and language impairments like aphasia (Wernicke, 1874; see review by Kertesz , 2010); psychiatric disorders like schizophrenia (Gerretsen, *et al.*, 2013; see Pia & Tamietto, 2006, for an account) eating disorders (see Vandereycken, 2006 for an analysis); and for a variety of neurodegenerative conditions (see review by Rosen, 2011). Nevertheless, the degree to which unawareness in all these disorders can legitimately be characterised as *anosognosia* or *denial* is still a debated issue. For instance, anosognosia for Alzheimer's disease involves unawareness or denial of a neurodegenerative illness, which is very different in nature to a stroke. Moreover, terms commonly found in literature on anosognosia such as *insight*, *lack of awareness, of knowledge* or *denial* are often employed interchangeably despite taxonomical differences subject to the historical context of specific aims pursued when authors undertook research (Gilleen, *et al.*, 2010).

AHP and the senses of ownership and agency

Current research indicates that there is two basic concepts involved in the successful operation of *intended* movements: a) *sense of ownership,* defined as the experience of the body as belonging to oneself (Ehrsson, 2012); and b) *agency* or *authorship*, a sense of being the source of one's own movements (Synofzik, *et al.*, 2008). Voluntary action and the two aforementioned senses are 'coupled and indistinguishable' in normal, everyday phenomenology (Gallagher, 2005). DSO and related disorders arise when the senses of ownership and/or agency are impaired and reflect manifestations of denial as well.

Kalckert & Ehrsson (2012) introduced an experimental manipulation whereby participants control the movements of the index finger of a human-like, rubber hand, with their own index finger. The timing of the finger movements were varied synchronously and asynchronously; both passive and active modes of movement were probed, and the rubber hand was placed in anatomically congruent, and incongruent positions. It was seen that asynchrony eliminated ownership and agency, whereas passive movements eliminated only agency, and anatomically incongruent positions decreased ownership, but not agency. The authors thus conclude the possibility of double dissociation between ownership and agency, suggesting that distinct cognitive processes underlie each of the senses.

Baier & Karnath (2008) reported in a study that 92% of their AHP patients presented DSO. They performed lesional studies and used questionnaires to assess different conditions. It was found the right posterior insula to be a significantly compromised anatomical area in DSO and AHP patients when compared to other right hemisphere acute stroke subjects that did not show abnormal attitudes regarding the paralysed limb. These findings account for part of the similarities that entail both phenomena at their pathophysiological and clinical levels. AHP and DSO are thus different phenomena, which share underlying mechanisms and often (but not always) present in conjunction. Each of them may show different ways in which denial operates and manifests in

patients.

The questions that interest us are: how do mechanisms such as denial or disavowal of illness operate in AHP? How is denial reflected in the observable clinical symptoms that a patient shows if at all? What is the difference, for example, between denial in AHP, in other illnesses, and in everyday life? Can the mechanism be called the same in all cases?

It is of interest for the present thesis to take into account the array of ways in which denial may function. The fast pace in progress in the field of cognitive neuroscience is accompanied by an attribution of multiple meanings to concepts commonly used in literature. It is a widely discussed term in research and clinical practice and the nomenclature has evolved 'to suit clinical experiences' (sic.) (Salander & Windhal; 1999). The multiple attribution may not only cause divergences in clinical conclusions, but also inconsistencies in research results (Lazarus, 1983). It is henceforth necessary to address these inconsistencies in the understanding of denial in order to have a common basis to discuss it.

Future directions in the study of denial and unawareness following stroke thus promise to contribute to an improved care of stroke patients, and to a better understanding of how the mechanism of denial operates in daily life, in health and illness. The following chapter will discuss the aims, objectives, epistemological approaches, and methods for the present investigation on denial in AHP.

CHAPTER 2
Goals, Methodology and Epistemology

Goals of this work

The main goal of this project is to establish *denial* as a common and central concept of interest for research on AHP and for psychoanalytic theory. Many could associate inquiry into *denial* as related to fields such as philosophy, psychology or psychoanalysis. The mechanism is nevertheless clearly present in AHP and DSO, and have thus been analysed from neuroscientific research as well, as will be reviewed with more detail in the next chapter.

This work also aims at opening a debate for potential epistemological and methodological contributions of neuropsychology and psychodynamic theory to the understanding of denial in AHP. For the purposes of this work, it is considered that both fields can contribute to current comprehensive models of the mind, the body and the world. It is of interest to critically explore ways in which differing views may complement each other in light of evidences and observations stemming from both traditions.

Discussions and their implications within each field will be explored separately to be later included in a debate. The debate will use a psychoanalytic model of denial that has been previously proposed in literature. This model takes into account sensory, perceptual, and cognitive aspects, and could therefore potentially contribute to the development of research and treatment of syndromes of unawareness following stroke such as AHP or DSO.

This work also aims at providing viable examples of how the proposed epistemological and methodological framework could impact research and clinical management of AHP positively. A focus in the roles that motivation, affect, cognition, and subjectivity play in the manifestation of denial in AHP will be in place as means of support for the notion that these are important elements to consider when studying and/or treating syndromes like AHP.

Epistemological framework for this study

For the purposes of this study, the orienting epistemological approaches will be those from (standardised) neuropsychology, aspects of psychodynamic theories, and aspects of embodied phenomenology which, if applied in an informed manner and grounded in evidence on the overall design of the project may allow a comprehensive account of denial in AHP from a multi-disciplinary perspective.

As reviewed so far, throughout history the mind-body problem has been at the centre of numerous inquiries by philosophers and scientists in the search of an explanation of how are mental (i.e. immaterial) and physical processes (i.e. material) related in human beings. The approach to this question in Western thought has been dominated by René Descartes' dualism, which sustains that specialised organs detect sensory stimuli and transmit them to the *epiphysis cerebri* and from that point are passed to the immaterial realm. The key contributions of these views are based upon 2 principles: 1) Intellect is the only viable mean towards understanding, and 2) Reason and emotion are dissociated and are not to be reconciled (Rendón, 2000). It is claimed that this eventually led to the current crisis in the biomedical model (Mehta, 2011). Another argument proposes that the current crisis in the biomedical model is not a product of *dualism* as it is claimed, but rather of physicalism and reductionism (Joubert, 2014). There is currently however significant consensus around the notion that emotions may impair rationality (Damasio, 2006) precisely because they are not separable from our bodies.

Methodological background

There is a significant lack of understanding of cognitive functions when compared to other types of functions that fall into the category of 'the tangible', which have been privileged as already discussed. In light of this, some recent neuroscientific methods have integrated into their research a host of statistical, technological,

and clinical practices, which have all together led to key discoveries in the field. One characteristic that has emboldened some of such methods beyond their reliance upon trans-disciplinary cooperation and understanding is the readiness to engage aspects of the traditional 'sciences of the mind' with aspects of the traditional sciences of the brain and/or the body.

The case with AHP the trajectory of research on the topics includes the different lines within the philosophical debate of the mind and the body and its' implications for clinical practice. Researchers on these topics have used a plethora of physiological, neuroimaging, senso-perceptual, cognitive, and technologically-assisted techniques; yet there are more instances than not when these syndromes pose additional methodological and clinical challenges due to their complexity, which lies mainly in the heterogeneity of the symptomatic presentation, the multi-level pathological mechanism of the disease, and their neurological nature. These elements create a highly restricted framework in which not any single approach can account for the syndromes comprehensively and overwhelmed by technical difficulties, such as the recruitment and assessment of patients which are directly subjugated to these epidemiologically rare disorders (in developed countries) and the highly dynamic and rapidly-changing situations during acute and post-acute stroke care.

Generation of theories or hypotheses under circumstances restricted in such a manner is no easy task and it is therefore considered for the purposes of this study that only an effectively multi-disciplinary approach may lead to a comprehensive understanding of the phenomena with the ultimate goal of designing appropriate techniques of treatment to promote long-term recovery not only of physical function, but of the function of 'the body as a whole'. By *effectively* in the above line it is meant that interdisciplinary cooperation does not limit itself in the coordination of professionals who are experts in their own compartmentalised field, it involves engaging with the literatures and experience of other disciplines to inform and update knowledge of our own to a sufficient extent that triggers intellectual openness and flexibility that may in turn allow to expand previously assimilated knowledge further.

As may be observed, the purposes of this study are compatible with the consideration of quantitative and qualitative evidence, of individual and group reports, of pilot and randomised controlled trials, stemming from disciplines that could be compromised within the relevant fields of study. Overall, this work parts from the premise that our bodies are an inherent part of that internal and external world that is right here for us to experience and are not a separate reality that exists only metaphorically or in academic debate. The body is not a simple all-inclusive, automatic package that counts with everything we need (from sensory receptors to the biological and physiological processes that make our very existence feasible) to be able to bring into the world actions or behaviours that are deemed as convenient by oneself or others or that are congruent with specific situations or combinations of factors. All facets of these functioning are not divisible from the organism and its' perception, interpretation, articulation and reaction to both internal and external stimuli and do not operate in a straightforward fashion lacking of complexity. Our subjectivity, motivation and the social and cultural environments we are exposed to, function as constant intermediaries in these processes and contribute to the determination and manifestation of physical and behavioural outcomes and in processes of decision-making.

Methodology for the present work

Firstly, a review of theories, evidences and approaches to *denial* in AHP will be presented. The third chapter of this work will review neuropsychological approximations, whilst the fourth chapter will focus on the psychodynamic understanding of *denial* and further debates and issues arising from AHP particularly. As per the scope of this project, the approaches to *denial* in AHP to which increased attention will be allocated are:

i) The influence of motivation and affect on cognition and denial;

ii) Relational and social, cognitive aspects of denial;
iii) Qualitative aspects and the subjective experience of denial.

Topics on the following categories will be considered when developing the revision of literature in each of the fields:

i) Debates within the field;
ii) Terminology employed, implications;
iii) Research approaches (neuropsychology) / theories and hypotheses;
iv) Clinical issues (understanding of the patient, diagnosis, treatment).

In the third chapter, issues on neuropsychology that could potentially be informed or expanded from a psychodynamic perspective will be later included in the fifth chapter: a debate between neuroscientific and psychoanalytic perspectives on denial in AHP. Points, in which neuropsychological methods or evidence may assist in the enhancement or specialisation of psychodynamic theories or techniques in the fourth chapter, will be addressed as they emerge and be considered more carefully in the fifth chapter.
The aim is to assess whether arguments can be grounded in empirical or clinical observations available from the disciplines that are being considered, or whether there is potential to develop research on the respective line. This will allow a delimitation of *denial* that can be approached with the cognitive arrest hypothesis (Dorpat, 1983), and to clarify whether that model applies in AHP, and to potentially contribute to the understanding of the syndrome as a whole.
The overall argumentation in this thesis will follow some basic principles of Grounded Theory will be employed according to the needs of the study:

Concept of categories - It is customary in Grounded Theory to build categories according to different degrees of abstraction as they are generated or as they emerge from data. However, the categories of information that will be emphasised in the literature reviews have been defined *a priori* given the nature

of the study. It is of capital importance to cover issues on terminology, debates within the field, and clinical understanding of the syndrome (i.e. The influence of motivation and affect on cognition and denial; relational and social, cognitive aspects of denial; and qualitative aspects and the subjective experience of denial).

Constant comparative analysis – Arguments from both fields on the same line will be constantly compared in order to identify common features that unite instances of the syndromes studied.

Negative case analysis – Instances in which what is proposed does not apply shall also be considered.

Theoretical sensitivity – In order to increase levels of abstraction, further questions around the information being treated will be constantly considered. This allows to generate and adapt judgements accordingly.

It is however important to note that the nature of this work demands increased alertness of emerging views that may alter the trajectory of the argument or theory being developed, as previously advised (Glaser & Strauss, 1967).
Views characteristic of the phenomenology of perception and the body will be used as a tool to facilitate a theoretical framework for the emerging concepts. This framework allows neuropsychological and psychodynamic central concerns to remain essentially not contradicted, but rather considered as part of a whole, mainly: the patient and his/her experience of stroke and *denial* concomitant to neurological damage.

As a way to further illustrate the applicability of the arguments presented in this work, two feasible research design and experimental protocols will be presented. The goal is to exemplify further potential contributions that the approaches

employed in this study may have in the conceptualisation of *denial* in AHP and ways in which they may be applied in research and clinical reality.

The experiments will approach the affective neuroscience, self-other/social cognition, and subjectivity of denial in AHP in the context of the epistemological/methodological approaches considered for the purposes hereby presented. This will in turn yield clear conclusions, future directions and a deeper understanding of limitations in this and similar research to be accounted for in the fifth chapter of this thesis.

CHAPTER 3
Neuroscientific Perspectives of Denial in Anosognosia for Hemiplegia

Introduction

More than 100 years have passed since AHP was first conceived as a diagnosable neurological syndrome, opening the door to what would become an extensive field of inquiry within the sciences. Once there was a basic operationalisation, research on the aetiology of AHP can be characterised by arguments that cannot account for a unitary or generalisable explanation of the syndrome as often intended. With time, hypotheses aiming at approaching the syndrome in more comprehensive terms have been proposed. Over a century of research into the nature of denial concomitant to right hemispheric damage has yielded a vast array of hypotheses and theories, all of which have employed a plethora of methodological approaches in their quest for understanding. Each of these approaches reflects the broader state of science and research, including the technological means available throughout the decades.

This chapter will offer an overview of some of the major explanations of AHP proposed until very recently, and of their context within broader approaches in the fields of neuroscience. Different types or categories of hypotheses, evidence found in their support, and debates around them will be reviewed, for instance: the neuronal disconnection hypothesis, feed-forward models of motor control, psychogenic theories, sensory deafferentation, and multi-component approaches grounded on neuroanatomical findings. Person-perspective paradigms and Bayesian inference formulations will be used as examples of developments based on notions of a multi-factorial aetiology of AHP. Additionally, emphasis will be placed on developments surrounding the motivational and affective aspects of the syndrome, beyond the previous psychogenic propositions and in light of

relevant evidence. Future directions will also be explored by taking into account the neglected role of subjectivity and other qualitative factors in AHP.

Hemispheric connectivity

Meynert's pioneering studies on white matter anatomy established since the 19th century three categories of fiber pathways connecting different parts of the brain: i) Projection fibers connecting the cortex with lower parts of the brain and the spinal cord; ii) association fibers, connecting regions within the cortex of each hemispheres; and iii) commissural fibers (conforming the corpus callosum) that connect both hemispheres (Catani, M.; 2005).

Disconnection hypotheses of neurological syndromes started to emerge when it was observed that some of the disorders ensue as a consequence of impaired communication between areas of the brain. For instance, the belief that lesions in the corpus callosum may cause mental symptoms, allowed developing the notion that the right and left hemispheres work in a unified manner (Finger, 1999). The term 'disconnection' was popularised since Wernicke (1874) coined it to explain conduction aphasia; the term is generally used to refer to those syndromes generated by compromised white matter connections that produce dysfunction of higher cognitive processes (Mesulam, 2005). Bykov was the first to study operated callosal connections in dogs in an attempt to control for concomitant conditions, which is a hard enterprise with human subjects. All previous clinical cases had been reported as presenting additional conditions, and the analysis of the role of this specific anatomical structure was very hard to do in isolation. He observed that as opposed to control dogs that could be conditioned to salivate by stimulating equivalent bilateral locations of their bodies, operated dogs could not be so (Finger, 1999; Bykov, 1924). Furthermore, one of the equivalent parts to be stimulated could be conditioned to respond differently.

It was however until the influential works of Geschwind that research on neuronal connections could move from studying hand dissections or operated specimens, to physiological and neuronographic investigations with humans and animals

(Geschwind, 1970). In AHP, he hypothesised that lesions in hemispheric connections might result in agnosic disturbances (Geschwind, 1965), and that these need not be located in the corpus callosum itself. The lesion(s) may be located within the right hemisphere only, compromising normal intra-hemispheric functioning. The author argues that impaired intra-hemispheric processing could result in the transmission of hindered information to the left hemisphere via the corpus callosum. Verbal functions in the unaffected (by stroke) left hemisphere may then compensate for the lack of access to the information processed by the right hemisphere. This lack of access gives rise to 'fabricated responses' (sic.). According to this view, it could be assumed that in AHP the left hemisphere may not be updated with input from the right hemisphere, in a way that verbal acknowledgement of weakness in the left arm becomes difficult.

A later inquiry into AHP however showed that, even if the right hemisphere was anaesthetised (as a model for sequelae of right hemispheric brain lesions), 5 out of 15 patients reported awareness of left hand paresis when experimenters simply moved the left hand to the right visual hemifield (Adair, *et al.*, 1997). This allows the left hemisphere to perceive the information directly, and demonstrates that at least in some cases the supposed hemispheric disconnection is bypassed, deeming this hypothesis of denial in AHP non-generalisable. It is important to note, though, that the validity of AHP models that involve its simulation or inducement remains debatable, as there is uncertainty pertaining the extent to which the different techniques can actually reflect AHP.

'Feed-forward' models and motor control

These models propose the existence of *comparators* and *predictors*, which exist at different points in the neurocognitive system and regulate the processes of movement generation, monitoring for errors, and updating senso-perceptual information as means for correction.

The basic assumption of these models is that the brain has access to information regarding the result of motor commands originating in the central nervous

system. In other words, the models maintain that AHP originates from impairment in anticipatory awareness (Berti, *et al.*; 2005).

The *comparators* approximate the difference between the motor command and the current state with the aim of reaching the desired state (e.g. successful completion of movement). On the other hand, *predictors* estimate the expected sensory events involved in the movement by means of an *efference copy* (i.e. motor predictions) of the end-result of the motor command (Frith, *et al.*, 2000). Awareness should thus be ideally updated assisted by a comparator that detects errors (i.e. mismatch between the intended and the actual states) and sets the basis for the correction of those errors.

Heilman *et al.* (1991) proposed the intentional model, whereby a deficit in the intentional system does not allow an expectation of movement to be created. The authors emphasise the role of the intention to move and the mechanisms employed for creating and matching (or not) the expectation and the actual motor outcome. They tested an AHP patient and a hemiplegia-only control group to find out whether they are able to generate movement of the arm intentionally. This was done using an electromyogram to measure stimulation of the pectoralis muscles of both sides of the body whilst pressing a dynamometer 'as hard as they could' (sic.) in separate trials with each hand (Gold, Adair*, et al.*, 1994). It was found that hemiplegia-only patients presented stimulation of the muscles in both sides. However, in the AHP patient this stimulation was present only when pressing with the right hand. When pressing with the left arm, this patient showed no stimulation of the muscles on either side. The authors conclude from this evidence that the AHP patient's intention to move the left arm was compromised.

However, evidence that this hypothesis does not apply to all AHP patients has been found. For instance, a study showed that when hemiplegic-only, AHP, right hemispheric brain-damaged patients with motor neglect, and healthy subjects are asked to simultaneously trace lines (with the unaffected limb) and circles (with the paretic), only healthy subjects and AHP patients present what is called a *bimanual coupling effect* (Garbarini, *et al.,* 2012). This means that one of the

programmes performed by one of the hands can influence the performance of the other hand. In the case of this experiment, the trajectory of the movements performed by the unaffected hand are influenced by the request of the paretic limb to draw circles, in a way that the previous tends to acquire an oval trajectory. This research shows that some AHP patients without motor neglect may have intact motor intentionality, putting into question how generalisable the 'feed-forward' theory is. Additionally, the reason why patients assert to have moved their plegic limb despite contradictory evidence remains unclear.

Frith, *et al.* (2000) thereby proposed that denial of a motor impairment in AHP is caused by a failure to grasp a mismatch between the predicted state and the actual sensory consequences of the action, and to use the incongruences to update the operations of the predictors. As previously mentioned, this model involves *comparators* and *predictors* at different levels of the neurocognitive system that regulate motor control, that is: movement, error, and correction.

Additionally, a lesion analysis study later proposed that AHP involves direct damage of areas associated to the function of comparators that normally identify mismatch between actual and intended states (i.e. insula and Broadmann's pre-motor areas 44 and 6), whilst motor planning areas remain intact (Berti, *et al.*, 2005; 2006). The conclusions of this lesion analysis provide grounds to understand a case of reinstated unawareness in AHP, following the patient's view of a video replay of her actions (Fotopoulou, *et al.*, 2009). As the patient received visual feedback of their hemiplegia and was not attempting movement, it is possible that no forward signals were affecting the awareness of the patient (Fotopoulou, *et al.*, 2009; 2008)

Other studies point to the relevance of the motor control models mentioned in this section. Evidence stemming from the ability of a chronic AHP patient to detect and correct movement errors using the non-paralysed hand, as assessed using a movement agency task (Preston, Jenkinson, *et al.*, 2010). The patient was instructed to reach a target after disappearing from a screen, and given visual feedback on a cursor representing either his actual reaching movement, or

the reaching movement but with some angular perturbation. A subsequent verbal report stated whether the movements shown in the cursor represented the actual movement, or whether the computer had modified it. He was additionally asked if he had to correct any of the movements in order to reach the targets. The patient reported 100% reach accuracy and having had no need to correct movements. There were nonetheless important inaccuracies and corrective movements of which the patient was unaware. These corrective movements were capable of some degree of compensation of large visual feedback alterations, which according to the authors suggests that the forward model comparators are not dysfunctional but may be rather allowing a more permissive leeway in the thresholds they operate with. Moreover, the authors found that a deficit in awareness of the performance of the healthy limb was also present, suggesting that both hands may share common right hemispheric networks of awareness of movement, in which case AHP would likely be a global impairment in motor awareness, rather than a specific lack of it for a particular motor deficit or for a particular comparator. In other words: AHP might not be a lack of awareness of paralysis in itself, it may rather be a global unawareness phenomenon that blocks the patient from comprehending whether the arm is plegic or not.

The precise function and number of comparators and their supporting brain mechanisms remain a matter of debate (Berti & Pia, 2006). Evidence put forward has not yet been able to account for the heterogeneity in the presentation of the syndrome and how these comparators operate anatomically and between patients. Moreover, these models fail to explain cases whereby AHP emerges following damage to regions *not* associated with motor functions (Fotopoulou, ***et al***., 2010), and to account for the reason why patients do not report or complain about their hemiplegia.

Sensory deafferentation

Sensory deafferentation in AHP is understood as loss of sensory input in a portion of the body due to damage to sensory cortices of the brain. According to

the hypotheses of AHP developed in this context, the stroke damages the system and leads to the impairmet of senso-perceptual processes that normally inform the person about the status of limbs. A combination of sensory and perceptual impairments, together with cognitive or 'intellectual' defects, may thus derive in the failure to 'discover' paralysis (Levine, 1990). Groups of participants with persistent AHP and with little or no anosognosia were recruited to compare cognitive skills, sensorimotor defects, attitudes towards illness and the nature of their right hemispheric lesions (Levine, *et al*., 1991). Patients with persistent AHP showed more severe sensory deficits and cognitive impairment, whilst the non-AHP group showed wider ranges of severity and less impairment in an array of areas tested (e.g. memory, verbal reasoning, visuo-spatial problem solving). Mood and affect were also much more altered and lesions resulting from the stroke were larger in the persistent AHP group.

The authors stress the role that sensory feedback has in the denial of left hand hemiplegia, and to some extent fulfils Babinski's (1914) expectation that *"if anosognosia is real, the sensory disorders very likely play an important role in its pathogenesis"*. Their evidence however leads them to acknowledge that it is not impaired sensory feedback alone that generates AHP. The persistent AHP group presented with impairment in the range of memory and intellect tests when compared with patients with less persistent AHP, leading to the conclusion that mental, cognitive, and intellectual defects diminish capabilities needed by AHP patients to 'discover' that the arm is paralysed. Interestingly, and perhaps contradictorily, the authors report that even persistent AHP patients may present several aspects of mental function quite normally (e.g. orientation in place and time, appropriate conversation, recognition of staff members). This still leaves the question of what degrees of impairment in mental function are needed in individual cases to generate AHP, and how essential are they in the overall presentation of the syndrome versus sensory feedback, as even in persistent cases important aspects of it remain unimpaired.

Additionally, double dissociations between AHP and tactile-proprioceptive impairments have been reported, which means that AHP patients who have no

sensory deficit but deny hemiplegia do exist, along with patients who present the opposite manifestation of symptoms (Spinazzola, *et al*., 2008). This leads to the conclusion that somatosensory information is not enough or essential for coherent motor performance (Berti & Pia, 2006), and supports the premise that awareness of movement precedes sensory feedback (Libet, *et al.,* 1983).

Neuroanatomical findings: AHP as a multi-component disorder

The difficulty to find theories or hypotheses that account for AHP in generalisable ways can be appreciated from what has been so far revised (see Adair, *et al.,* 1997; Heilman & Harciarek, 2010; Berti, *et al*., 1996). The variable and heterogeneous nature of AHP has been recognised, and more comprehensive accounts of the syndrome are ever more needed. As methodologies and technology have progressed, important findings in the neuroanatomical substrates of AHP have provided valuable information in the understanding of the nature of syndrome.

Vocat, *et al.* (2010) argue the importance of viewing AHP as a multi-faceted disorder. In a novel approach, the researchers performed an overlap lesion analysis of 58 right hemisphere stroke patients that examined the different degrees of anosognosia across subjects, and its progression throughout certain post-stroke stages. Each case was achieved by using the voxel-by-voxel lesion symptom mapping (VLSM) method (Bates, *et al.*, 2003) designed to look for the relationship between tissue damage and behaviour. During the hyper-acute phase the areas that are more commonly damaged were ‘the anterior insula, anterior claustrum and putamen, anterior internal capsule, head of caudate and anterior paraventricular white matter within the right hemisphere’. Patients with sustained AHP (after 1 week from onset), showed additional regions in the right hemisphere that were selectively damaged (i.e. premotor cortex, temporo-parietal junction, frontal white matter in anterior internal capsule, hippocampus and amygdala). A dynamic progression of the phenomenon that changes in its

clinical and anatomical presentations over time was revealed. They suggested that AHP may reflect a 'multi-component disorder' with underlying distributed lesions in a specific group of brain regions, which can lead to a high comorbidity of deficits in sensation, interoceptive bodily representations, motor programming, among other processes. For the purposes of this work, it is henceforth reasonable to think of AHP as a multi-faceted phenomenon that cannot be completely accounted for by a single set of hypotheses or approaches, that is dynamic in nature in terms of how an array of components interplay differentially across patients in its manifestation.

Social cognition: The self and the other

There is another line of research being developed under the notion that complex dynamics between different elements such as motivation, cognition, and physiology are implicated in producing the heterogeneous set of manifestations characteristic to AHP. This line introduces the role of perspective taking in the emergence of denial in AHP patients. The study of the role of perspective-taking has shed light upon the importance of a *social* or *otherness* factor in the disorder, namely: What do others see? This question has not been sufficiently explored in AHP, yet demonstrate a compelling relevance for the understanding and ultimate treatment of the syndrome.

For instance, Ramachandran's (1996) case studies documented that when it comes to recognising an equivalent deficit in another person, 2 out of 3 AHP patients did not succeed in doing so, leading him to conclude that a person needs to access representations of his or her own body when judging other people's body parts.

The effects of prompting the patient to observe their deficit (left-hand paralysis) from 'view-points' other than 1st –person perspective (e.g. in another person and 3rd –person perspectives), have been investigated and add to the already complex picture of AHP as a multi-component syndrome. Prompting the patient

to view the deficit 'from the outside' (as a 3rd person would view it) has been previously studied. Marcel, *et al.* (2004) recruited 64 hemiplegic, post-stroke patients into two clinical and one control groups: Left brain damage and right brain damage; and a control group of 24 healthy subjects. Participants were assessed for awareness of different capacities, cognitive and motor functions, and estimation and evaluation of abilities from 1st and 3rd-person perspectives. 23% of the sample presented AHP. For the right brain damage group, awareness of hemiplegia seems to highly depend on the way in which the subjects are asked about their deficit (e.g dichotomic questions, open questions, asking what doctors or nurses see, etc.). Moreover, these patients overestimated current abilities when asked to rate from a 1st person-perspective (in themselves). The authors state that 3rd person-perspective tasks, rather than 1st person-perspective, may increase motor awareness in some AHP patients. This has been supported by later investigations on AHP (Fotopoulou, *et al.;* 2009; 2011) and on limb ownership in somatoparaphrenia, whereby patients are unable to recognise the affected limb as belonging to him/herself (Jenkinson, *et al.*; 2011).

In another study, Moro, *et al.* (2011) asked AHP patients to report how capable they are to perform a series of actions (i.e. cutting meat, hammering a nail) and, after a short interval, answer the same questions, but referring to the performance of another hemiplegic patient that was seated in front of them. The results revealed that seven patients were anosognosic for both self and other-referred conditions, whilst four others showed lack of awareness only in the self-referred interview. These reports were made in a moment-to-moment, live cognitive process (i.e. online cognition). This means the patient directly observes the live performance of another person. Online cognition is important as it is in a moment-to-moment performance where the successful monitoring of an error and its' corrections should occur (Robertson, 2010). Online detection of errors (as they happen) for clinical and experimental purposes, as in the studies mentioned above, has been manipulated in research on brain-injured patients mainly by interviews, explicit reports and by using mirrors (Michielsen, *et al*., 2011; see Thieme, *et al*., 2012 for an example of effectiveness for severe post-

stroke arm paresis; and Tyson, *et al.*, 2015 for neglect). For instance, it was found that unawareness of ownership of the hemiplegic limb remits during direct view in the mirror (online) and is reinstated when direct view is no longer allowed (Fotopoulou, *et al.*, 2011). In opposition, AHP was seen to fully and permanently remit in a case after self-observation of paralysis in an offline, third person perspective video replay (Fotopoulou, *et al.,* 2009). Showing evidence of some behaviour *after* it happened with pictures or video-replays is a way to prompt offline cognitive processes.

Recent case studies have provided preliminary data supporting the use of offline, video replays to increase motor awareness in AHP patients. For instance, Besharati, *et al.* (2016) investigated their use with two AHP patients. An acute patient went through multiple sessions of video-based self-observation (self-reference) of his/her performance in the Berti, *et al.* (1996) interview, which includes instructions to move the paralysed hand, among other questions to measure awareness. The same questionnaire and video procedures were used for a second, chronic stage post-stroke onset AHP patient. In this case, the intervention was based upon a single session in which, in addition to the self-referent video, the experimenter showed an equivalent video of the performance in the same interview of another age and gender-matched, hemiplegic patient without anosognosia (other-reference). Both patients showed increases in self-awareness immediately after the re-plays, even if the changes did not persist into complete recovery. The authors conclude that video-replay seems to be what could be called a 'first step' towards rehabilitation of awareness within a more elaborated programme. References to the use of offline observation of a motor deficit from a first-person perspective (that is, an offline view of the patients' own perspective) are nevertheless not to be found in existing literature. A new empirical research proposal shall be put forward in this line for the purposes of the present work. This empirical study intends to assess whether offline view of the motor deficit, from a first-person perspective under self and other-reference conditions, facilitates an increase of self-awareness in an AHP patient.

Bayesian inference, predictive coding and the free energy principle

The heterogeneity of symptoms presented among AHP patients is a good example of the uncertainty inherent to neuronal processing. In everyday phenomenology, if one hears thuds whilst walking in a dark place in the city at night, it may be vital for the organism to decrease that uncertainty by inferring whether the origin of the noise stems from a cat engaging with some bags of garbage, or whether it finds itself in a potentially vulnerable situation. The causes are 'hidden' and we therefore rely on inference.

The brain has been long ago understood by some researchers as an 'inference machine' (Helmholz, 1909), and neuroimaging evidence has for instance shown that sensory cortical areas are influenced by expectations or predictions about a stimulus as much as by a stimulus itself (for a review, see Summerfield & de Lange, 2014). There are bottom-up connections carrying information about a stimulus, as well as connections within and between brain areas that create the context in which the stimulus will be apprehended. The combination of predictive coding and inferential approaches has contributed to the formalisation of the principles regulating the cognitive computation and its' integration with sensory information (Aitchison, *et al*.; 2017).

Predictive coding has its basis in the notion that rather than making a simple, direct cognitive representation of a sensory input, it is the difference (i.e. error) between a sensory input and a prediction of a result (i.e. action, behaviour) that are being mentally represented by the person. It does not however account for how is this process coded cognitively, nor explains how is the 'error' ultimately corrected. The organism needs to furthermore respond to the environment at near-optimal levels of performance in an array of situations to be encountered in everyday life, and it may do so by following rules of probability in order to estimate the 'hidden' variables. The variables are 'hidden' (i.e. random) as sensory input may originate from a wide array of causes, such that there is no way to know which is the precise influence of each and every stimulus in the environment on the system. The nature of predictive coding is therefore

probabilistic and as such, it may be described in *Bayesian* terms (Friston, 2009). Bayesian approaches are based upon the Bayes theorem. The theorem estimates the probability that an event or phenomenon has of happening, based on previous experience or knowledge (i.e. subjective belief). That estimation process is called *Bayesian inference.* The Bayesian theorem and inference may provide satisfying accounts of how predictions of errors and of the environment are computed by cognition. However, Bayesian approaches do not specify underlying neuroanatomical mechanisms, they rather describe the end-result of computation (i.e. behaviour) (Aitchison, *et al.,* 2017).

The free energy principle

These predictive and inferential approaches have been critiqued as being 'devoid of psychological substance' (sic.) (Jones & Love, 2011). Predictive coding and Bayesian inference have been albeit employed in conjunction to advance the study of cognitive, perceptive, and neuropsychological processes. For instance, the *free energy principle* has been borrowed from thermodynamics to explain the way in which biological systems maintain their form and integrity. The term has been simply defined as the capacity (i.e. energy) of a system to perform a task for a particular purpose, and has been applied to explain the way in which biological systems maintain their form and integrity (Kauffman & Strohman, 1993; Ashby, 1947). Biological systems (e.g. a cell, the brain) are capable of self-organisation by minimisation of free energy in the face of an ever-changing environment (i.e. homeostasis). In the case of biological systems, *free energy* refers to a measure of statistical probability in the exchange between the intrinsic order of biological systems, and the 'surprise' (i.e. chaos or disorder) in the environment (Friston, 2007). In other words, biological agents must attempt avoiding, anticipating or controlling 'surprise' in order to be able to conserve themselves within physiological bounds.

AHP: Free energy, predictive coding, and Bayesian inference

The application of the free energy principle to neuronal science was introduced quite recently (Friston, 2010). It is based on the fact that just like other biological systems, the brain regulates itself using different mechanisms to find routes with lesser (i.e. safer, more conservative) degrees of free energy and with less probabilities of 'surprise'. In this context, the hypothesis stipulates that when free energy is minimised, statistical probabilities for the inferences described earlier, will decrease and limit the number of states that could be potentially acquired. This in turn optimises the mutual information for sensory and internal states used as parameter for the variation in probability, ultimately contributing to the most optimal possible adaptation of the system to the environment (Friston, 2012). More specifically, the minimisation of variables corresponds to inference, whilst encoding of uncertainty implies the minimisation of precision, and learning, that of parameters.

In summary, the brain is being understood as an organ that generates internal statistical models of the contingencies (i.e. 'hidden' states) presented by the environment, and uses them to constantly develop predictions to optimise adaptive behaviour and perception (Friston, *et al.*, 2018). Some neuroscientific models combine the free energy principle with insights in mathematics and other fields to propose broad theories of normal brain function.

In AHP, a speculative formulation based on the concepts described above, has been put forward in an attempt to comprehensively account for the heterogeneous presentation and multi-component nature of the syndrome (Fotopoulou, 2015). The model proposes that the array of symptoms manifested in AHP is caused by functional disruptions to be found at different levels in the hierarchies of mind-brain organisation. Furthermore, the symptoms are not mutually exclusive. Different domains within this organisation may be affected depending on how and where do lesions damage (i.e. size, location of stroke). These hierarchies frame the dynamic relation between expectation and experience. We could hence assume that AHP may result from aberrant

predictive coding. Disruptions of the systems may manifest as an inability to perform active sensory sampling of the world; as general impairment of updating and learning, whereby the patient strongly relies upon previous expectations that used to characterise the states of the body that is now affected; or as a general difficulty to optimise precision (i.e. decrease uncertainty) of prediction errors due to dopamine-depleting lesions in fronto-striatal networks (Fotopoulou, 2010). It has been shown that optimal perception and consequent behaviour depend on the cognitive representation of uncertainty in the world, which can be encoded by neurons modulated by dopamine (Friston, *et al.*; 2012). However, these hypotheses require proper empirical testing and computational modelling at different behavioural and neural levels.

Psychogenic and motivational theories of AHP

Another line of research suggests that AHP is a psychological defence that is closely associated to premorbid personality traits, and is triggered by events that are deemed threatening to the self. In the case of AHP, it is the loss of function of the left arm that causes such a life-changing threat that pushes the patient into denial rather than into the complicated path of readjustment and recovery (Weinstein & Kahn, 1950).

Weinstein & Kahn present data accumulated in over a decade of work using diverse research methods, such as EEG, interviews over long periods, control studies to compare AHP patients with other similar brain damaged patients, and systematic evaluation of pre-morbid personality (Weinstein & Kahn, 1955). They note that it was becoming increasingly evident that a motivation for denial of the impairment can operate as a unifying explanation of the different behavioural symptoms in patients whose brain functions have been damaged. This is because ‘anything’ (sic.) can be denied (e.g. blindness, weakness, diagnosis) and, as they note, *“some motivation to deny illness and incapacity exists in everyone*”. The meaningfulness of this hypothesis from a psychodynamic standpoint has been recognised, it has however been criticised, among other

things, for lacking neuropsychological modelling of conscious processes (Berti, *et al*.; 1998). Although the possibility of personality traits influencing anosognosic behaviour is not necessarily denied, psychogenesis or motivation do not seem to provide a comprehensive theory of the aetiology of AHP.

The works of V.S. Ramachandran have supported motivational theories that integrate psychogenic, cognitive, and physiological considerations. Remission of unawareness by irrigating the left ear of an AHP patient with cold water was reported until caloric effects worn off (Ramachandran, 1995). The emergence of awareness of the paralysis 'to the surface' (sic.) was temporally facilitated by the vestibular stimulation procedure, suggesting that a mechanism with a function such as that of 'repression' is being lifted. Moreover, once this patient was no longer anosognosic, she acknowledged that she had been paralysed for several days. Importantly, Ramachandran notes that denial did not interfere with consolidation of memory and noted that it may result from a temporary impairment of some right hemisphere neural circuits, rather than permanent ablation of brain tissue. He nonetheless acknowledges as well that psychogenic causes alone cannot explain the heterogeneity observed in AHP. Ramachandran thus proposed that in the face of discrepant evidence (i.e. expecting movement of the arm and failing to see it), the patient prevents conflict or 'oscillation' between cognitive decisions to which we are confronted by the error. Prevention of conflict is achieved by means of denial (i.e. ignoring conflicting evidence) or rationalisation (i.e. fabricating new evidence).

Revisiting affective and motivational components

Studies of AHP as a psychogenic phenomenon by Weinstein & Kahn are part of most historical accounts of the study of this disorder. As mentioned earlier, the authors propose a motivated hypothesis of denial AHP (Weinstein & Kahn, 1955) that follows the idea that the patient *defends* him/herself against emotionally threatening events. However, as mentioned, the purely psychogenic hypothesis

cannot be accounted as a single or central cause of AHP. And judging by literature revised so far neither does a purely cognitive explanation.

Motivational theories have been challenged throughout the historical development of research on AHP. For instance, Bisiach and Geminiani (1991) summarised in a review arguments that have been put forward against the motivational explanations. On the other hand, these stances have been recently reviewed (see Turnbull, Fotopoulou, & Solms, 2014) and, drawing from previous and recent data, counter-arguments and future directions were articulated to enrich the debate on motivational factors influencing AHP.

One of the criticisms against motivational theories implies that observed sudden remission of extreme unawareness discards the appropriateness of those hypotheses. Turnbull, *et al.* note that spontaneous remission does not happen to all patients, there are moreover documented cases of chronic anosognosia (for a case report, see Cocchini, *et al.,* 2002), and other common cases in which recovery of AHP is rather a transit from higher degrees of denial to milder ones (i.e. anosodiaphoria). Additionally, they suggest that typical presentations of anosognosia (i.e. acute anosognosia with spontaneous remission) are consistent with a defence hypothesis of AHP, in which the downplayed negative news go through an eventual 'mourning of loss', implying that defences can decrease as cognition is re-organised.

Another argument against defensive theories states that denial is far more frequent after right brain hemisphere stroke in particular and lesions in the left hemisphere have 'equally (emotionally) devastating effects' that would deserve a defensive reaction from the patient, implying that motivational accounts cannot explain the selectivity of the right hemisphere in producing AHP. Turnbull, *et al.* remind the reader that AHP (as mentioned elsewhere) can ensue after left hemisphere damage as well and add that this argument does not contradict the notion that specialised right hemisphere mechanisms might be involved in the orchestration of affective and cognitive processes underlying denial. In this respect, Kaplan-Solms and Solms (2000) concluded from five clinical cases integrating in-depth psychoanalytical and neuropsychological observations of

patients following right perisylvian lesions, that damage to this territory produces deeper alterations of emotion, motivation and personality. These patients' psychological reactions can be grouped under narcissistic withdrawal, melancholic and paranoid traits, which may impede a normal process of 'mourning of loss' and point to deeper ego organisation problems. In contrast, three other cases with equivalent left-hemisphere damage presented more 'practical' impairments (i.e. aphasia) and emotional reactions typical of 'normal mourning of loss', which necessitates a more healthily functioning ego.

It has been albeit argued by other authors that differential diagnosis of psychological denial should not be underestimated during assessment of AHP (Orfei, *et al.*, 2009). The effects of anosognosia on awareness are often not accessible to overt examination and the disorder does not only consist in the mere denial of a deficit; it rather implicates an array of factors including causal attribution, modality specificity, implicit knowledge, expectations of recovery, need for rehabilitation and estimation of functional limitations.

The authors advocating for a revision of motivational hypotheses cited above have moreover made it clear that, contrary to Weinstein & Kahn (1955), they are not arguing that AHP has a psychogenic origin. They rather understand the neuropsychological picture of AHP as revealing some of the functional mechanisms upon which defences operate. They propose that the neurological and cognitive deficits found in AHP, hinder a specific aspect of the mechanisms that usually regulate emotional responses to threatening stimuli (i.e. paralysis), and conclude that the greater the damage to cognitive modulation of emotion, the greater is the influence of emotion on cognition. What the authors are trying to convey is that the motivational *component* of the syndrome deserves further revision, not that it provides a comprehensive explanatory power about AHP.

It is reasonable to conclude from the discussion above, that a re-visit to the motivational factors of AHP, in light of evidence yielded by different methods and more recent techniques could be a favourable step towards a more integral understanding of the nature of denial in this disorder.

A feasible empirical study, with its respective design and experimental protocols, will be presented later in this work. The rationale behind the inclusion of empirical research proposals, is congruent with the intention to illustrate how can issues, topics, and approaches treated in this work be practically applied to advance the understanding of aspects of AHP. This can in turn serve the purpose of clarifying future research directions. The aim of this proposal is to investigate the role of motivational factors (e.g. mood, confrontation with deficit) in the modulation of denial of left-hand hemiplegia.

Denial: Affective modulation and motility

It has been observed that brain systems involved in affective and emotional processing and selective attention interact to assign a motivational value to sensory inputs. Furthermore, emotional factors can enhance assimilation and competitive strength of salient events, and does so with preference on threatening stimuli (see Pourtois, 2013, for a review), which can interfere with motor processing and programming of responses. For instance, emotional stimuli are often detected more accurately than neutral ones by healthy subjects (Eastwood, 2001).

In the past, L.S. Vygotsky (1896-1934) studied the links between the motor system and internal affective processes. He stated: *"Motor reaction is so merged… in the affective processes, that it can serve as a reflecting mirror in which it is possible to… read the hidden structure of the affective process… hidden from direct observation"* (Vygotsky, 1999). But how is it that motor reactions and affective processes interact? According to this statement, it could be assumed that the *lack* of motor reaction in left-hand paresis reflects the affective and motivational processes of AHP patients. If so, how? After all, only some individuals present denial of their weakness.

Fotopoulou, *et al*. (2010) recruited 14 right hemisphere stroke patients with complete left hand hemiplegia (7 with AHP and a control group of 7 with hemiplegia-only [HP]; mean age 64, SD 6.06) and measured implicit and explicit

processing of emotionally threatening material (deficit-related). The goal was to analyse their performance in an inhibition task for the previous, and a rating task for the latter. The authors were looking for the effects of the deficit-related words on aspects of cognition. The experiment intended to compare how AHP and hemiplegia-only patients perform in implicit (i.e. reaction times), explicit measures (i.e. ratings of self-relevance), and number of suppression errors in a Stroop-like task in the face of negative, neutral and deficit-related emotional content in sentences. Interestingly, all AHP patients rated the deficit-related sentences as less self-relevant than any control. Additionally, they were slower than hemiplegia-only patients in automatic inhibition of responses to deficit-related sentences, relative to neutral sentences. Increased latencies for emotionally threatening words (disability-related) has been considered as a sign of implicit awareness of the deficit in AHP –despite overt denial –due to "new" associations imposed by words related to disability (Nardone, *et al.*, 2008). Drawing conclusions from the neuroimaging enquiries accompanying the investigation described above, the authors propose that sensorimotor awareness is 'affectively personalised' and requires: Firstly, the representation of an intended state (e.g. left arm as being moved), and secondly, the re-representation of multimodal sensorimotor information in the insular cortex and potentially involve limbic and basal ganglia circuits, to attest that the desired state is being achieved. This in turn personalises affectively the sensorimotor information in self-awareness. The authors attribute denial in AHP to a failure in the second process: the re-representation of sensorimotor information.

Another recent study with 16 patients (9 women; 8 AHP, 8 HP controls; mean age = 68.19, SD = 14.27 years, age range: 41-88) further investigated the effects of affective processes on cognition (Besharati, *et al.*, 2014). The authors were interested to investigate whether an experimental induction of negative feelings by verbal feedback affects awareness of hemiplegia (Besharati, *et al.*, 2014). A task involving factors of different difficulty with the respective matching valence of the feedback provided to the patient's performance was used to assess the role of emotion in motor awareness. Following the negative induction only, the AHP

group showed greater change (temporary, rather than permanent) in awareness than hemiplegic controls and reported lower emotional ratings (i.e. less happy) compared to the positive emotions induction, which would support an emotional valence hypothesis. Additionally, the AHP group reported lesser degrees of depression and more positive emotions throughout the experiment than controls. However, since AHP patients were able to experience both positive and negative emotions following the corresponding feedback, it can be concluded that the emotional impairment is not due to a primary deficit in its' processing. The authors henceforth attribute this finding not to the mood inductions, but to the overall tendency in AHP of overlooking the report of negative feelings.

The authors propose that the compromise of emotional processing of the deficit is specific to motor awareness, suggesting that the emotional impairment lies rather in higher-order levels of cognition in which attribution of negative emotions to self-representations (e.g. of the body as having hemiplegia versus a healthy body) is impaired. This may derive in reliance on premorbid affective states of the body (when there was no hemiplegia, and self-attribution of emotions was not impaired) and ultimately to the discarding of the present ones with assistance of denial. What these pre-stroke states are relying upon constitutes what the authors called *pre-morbid priors*, which are listed among different examples whereby disturbances to optimal active inference –and thus, to minimisation of free energy –have been speculated to take place in AHP (Fotopoulou, 2014). According to Besharati's account, some of these pre-morbid priors may be particularly resistant to change. In addition, different patients may adhere to past self-schemata and experience differentially, which may weaken the prediction of errors.

Subjectivity: Qualitative factors of AHP

Another issue that remains to be attended, and is relevant to consider for any future directions in research on AHP, is that of subjective experience. The importance of qualitative research methods for the study of medical and

neurological populations has gained increasing acceptance within different fields. There is a widely explored body of qualitative research on the subjective experience of several types of illnesses. The subjective experiences of neurological patients within clinical settings have also been explored. For example, the *self-regulation model* (Leventhal, *et al.*; 1984) has been applied to investigate the subjective experience of early stages of dementia (Harman & Clare; 2006). The model has been previously employed to understand how people manage a range of psychiatric and physical conditions. The central proposition is that when people perceive a threat to their health, they try to deal with the objective features of the illness (e.g. illness identity, timeline, consequences, causes, and controllability) and its emotional impact to create a mental representation of the illness (Leventhal, *et al.*; 1997). A successful management of the illness is undertaken through stages of awareness, coping, and evaluation. To investigate this model in dementia, Harman & Clare (2006) recruited nine participants that had received and were aware of diagnosis, able to retain this information, and in the early stages of dementia. The research involved a qualitative study based on semistructured interviews that were transcribed and subjected to Interpretative Phenomenological Analaysis (Smith, *et al*.; 1999). The aim was to generate a thematic account at a group level reflecting key components of the patients' understanding and experience of the illness. The key themes that emerged from the interview were labelled 'I want to be me' and 'It will get worse', which according to Harman & Clare (2006) reflect an ambivalence towards acknowledging the progressive nature of dementia, and wanting to maintain a congruent identity. In some domains patients' experiences resemble observations made by professionals and researchers. Confusion however remained in the domain of identity of illness, as the meaning of terms like *dementia* and *Alzheimer's* are understood and interpreted differently among patients.

Subjective experience of being a stroke survivor has been investigated (Murray & Harrison, 2004) and also non-focal neurological symptoms after stroke. Such is the case for the subjective experience of non-focal neurological symptoms

associated to transient ischaemic attack, of hemispatial neglect, and self-perception just to name a few examples (see Kirkpatrick, *et al*., 2013; Klinke, *et al.*, 2015; Kitzmüller, *et al.*, 2013 respectively).

A study investigating the hemiplegic patient's perspective of upper limb recovery after stroke comes closer to the topic of AHP (Barker & Brauer; 2005). In this study, 19 stroke survivors were interviewed with the objective to explore their definition of recovery, and to identify factors they believe to influence it and determine strategies to maximise it in the upper limb. The authors found that stroke survivors maximise upper limb recovery by 'keeping the door open', which they describe as a continued process towards improvement in the midst of change. The patients describe 'hanging in there', 'drawing support from others', 'get and keep going with exercise' and 'finding out how to keep moving ahead'.

Unfortunately, in spite of all the existing knowledge on subjective experience of illness (including those in neurological contexts), and accumulating empirical evidence suggesting individually tailored approaches for a more integral understanding of syndromes, no study has ever addressed the experience of denial from the AHP patients' own point of view. The situation is such mainly due to the fact that quantitative research methods predominate over qualitative methods in neurological settings. But when scores and questionnaires fail to comprehend all aspects of a phenomenon, qualitative research may as well be of assistance. For the purposes the present project, it is considered that qualitative accounts can usefully complement quantitative methods. Therefore, a sketch for a qualitative research proposal will be included in the last chapter of this work.

CHAPTER 4
Psychoanalytic Perspectives on Denial

Introduction

The understanding of *denial* as a mechanism employed to avoid displeasure and anxiety was first conceptualised in early psychoanalytical literature. This is achieved by warding-off stimuli considered affectively threatening for a subject. The concept intends to encompass a phenomenon that is central for psychoanalytic theory and for the understanding of AHP. It was S. Freud who introduced this notion (1894), and several decades of psychodynamic study of the mechanism have developed into significant contributions. Since Freud's conceptualisation, and much further beyond psychodynamic theory, the term *denial* was borrowed or adopted by other fields that often parted from Freudian approaches (Salander & Windahl, 1999). Many of these models –often behavioural in nature –were eventually employed or adopted by researchers in neurological and brain disorders, including AHP.

The study of denial thus extends to an array of manifestations under the scopes of different research traditions, inclusive of their respective epistemologies, preferred methods and techniques. This has derived in a vast and heterogeneous literature, to which the characteristics of denial in AHP only contribute with further complexity. For instance, as it was mentioned in the first chapter of this work, it has been long argued that *denial* is often employed as an overinclusive term covering too wide a variety of processes, to suit clinical observations or interpretations, interchangeably with other concepts, and in disregard of the historical context in which these were conceived (Janis, I.L., 1958; Salander & Windhal, 1999; Gilleen J, *et al.*, 2010). Meanwhile, consensus on what is denial, which are the mechanisms employed for its manifestation in health and illness, and what are the similarities and differences with other concepts (e.g. negation, disavowal, avoidance) remains elusive and a source of

divergent and confounding inconsistencies in clinical observations and research conclusions (Lazarus, R., 1983).

A further basic issue that is necessary to keep in mind when searching for 'raw' definitions of the concept, is that of the language in which researchers develop their conceptual bases. Different languages have an array of ways to refer to or to understand operations that we usually associate with denial. What decisions do *different* translators take when naming clinical terms? It was indeed Freud who introduced the notion, but how did he call it in his native German? How are the concepts he employed for denial and associated phenomena formed as his theory developed, and how loyally do their translation reflect the intentions of the author? Can research findings on denial made in one language hold for other languages? Providing a full review comparing the different translations, definitions, meanings, and implications for individual languages lies beyond the reach of this chapter or this work. Only some of those that have been deemed directly relevant to AHP and the general purpose of this work will be addressed.

Despite their heterogeneous nature, some of the lines of research, such as coping theory, have nevertheless the potential to contribute to the study of AHP. These contributions will be considered when relevant, as they might help complement the 'gestalt' of denial viewed as a defensive mechanism or a coping strategy in AHP. These lines rely upon observable behaviour and are valuable for the present study inasmuch as they can correlate, question, or complement the *less* observable or *subtlest* aspects of the syndrome in which we are interested. Psychodynamic approaches work under the premise that 'inner' processes – difficult to come across upon overt examination –must be understood as well. The case with AHP is no exception, as cognition, perception, and other essential aspects involved in its manifestation are 'inner' processes as well. Emphasis will consequently be placed in explorations stemming from psychodynamic formulations.

The decades long development of the concept and understanding of denial in psychodynamic approaches is vast, and remains largely unexplored by other fields beyond the early Freudian notions from which the borrowed term

originated. This chapter will therefore commence by reviewing the basic milestones in the development of the concept of denial as proposed by Freud. Complimentary and divergent views developed after Freud will follow, attesting the expansion of the concept within the psychodynamic tradition and the implications that such extension may have for the study of AHP from a psychodynamic point of view. It is however not within the scope of this work to provide a detailed review of the evolution and use of the term in psychoanalysis.
It has also been considered that psychodynamic approaches may be good hypotheses generators in the face of complex phenomena, such as the one subjected to scrutiny in the present work. The arguments will be introduced on the basis that they have an increased potential to inform the neuropsychological research on AHP addressed so far (and potential to be informed vice versa as well), as such possibility has been previously suggested in literature (Fotopoulou, *et* al., 2012; Turnbull & Solms, 2007 ; Kandel, 2005).

Denial: Back to the root

As mentioned earlier, the understanding of denial as a mechanism allowing us to maintain out of consciousness stimuli or information to avoid anxiety, is rooted in early psychoanalytic thinking. As discussed, such notion has permeated not only psychoanalytic theoretical development, but also research in other fields. In order to discuss the inception and development of the term *denial* in psychodynamic theory, it is of upmost importance to revise the trajectory that it followed in the works of Freud and those who came after. When the term is reviewed in AHP literature, what many authors take as being his central or 'essential' proposal (and often rejected or dismissed along psychogenic and motivational hypotheses) is not necessarily so, or at least not completely. For instance, *negation* and *denial* for Freud are rather intellectual processes, as it will be later explained; the 'motivational' or 'affective' elements were introduced with greater depth in psychodynamic understanding of denial later (in a time no longer cited

or referred to in AHP literature as it shifted focus to other discoveries being made as research progressed).

The works of Freud are diverse in terms of format, structure, style, and underlying thinking. Moreover, as time passed, the author questioned, reformulated, and reconsidered previous knowledge based in clinical observation in order to build upon it. When literature explores the origins of the term and the first steps of research on AHP, more often than not, important milestones in the discussion and demarcation of the problem and phenomenon of denial as advanced in psychodynamic theory before and after the term was borrowed, are omitted. The main justification is usually that motivational explanations of AHP do not account for the manifestation of the array of symptoms presented by patients. However, beyond the relevance of Freud's notions for motivational accounts, it is considered that this work would be enriched by taking into account more specific elements from the process that led him and others to their conclusions. These elements may enhance the analysis of how some cognitive, affective and perceptual processes develop in AHP in light of current neurological evidence.

'Denial' in Freud's works

Pre-psychoanalytic writings

In Freud's pre-psychoanalytic works there is already reference to a process that allows the powerful rejection by the patient of his/her own complaints in the context of hysterical paralysis, whilst under the effects of suggestion (i.e. hypnosis). He termed this process *Verwerfung* (Freud, 1891/1979). It could be translated as 'discarding'. The German word is composed by the verb *werfen* (throw, cast, toss), and the verbal prefix *ver-*, which refers to a transition of an object to a state: in this case the complaint (i.e. symptoms) to a state of rejection or dismissal. It is thus by means of *Verwerfung* that hypnotic negation operates. However, he soon realised that no matter how vigorous that negation was during

suggestion, what was being negated was not destroyed, but 'discarded' in the direction towards the pre-morbid state when there was no complaint.

At this point, Freud had not yet elucidated the different ways by which denial is manifested. It can henceforth be observed that the already mentioned *Verwerfung,* and the concept of *Verleugnen* (composed by the German verb *leugnen* [to deny], and the verbal prefix *ver-* which operates as mentioned above) are used interchangeably to designate an undifferentiated set of processes during this phase of his thinking (Bornhauser & Rosales, 2015). *Verleugnen* has been translated into English both as *denial* and *disavowal* (which Freud himself preferred), and defined as the subconscious process of self-deception, used by individuals to protect themselves by not acknowledging a reality perceived as causing anxiety. In any case, it was recognised that this operation may be employed indiscriminately in the objective reality (e.g. in psychosis), and in the subjective representations (e.g. in neurosis); it is however always presented as a defensive mechanism activated in the face of intolerable facts (Freud, 1894).

Psychoanalytic works

Some years later, in what is often considered the first psychoanalytic text, it is proposed that denial does not exist in dreams during sleep. It is albeit admitted and expressible by judgement, which operates while we are awake, and is therefore implicated in the manifestation of the phenomenon in everyday life (Freud, 1900). On the other hand, even if the unconscious does not recognise denial (or limits), a dream may offer the possibility to deny something that in reality stands on the way of some desire. He uses a pained patient with serious limitations of movement that dreamt about performing a physical activity with ease. The dream illustrates how reality is being denied (i.e. the patient is actually handicapped), whilst reality effectively denies or limits the fulfilment of desires (i.e. performing physical activities with ease). In other words, the operation can simultaneously deny *and* reveal reality. The contradiction between the impossibility of the unconscious to admit negation or limits, and the ability to

nonetheless manifest it, leads to the notion of a split between judgement and desire. The primacy of desire, in its intent to avoid intolerable frustration, overrides and impairs the judgement of reality. Desire corresponds to affective life, impulses, and primitive features; judgement to cognitive, intellectual processes.

He added that the loss imposed by reality should be disavowed (by means of *Verleugnung)* with the ultimate goal to deny such reality. This may be displayed by some patients as confusion or clouding of functions of judgment and intellect (Freud, 1917/1976). Freud shows an awareness of the role that affective life may have on cognition in the act of denial. The notion of an affect-judgment divide determined the direction of his thought and is essential for the understanding that he builds on the subject. The author does acknowledge and recognise the defensive nature of the phenomenon, as could be expected by readers or researchers in any field with basic knowledge of psychoanalytic premises. Affect, impulses, and unconscious drives are indeed a central concern in psychoanalytic approaches. These are however not part of the operation of denial itself, as Freud understands such operation as *intellectual* by nature, and therefore leads his attention to elements of higher order (i.e. judgment, language, logic, reality testing). The importance of these observations for the overall structure of cognition, led some to consider them as the first steps towards a psychology of thought processes with a biological basis (Ferenczi, 1926/1994).

Freud reflects upon these issues when he introduces the term *Verneinung* (translated into English as *negation,* from the German *nein* for *no*) in a work with the same name as title (Freud, 1925/1961). This compact work reflects the development of his views on the subject and is the only one dealing specifically with the issue, as opposed to his previously cited notions to be found in different writings on other subjects.

The author provides two major examples to illustrate *verbal* ways in which patients may display the act of negation: i) rejection of idea(s); ii) disinclination to let an association count; which fall within the range of behaviours that AHP patients may present upon examination.

He proposes four steps that are common to all examples. Firstly, patients detect, label a phenomenon *correctly*; secondly, they deem the label *incorrect* and conceive it as threatening; thirdly, the phenomenon is repressed; and lastly repression is overcome in a way that intellect can present the phenomenon under a more tolerable light (by means of negation). As the author states: *"…the content of a repressed image or idea can make its way into consciousness, on condition that it is negated. Negation is a way of taking cognizance of what is repressed"* (Freud, 1925/1961). In this line, the acceptance of unpleasant ideas into judgment was assumed to arise from the neutralisation of two negatives: An original attempt to deny the facts implied, and a fresh effort to deny that negation (Ferenczi, 1926/1994). The emphasis placed on the role of judgment in the operation of denial, as it was being understood by psychoanalysis, may be reflected in this 'algebraic' view of two negative signs producing a positive one. Additionally, efforts such as those by S. Ferenczi to direct psychoanalytic inquiry towards describing the development of reality-testing mechanisms in the brain (Ferenczi, 1913, 1926/1994) may as well be witness to the importance placed in the role that judgment plays in denial. Such mechanisms would ideally lead to acceptance of unpleasant information into consciousness, as per the demands of the sense of reality. However, this 'lifting of repression' (sic.) by means of negation does not imply that the repressed idea has been *fully* accepted. It rather results in what Freud describes as an *"intellectual acceptance of the repressed, while at the same time what is essential to the repression persists"* (Freud, 1925/1961). It is in this sense that Freud understands an act of negation as a manifestation, display or substitute of repression in conscious thought, as opposed to non-verbal, repressed material.

Perhaps as a result of an emphasis on judgment, the author refrains from elaborating on what is required to *fully undo* a denial (Ver Eecke, 2006). He does consider some basic observations of phrases, prompts or questions that the analyst may find useful to employ in the context of the examples of verbal manifestation of denial he provides. There are however a variety of issues relevant to the very process that makes denial possible, and in terms of how may

denial be displayed or presented in patients, that are left unattended or undeveloped by Freud. Different authors nonetheless addressed the task to further explore the mechanism beyond intellect, deeming his understanding of denial a fraction of what has been pondered on the topic in psychoanalysis since his formulations. In the case of AHP, Freud's view of denial would only allow to account for a handful of the complex reactions that patients manifest, namely verbal instances such as 'I have no problem in my arm', or 'It's not like I have a problem in my arm, but rather…', or even saying *yes* if the researcher asks whether the patient moved his left hand for a task

Reactions such as silence, confabulations, or complaining about some other minor ailment whilst failing to report paralysis would not be accounted for by Freud's view. Henceforth, several debates that developed from Freud's theory will be explored below in order present further psychodynamic theories that could assist in understanding the manifestation of denial in AHP from psychodynamic perspectives.

Further debates in Psychoanalysis:
Modes of denial, developmental views, and the role of affects

The most important considerations that followed (and that are often discussed to this day) include debates on *what* is being denied or defended against (i.e. affects, impulses versus 'external reality' only); discussions regarding expansions of the term with the aim of comprehending other modes of denial, such as what are perceived as non-verbal manifestations of the mechanism; integration of developmental, interpersonal, and affective views; arguments on viewing denial as a defensive process, or as a coping strategy; and in the case of our object of study, the need to differentiate between denial of illness and anosognosia, and between defensive and adaptive strategies that manifest in both health and illness.

The following sections intend to explore these debates and how a particular psychodynamic hypothesis previously proposed that takes into consideration neuropsychological elements, holds the potential to illustrate the different aspects of denial as put forward by both fields. Such progress could be eventually reflected in research and clinical treatment of AHP. This later issue is not on the scope of this chapter and will therefore be addressed in the next.

Modes of denial

Otto Fenichel argued that it is not only perceptions of external reality that may be denied, as Freud suggests, but also for affects (e.g. anxiety, guilt) (Fenichel, 1941/1957; 1945/2014). Since denial is essentially a denial of perceptions (achievable by withdrawing investment of mental energy from an undesirable perception), it is argued that it may as well apply for those stemming from 'internal reality'. The conditions for denial would be met as long as it assists or replaces repression, and this may happen only when *"the instinct representations have become conscious and make a claim on the ego to be accepted as reality"* (Lewin, 1950/2013). Denial may thus be able to oppose the affective impact of an external fact. Some authors nevertheless remained on the line that it is only 'external reality' that can be denied in the technical, psychoanalytic sense (Brenner, 1982; Freud, A., 1936/1992).

Other authors did follow the view that affects can also be subject to denial, which takes us to another related debate mentioned above. The meaning of denial was expanded to include non-linguistic forms, such as types of amnesia, avoidance, or reality distorting fantasies (Jacobson, 1957, 1964). It has been claimed that current psychology predominantly employs the term for both verbal and non-verbal forms of denial as it seems to be the case in AHP research, such as views on *explicit denial* (verbal report) and *implicit denial* (showing indirect awareness by means of a compensating behaviour) (Cocchini, Fotopoulou, *et al.*, 2010). In psychoanalysis, this inclusivity is nonetheless said to blur the distinction between *repression* as a refusal to acknowledge affects and impulses, *denial* as a refusal

to accept factual reality, and *disavowal* as a refusal to acknowledge emotional meanings of that reality (Ver Eecke, 2006; Wurmser, 1985).

Developmental views

In regard to the importance of developmental views, S. Ferenczi discusses the acceptance of unpleasant ideas into consciousness (Ferenczi, 1926/1994) considering Freud's notions of the reality principle as explained above, and Tausk's ideas about discounting the motive of repression (Tausk, 1924). The latter elaborated an interesting proposal on how is it that repressed ideas are accepted into consciousness at a particular point in a chain of associations. The author develops his premises based upon the notion that the repressed idea loses or degrades its status as a motive for repression as a greater gain is expected from acceptance. He proposes that acceptance (i.e. overcoming of denial) takes place when a motive of repression is 'discounted' by compensation. By *compensation* the author means *"It is as if* (the subject) *tried to brace himself against the distress he anticipates by emphasizing encouraging factors, and by a cheering contemplation of himself he robs of its sting the pain he is about to experience"*. Ferenczi nevertheless takes into consideration the evolutionary nature –physical and psychological –of the gradual establishment of the sense of reality, and how it operates throughout the lifespan to allow threatening information into consciousness. He does so by referring back to previous work in which he proposed a number of stages that the child goes through during the complex endeavour (Ferenczi, 1913/2018). The author concentrates on the role of omnipotence in terms of attitudes towards objects chosen from the environment to be incorporated into the organism, and how is this process updated throughout the stages until a 'final renunciation' (sic.) of omnipotence is reached (which would not be the case in psychosis). He understands *omnipotence* as a feeling that persists when there is *"no inhibiting, postponing, reflecting thought-activity interposed between wishing and acting"*, and attributes it's changes to the need of the child to respond to the reactions of the libidinal

figure (e.g. mother, caregiver, nurse). In that sense, Ferenczi set important bases for the eventual development of object relations theory. But, when exactly does the child equate wishing and acting, and when does she cease to do so? And how about AHP patients? Is there inhibition, or reflective thought activity interposed between wishing and acting, like in normal adults? It could thus seem to be the case that denial in AHP reveals a 're-visiting' of the previously renounced omnipotence (in childhood), which is manifested in the outright disavowal of the reality that allows the patient to act upon a desire of wellbeing.

These important explorations address the development of conditions that determine how and when may unpleasant objects be accepted into awareness. But viewing the situation from a different angle, there are other questions that remained unexplored: What is the role that the emergent anxiety plays in a baby, in the face of limitations to her omnipotence? What is their effect in perception and understanding of negative experiences? When and how does the first *No* of a child come about, and what implications does it have for the attachment with libidinal objects (e.g. mother, nurse, caregivers)? And to what effect could this apply to AHP patients?

It was until the works of R. A. Spitz that the issue was analysed systematically from a developmental perspective, including physical, motor and psychic elements (Spitz, 1957). The author argues that the libidinal object imposes frustration and displeasure in the baby with the word and implications of *No*. The word and associated gestures are integrated as memory traces in the ego's memory system, and the unpleasurable affect is attached to the memory traces in the unconscious. Importantly, the accumulation of unpleasurable experiences connected to the memory trace, make the word *No* an optimal mean to express aggression. The aggression is in this case directed against an object that is both libidinal and a source of frustration, and the child resolves this contradiction by means 'identification with the frustrator' (sic.). *No*, then, emerges as a device with the end of expressing such aggression as it creates distance with the caregiver. Saying *No* affirms the fifteen-month-old child's autonomy, will, and right to a point of view within the mother-child dyad (Ver Eecke, 2006). Interestingly, the author

points that those familiar with children's role-playing in their second year of life, have observed that they start saying or gesturing *No* to themselves as well. This is said to create an inner 'cleavage' in the child between himself as an observed object (by the mother), and as an active observer (Ver Eecke, 2006). A deeper exploration of these notions will be discussed in the light of evidence on perspectives of the self and of the other in AHP research in the next chapter as part of the debate with neuroscientific approaches to denial.

The role of affect

Another important strand of debate around denial that followed after Freud is that of the role of affects in the mechanism. It is not only in AHP research, or in cognitive neuroscience in general, that a more thorough scrutiny of this issue is lacking. Psychodynamic thought has historically emphasised the study of drives, cognitive, and intrapsychic functions. It has been claimed that such focus has overshadowed the importance of affect, its' expression and transmission (Nathanson, 1989).

As mentioned earlier, the study of denial is interested in what happens with internalised mental representations of objects deemed threatening to the self. Affects function as a medium through which internalisation takes place, and have been thus considered to be essential to be able to theorise about internal representations (Tuber, 2012). They have been albeit relegated to an 'awkward' (sic.) position in psychoanalysis (Fonagy, *et al*., 2002), perhaps due to the fact that Freud himself did not address why can they be on the one hand tied to drive, but on the other so transcendental for what occurs in human interactions (e.g. between patient and analyst in a clinical setting, and we may add, with researchers under experimental situations).

For instance, in analysing what develops in these interactions and how denial comes about, D. L. Nathanson (1989) reminds the importance of the expression and communication of affect between people. The author however considers the ways in which such transmission may be blocked, or confronted with a *not-*

mirroring (sic.) situation, more essential to his proposal. He asks himself: *"…how do we learn to remain self in the presence of the affect of an other?"* and proposes that it is possible by means of what he called the *empathic wall*. This mechanism assists in the differentiation between self and other, as it allows the person to monitor affective experience to ascertain whether it emerges from internal or external sources. On the one hand, this 'wall' serves the purpose of individualisation of the self by separating the child from affective states of the mother. On the other, the wall must act as a gate to allow maternal love through. This concept furthermore echoes some of the proposals discussed along the lines of developmental considerations, whereby the child experiences ambivalence towards the mother as it is both a source of frustration and of survival. Such affective transmission was at the time often referred to as *empathy*. Nathanson (1989) argued that not *every* affective transmission might be called *empathy*. He understood the concept as an *intentional acceptance* of the transmission that is consolidated in the form of *mature empathy* in subsequent stages of development.

According to Nathanson's model, denial employs the affect-blocking properties of the empathic wall. For instance, a child that has at a moment allowed too much (maternal) affect from the outside across the empathic wall (potentially facilitating a noxious internal environment) will strengthen it to explain away the experienced displeasure. The empathic wall thus allows the child to maintain affective ties with the caregiver by separating from the feeling. An optimal use of this mechanism allows the self to remain self in the face of affect broadcasted from the outside. The author describes the effects of this dynamic activity of the wall as some type of relapse into primary processes (to be able to briefly 'merge' with the affects of the other), and emerging back into secondary processes with 'data' (sic.) learnt during the empathic link.

The author views manifestations such as denial, projection, and some aspects of different psychopathologies, as optimal examples to illustrate his proposal. Furthermore, he observes that these mechanisms constantly emerge from clinical practice, making them all the more relevant for consideration. Nathanson

(1989) nevertheless clearly states that he has ‘always been bothered’ (sic.) by commonly held notions of denial or defence mechanisms in general as being intrinsically pathological. He hints that, for instance, the operation of denial may demand the employment of skills learnt whilst the empathic wall mechanism was under development. These skills are necessary for ‘normal’ development as well, and the difference with pathological presentations would rather lie in the characteristics and status of the empathic wall in each case. This last issue serves as an introduction to the next debate, which shall explore the understanding of defensive mechanisms and coping strategies, and the implications each view has on the study of denial.

Denial: Defensive process or coping strategy?

As it can be observed thus far, the idea of warding off information considered a source of anxiety or negative affect by the subject, is a central notion in psychodynamic theory. The existence of defensive mechanisms as means that allow such process to be successfully undertaken has been proposed since the earliest stages of psychoanalytic thought (Freud, 1894/2014; 1896/1956). It has been argued that negative connotations have been ascribed to denial despite the fact that its role for everyday life has been acknowledged. Its categorisation as a primitive process often associated to severe disorder, and the views often held regarding it as intrinsically pathological as discussed earlier (Nathanson, 1989), have nevertheless overshadowed important aspects that are seemingly not covered by the viewpoint of the defensive approach.

Another view of such defensive mechanisms was developed parting from psychoanalytic ideas. Ego psychology claimed that people are born with innate capacities that enable individuals to adapt to the environment (e.g. attention, memory, language) (Hartmann, 1939/1958). It was argued that an adaptive progression triggered by emerging demands takes place, and that the Ego increasingly masters skills needed to *cope* with them. *Coping* has been used as a general concept in research on disablement, cancer, other chronic illnesses,

and a plethora of other areas of knowledge. It has been defined as a sustained investment of cognitive and behavioural efforts in dealing with internal or external demands.

Defensive mechanisms have been criticised as concepts used to describe or reflect a theory about underlying structures. On the other hand, *coping strategies* (with the original psychodynamic element they possessed seemingly diluted) are rather behavioural descriptions and relate to no particular theory of the underlying causes (Salander & Windhal, 1999). Coping strategies have been categorised as focused in provoking change in reality (problem-focused); and in shifting attention invested in the stressor, or changing the relational meaning (emotion-focused) of the stimuli (Lazarus & Folkman, 1984). Positive or proactive coping involves any strategy employed with the ultimate goal of adaptation to reality and to manage stress (e.g. seeking social support) (Brannon & Feist, 2009) in daily life and in illness. In contrast, those behaviours leading to unfavourable outcomes in adaptation are understood as maladaptive coping (Zeidner & Saklofske, 1996). But where is the line between *adaptive* and *maladaptive*? When does denial serve the purposes of one or the other? Interestingly, some participants expressed in a qualitative research exploring gaining awareness of deficits following traumatic brain injury (O'Callaghan, *et al.*, 2006) that denial allowed them to "feel better" and "cling on". Some nevertheless recognised it as a "block to getting better" and to engaging in rehabilitation more satisfactorily.

This takes us to the following important questions: Should clinicians *always* strive to undo denial in all patients, irrespective of pathology? Or at which point in defence or coping processes? What would be, for instance, gained from undoing denial in a terminal cancer patient that employs it to remain calm in the face of unavoidable tragedy? It is albeit clear that working through denial in AHP patients is essential as important negative outcomes (including risky behaviour, worse treatment prognosis, decreased quality of life, and an array of negative consequences) are associated to its manifestation as mentioned in an earlier

chapter (Orfei, *et al.*, 2007; Patel & Prince, 2001; Starkstein, *et al.*, 2007; Gialanella, *et al.,* 2005; Pedersen, *et al.*, 1996).

Following a psychodynamic approach to the topic, Salander & Windhal (1999) conclude that whilst there are behaviours that could be clearly classified as coping strategies, denial is positioned as a 'tangential point' between both frameworks, and may therefore apply to defensive mechanisms as well. Coping literature has moreover acknowledged that the relationship and mutual implications of these frameworks have not been satisfactorily explored (Lazarus, 1983; Weisman, 1979). The use of the term *denial*, and the definitions of how it is observed or manifested additionally reveals the problem arising from transferring concepts from one framework to the other without these considerations (Salander & Windhal; 1999).

From the point of view of coping strategies, AHP patients that compensate for the lack of movement in their left arm when asked to lift a tray (showing implicit awareness of the deficit by placing their healthy hand under the middle of the tray, and/or using other parts of the body like the chest or stomach) with the intent to complete the task successfully with their only functional arm, are an excellent example of how are coping strategies employed to adapt to the demands of reality and avoid self-deception. It also illustrates how can denial in AHP be observed from both coping and defensive mechanisms, and therefore why it is important to consider both when analysing patients. The task confronts them with a challenging situation in which an experimenter (a sort of authority, similar to that of staff working with them) is probing certain aspects of their abilities, which are directly determined by their current medical status. By compensating, these patients manifest a way of coping with their bodily reality and with the 'pressure' entailed in showing to the experimenter (or staff in general) that they are capable of performing well in the tasks and tests. The patient however may present verbal denial and/or confabulations around their handicap as they fail to perform tasks or report the deficit.

But let's go back to a question relevant for this chapter: Is denial of left hand hemiplegia a defence mechanism, or a coping strategy? Are AHP patients *defending* against threatening reality, or are they applying means of *coping* with it? For the purposes of this work, the approach to be taken is that denial may assist the patient in a shorter-term management of the situation to which the environment confronts them. The same could apply in the potential case they are aware of hemiplegia. But as it has been argued in psychoanalysis, in spite of observable behaviours denoting adaptation to reality, what is essential to repression may persist. This is the main reason why it was considered that this work should emphasise the role and background of psychodynamic approaches to the topic. In AHP, the researcher is also interested in what is *not* observable. Not only the intrapsychic, psychodynamic aspects are less observable, but also several other neurocognitive processes that are not recognisible in overt examination.

There are other reasons for the emphasis in psychodynamic approaches. Coping theory does not offer a better operationalisation for denial, as different authors use the term in different ways. For some, denial is a coping mechanism in itself, for others, it's a mechanism involved in other coping strategies. For instance, Weisman (1979) proposes that denial is an act within the coping process in which the repudiated is substituted by something more agreeable. As mentioned earlier, such proposition can be found in psychoanalytic literature (Tausk, 1924). The author was actually among the first to conceive of denial in psychoanalytic literature as possessing characteristics of both defensive and adaptive functions. The approach taken in this work will henceforth consider the analysis of more observable *adaptive* strategies and behaviours as well. They are also informative of the overall status of denial patients. Coping theories have furthermore provided valuable operationalisations and methods for empirical research in cognitive sciences, and it may thus be useful as a bridge between psychodynamic and more 'observable' understanding of denial in AHP.

Anosognosia Vs. Denial of illness

The discussion of when should denial be understood as a defensive mechanism or a coping strategy has been previously discussed in the context of neurological disorders (including AHP) and lies at the heart of the need to distinguish between anosognosia (i.e. impaired self awareness) and denial of illness in clinical and research contexts.

Prigatano & Klonoff (1998) argue that denial is manifested not only in patients with brain dysfunctions, but also in those without them. In this sense, denial emerging in a neurological context must be seen within the restrictions and effects of a brain lesion or disorder. It also demonstrates the use the individual does of strategies previously employed to cope with or defend from reality; for this matter reality is defined according to deficits the patient is partially aware or unaware of. The authors are clear in that it is of high relevance to conduct larger and deeper studies on the matter, as the relationship and interactions between the manifestations they categorised as belonging either to impaired self-awareness, or denial of illness, are complex and multidimensional. Patients may show mixed symptoms, and may thus be hard to classify under one phenomena or the other. It also brings us back to a question mentioned in a previous chapter, namely *what* can be called 'anosognosia' when denial of some illness is involved beyond left-hand hemiplegia. Importantly, they remind the reader that opinions may vary widely between clinicians or researchers, which further complicates prospects for scientific research or more systematic understanding of denial in neurological and non-neurological patients. They nevertheless believe that this debate may assist in clinical contexts to distinguish the nature of denial manifested.

The cognitive arrest hypothesis of denial

As can be concluded from the debates explored above, there is a vast array of issues that need to be taken into account to understand comprehensively the phenomenon of denial within psychodynamic theory. The following section will address a proposal with a particular potential to contribute to the understanding of denial in its various presentations and in the context of this work.

T.L. Dorpat's (1983) formulation of the phenomenon of denial intends to integrate psychodynamic views on development and unconscious motivation, with contemporary theories of cognition and perception. In essence, it states that denial 'arrests' (i.e. inhibits) the perceptual and cognitive processes surrounding a disturbing object. Despite the fact that the hypothesis was not formulated with an emphasis on AHP, its' scope seems to cover the different manifestations of denial in the syndrome and, moreover, does not seem to contradict the essence of psychodynamic or of neuropsychological views as it will be explained in the next chapter. Dorpat, a medical doctor and psychoanalyst, creates a dialogue with cognition and psychiatry by using evidence available at the time.

His hypothesis agrees with classical psychoanalytic theories of defence in that denial affects perceptions. It nevertheless disagrees as to *when* does it happen (Dorpat, 1987). As it was explained earlier under the views of Freud on the topic, denial parts from correctly detecting and labelling a phenomenon that is threatening the Ego (1925/1961). Dorpat challenges the assumption that the denier necessarily forms a veridical, conscious perception before disavowing it to subsequently find a distorted idea as a substitute. The author takes one step back *before* the conscious perception and asks: What happens if the patient does *not label* or detect the disturbing object correctly? Or in other words, what happens *before* the either correct or incorrect labelling process takes place? That part of the process is of upmost importance in AHP, as the impairments associated to the syndrome may be found at different points of the senso-perceptual action system, making it extremely difficult to assert the extent to which a representation may be conscious judging by verbal and non verbal

behaviours. Dorpat thus shows interest in the *microanalysis* of denial, that is, in the sequence of events that give rise to it. These include the rapid pre-stages of acts of cognition (e.g. immediate perception of simple sense stimuli), which are of no object for awareness. In order to understand that sequence, it becomes essential to consider the first acts of perception, not only an analysis limited to conscious representations. The author henceforth makes a broader use of the term *denial* to indeed comprehend the full range of circumstances in which denial may manifest, including normal everyday life, neurosis, and cases of a neurological nature.

The four phases of denial

When the cognitive arrest hypothesis was proposed, four different phases inherent to any denial reaction were presented (Dorpat, 1983; 1987). According to the author, the process that gives rise to denial begins in a *pre*-conscious appraisal and an anticipation of a potentially dangerous or traumatic experience. This appraisal precedes conditions for affective responses, since they are dependent on automatic senso-perceptual processes and thresholds upon which affective life is built. As the necessary thresholds are reached, a 'painful affect' emerges and marks the second phase of the process. In this sense, as the author explains, what is denied may remain unconsciously active and inducing important long-term effects in psychic functioning until full perception is achieved. By *painful,* the author refers to 'pain-engendering' or to a 'source of unpleasurable affects'. Among these, he refers not only to anxiety –considered a central point of defensive operations and symptom formation (Freud, 1936) –but also to any other negative affects (e.g. depressive, guilt, shame, grief, helplessness) (Brenner, 1975).The painful affect triggers a shift of focal attention from the painful situation to something less threatening, which biases the denier's perceptions and cognitions of the painful object at a primary process level. This in turn blocks secondary processes (e.g. symbolisation) related to the object in question. The author explains that in this third phase *"denial interrupts the normal*

process of thought formation and prevents the construction of verbal representations about the painful object and the denier's relation to it". According to his view, what biases or interrupts perception and cognition is ultimately presented by unconscious fantasies of rejecting, destroying or expelling the painful object. The cognitive arrest thus interrupts constructive, integrative, and regulatory functions of focal attention and consciousness about what is denied.

The fourth and last phase involves the appearance of screen behaviours. Screen behaviours are ideas, affects, or overt behaviours used to fill the gap created by the arrest between primary and secondary cognitive processes. These behaviours manifest the psychic content of what is being denied in a derivative way. The 'screen' serves as a cover story to deny weakness and assert strength; it is restuitive inasmuch as it works as a substitute for the object relation that the person may have wished to have with the painful object destroyed or rejected in fantasy. In AHP, any behaviour reflecting denial or a lack of knowledge or acceptance of left hand hemiplegia could be considered screen behaviour as long as it is used for the purposes of avoiding acknowledgement of painful affects and/or objects. All examples of implicit denial (verbal or motor), such as using the stomach to try to hold a deck of cards to be shuffled upon request of the experimenter with the right hand, could be classified here. These behaviours are the result of the whole processes and therefore displayed overtly. It is important to specify that by *overt*, it is not meant that its' detection and interpretation by researchers and clinicians is straightforward, but only that it stand on the motor, behavioural end of the senso-perceptual-action system.

For the purposes of this work, the painful object could be considered to be the left hand itself, and or hemiplegia, and or any associated and emerging affects, depending on each individual case.

Denial: Disruption of perceptual and cognitive processes

The four phases explained above are certainly relevant for the topic of this work. It is however important to delve a bit further into how and why is cognition

compromised in the process of denial according to Dorpat's integrative, psychodynamic view. As mentioned above, the author attributes the *arrest* or inhibition of integrative and regulatory functions to focal attention being divested from the painful object. Unconscious fantasies of an aggressive nature are directed by the denier towards what is painful to reinforce a feeling of independence from it, as proposed by the developmental views explained earlier. There is consensus in the notion that attacks lead to disruptions of capacities for rational thought and communication of whatever the patient believes to be wrong. There is nonetheless a debate around *what* is being attacked, and the implications it has for cognitive function. For instance, it has been argued that deniers may attack anything that is perceived as having the function of linking the patient to an object (Bion, 1959). One notion proposes that patients intend to attack their own psychic functions, to destroy their own cognitive capacities with the aim to deliberately avoid comprehending the object (Bion, 1967/1984). Dorpat, on the other hand, proposes that it is a concrete primary process representation of the painful object that is attacked. Such attack, according to him, leads to the *unintended* consequence of cognitive arrest in what pertains the painful object and the link with it.

Interactional aspects of denial

Dorpat's view of defensive operations is not limited to the formulation of the cognitive arrest hypothesis of denial. The author also emphasises the interactional aspects of defence. He reviews psychoanalytic literature on the topic and, like others, concludes that interactional aspects were not satisfactorily explored (Dorpat, 1989). Too great an emphasis in the 'intrapsychic' aspects of denial has overshadowed attention to the role that object relations and interactions with others play in the manifestation of denial. The natural setting of psychoanalysis perhaps influences this fact, since the therapist and the patient meet in isolation from the outside world. In this sense, we could say that an analytic situation provides a 'laboratory condition' of how the patient's defences

work. A similar issue happens in the setting and relationship established between a researcher and members of staff with an AHP patient. The author thus states that everyday life does not happen in isolation, that both conscious and unconscious processes are only one aspect within the complexity of communication with others. Partakers of a link mutually project and introject what is communicated in what he calls *mutual projective identification.* In the process, people seek to influence the affects of others, and employ affect to communicate it. He therefore opposes the view of defences as operating in a 'closed system' (sic.), or as taking place in the mind (understood as a 'space' that, he argues, does not exist in material reality). According to him, this notion often leads to propositions classifying some defences as taking place 'intrapsychically' and some others externally, interpersonally. He states, *"Only in fantasy and not in reality do humans exist in two worlds"* (Dorpat, 1989). In this line, Dorpat proposes what he considers a more meaningful distinction: between *private* (as opposed to *inner*)(Schafer, 1976/1981) and *public* acts of defence (i.e. when transactions with others take place). Dorpat attributes the development of defensive activity as emerging from the individual's interactions with others, and interacting with others provides a fertile ground to manifest it. In the case of AHP patients in a stroke ward, those interactions involve family members, nurses, doctors, physiotherapists, and other staff. Both *private* and *public* defences involve conscious or unconscious fantasies and memories of a feared or wished relationship with an object, where the possibility of arresting or inhibiting certain cognitive processes lies. According to these views, it could be assumed that denial in AHP arises in the context not only of these interactions, but also of the particular brain lesion that characterises it. It is henceforth important to reflect upon the nature of the interaction with the AHP patient, and how is it that we, as researchers or other members of staff, could be participating from the defensive operation and how may that reflect in research results or clinical treatment. For example, health care staff may take advantage of denial of hemiplegia by the patient to assert they are doing a good job and reassure their self-worth. It may also assist the family in avoiding or disavowing implications of the stroke, and

AHP researchers themselves expect the defence to appear to advance the research agenda.

As this chapter has reviewed, the understanding of denial and defensive operations within psychodynamic theory is highly diverse as emphasis is placed in the different aspects that are considered to be involved. This work proposes that the cognitive arrest hypothesis and Dorpat's overall understanding of denial and defence offer a framework to accommodate a variety of the different aspects that have been put forward by AHP research from neuropsychological perspectives. The following chapter will aim at illustrating how theoretical proposals based on empirical evidence in neuropsychology and Dorpat's proposals (Dorpat, 1983; 1987; 1989) could mutually account for, or at least not contradict, each other and be applied to assist in advancing experimental and clinical understanding of AHP.

CHAPTER 5
The Cognitive Arrest Hypothesis of Denial In Anosognosia for Hemiplegia: Neuroscientific and Psychoanalytic Perspectives

Introduction

The previous chapters presented an overview of AHP, a syndrome whereby right hemispheric stroke patients deny ensuing left hand hemiplegia. Debates on the causes, onset, presentation, and neuroanatomical structures involved in denial in AHP were explored. Some empirical models and theories attempting to account for the heterogeneous symptomatology of the syndrome have been discussed, along their theoretical and methodological limitations. On the other hand, psychoanalysis has produced a vastly diverse literature on denial and defensive operations in general. Psychoanalytic observations that hold a potential value to contribute to the neuroscientific understanding of denial have nevertheless been excluded from revision. It was discussed that this exclusion could be attributed to a preference for biological models and empirical approaches in research and the healthcare system. Psychoanalytic views on motivation, drive, defense, and cognition are nevertheless complex and are not limited to the factors taken as reason to dismiss the premises and the whole field. The present work proposes that carefully considered psychoanalytic theories can contribute to the neuroscientific understanding of denial in AHP, and that neuroscientific evidence can shed new light upon, or support psychoanalytic hypotheses and formulations. A review of the development of relevant premises and debates surrounding denial in psychoanalytic theory was henceforth presented. Neuropsychologists and other professionals are confronted with the question of *what* is denied, and how can external observers judge the manifestations of denial. The lack of terminological consensus, scientists' continued struggle to find definite causes of denial in AHP, the precise points in the system that are

impaired, and the anatomical and physiological processes that orchestrate the mechanism warrants a deeper inquiry into what is known about denial beyond classical scientific methods.

Many important questions on how does denial manifest in AHP arise from psychoanalytic considerations revised in this work. For instance, let's briefly revisit Freud's views of the role of judgment and conscious processes in denial (Freud, 1925/1961) as revised in the previous chapter. Does the presence of negative grammatical statements denying hemiplegia (e.g. 'I do not have a problem in my left arm') are able to correctly detect hemiplegia and form a notion that awareness of the deficit would entail an increase in anxiety, to subsequently disavow the threatening event? What if a patient *can't* actually 'discover' his/her hemiplegia due to senso-perceptual deficits? Does absence of verbal report necessarily mean there is no representation of hemiplegia formed (i.e. mental representation of the threatening event), and that therefore there is no hemiplegia to be denied? In Freudian terms, as long as there is no language involved, the operation could as well belong to the realms of the unconscious where repression operates, as opposed to denial that operates in more conscious processes (i.e. when objects have already been represented). But on the other hand, how can researchers interpret blunt silence, tangents, and other types of compensatory behaviours? As discussed, both neuroscientists and psychoanalysts have considered implicit, or non-verbal forms of denial. Another important question in common both fields have is how can a researcher use the right term (e.g. repression, disavowal, avoidance, denial) for the right patient, if it is still a struggle to detect objectively the degree of awareness that an AHP possesses of the threatening information?

The consideration of non-verbal forms of denial enriches the debate in psychoanalysis inasmuch as it expands Freud's views into understanding denial not only from the point of view of judgment and consciousness, but also from the unconscious and primary senso-perceptual, cognitive and psychological processes. It also provides the opportunity to engage in analysing a wider phenomenology of the syndrome. Understanding the precise nature of what is

denied, the precise point in the systems orchestrating perception, thought, and action that are compromised in denial, are all in the best interest of scientists and psychoanalytically-oriented professionals. The fields are ultimately interested in finding which is the best treatment, technique, or way to proceed in each respective case. Trying to answer these questions from the points of view of neuroscience and of psychodynamic theories may thus proof beneficial for research on AHP.

The psychoanalytic review of denial developed in the previous chapter concluded with the presentation of the Cognitive Arrest hypothesis (Dorpat, 1983). This model of denial combines psychoanalytic thinking with sensory, perceptual, cognitive, and interpersonal aspects. The model therefore offers a framework whereby neuroscientific evidence and psychoanalytic premises can be discussed on a common ground and therefore serve as a bridge between the fields. Three different investigations will be proposed to illustrate how empirical and qualitative approaches could address the arguments presented in the debate between the fields. The rationales behind the experiments will be explained when the relevance of the topics they address emerges between the evidences and arguments of the debate. More details on the experiments, including their full procedures, shall be included in the annex of this thesis.

The cognitive arrest hypothesis of denial in AHP

The accounts of denial from the points of view of AHP research and of psychoanalysis presented in this work, yield themes that are of common concern for both fields. Each of the fields analyses their objects of study in the context of debates that develop within their reach of inquiry. Nevertheless, evidence and observations made in both fields reinforce the importance of revisiting and re-considering the role that affect, senso-perception, interpersonal and interactional aspects, and subjectivity, play in cognition and in the overall manifestation of denial. The manifestations are not limited to those in AHP, but also in other disorders and in normal, everyday life. The sections below will synthetise the

main common concerns on causes and manifestations of denial in AHP found in both fields, and discuss them in the light of the Cognitive Arrest hypothesis.

Negative or 'painful' affect and cognitive 'arrest' or compromise

According to the cognitive arrest hypothesis, the detection and anticipation of a threatening or displeasurable event for the ego gives rise to a 'painful' or negative affect. Affect in AHP has been mainly studied in the context of motivation and emotion. Theories of AHP involving motivational and emotional factors are usually understood to be associated to the psychogenic proposals (Weinstein & Kahn; 1950, 1955). The criticisms of motivational accounts cited in the third chapter of this work (Bisiach & Geminiani, 1991) contributed to relegating the attention given to affects in the aetiology of AHP despite grounded counter-arguments (Turnbull, Fotopoulou, & Solms, 2014). The case is not very different in psychoanalytic theory. As mentioned in the fourth chapter, affect in psychoanalysis has not gotten satisfactory attention despite how essential it is for internalisation of representations, and thus for everyday interactions (Tuber, 2012; Fonagy, *et al.*, 2002). There is albeit a large body of research on the role of affective states in emotional, cognitive, and behavioural processes. The evidence stems from experimental techniques to induce and measure affect for research, and from neuroanatomical studies.

In terms of the involvement of sensory regions of the brain in positive and negative affective experience, neuroimaging studies have accumulated evidence showing brain structures that underlie differential reactions involved in the reception of positive or negative feedback. A study investigating neural correlates of the different types of feedback found that positive feedback elicited stronger activations bilaterally as compared to negative, and neutral feedback, and stronger unilateral activations in neutral feedback when compared to negative feedback. The structures in common that are activated in all comparisons include the putamen, left amygdala, lingual gyrus, and thalamic structures (Drueke, *et al.*, 2015). There is however more structures involved that are not common to the

other comparisons, which reflects a high degree of dynamism between brain structures and networks when feedback of performance is present. This further complicates the picture of AHP in the light of findings on the progressively changing clinical and anatomical presentations over post-stroke stages (Moro, *et al.*, 2016; Vocat, *et al.*, 2010).

In what pertains to contributions in research contexts, Moore, *et al.* (1998) reviewed manners in which emotion and affect moderate responses to ourselves and to others. The evidence revised is very relevant for AHP on different grounds. Firstly, it supports the notion that affective states and experiences influence cognition; secondly, it stresses issues on affects, emotions, and mood as they present in the context of everyday interactions. For example, the authors address ways in which affect has been manipulated for empirical research purposes. Laboratory inductions of affective states have been of great value to investigate differences between positive, neutral and negative stimuli and affects, the function of neuroanatomical structures for each of the valences, and resulting changes in cognition and behaviour that are induced.

Among the techniques to produce affect in laboratory conditions cited by Moore, *et al.;* 1988), *success* and *failure inducers*, and use of disability-related (or in general negative) words have been employed by means of providing verbal positive, neutral, or negative feedback to performance of tasks, or by exposing patients to the negative words. The inducers affect the self-concept of the person (i.e. representation the person has of himself) and generate transient emotional states. For instance, evidence has shown that patients with depression are significantly more affected by failure feedback than control participants (Hammen & Krantz, 1976). The authors of this study add that the estimates of depressive patients regarding their own performance in a task are more affected by failure feedback (e.g. 'You performed poorly') than by success feedback (e.g. 'You performed very well'). It could be argued that these emotional states alter the self-concept and bias the patients' patterns of thought and behaviour; they are however unlikely to alter the overall structure of personality in a medium or long term (Moore, *et al.;* 1988).

The authors of the review cite a previous study (Moore, *et al.*; 1982) they made whereby subjects that underwent a positive affect induction, effectively recalled positive and negative affect words. Subjects that underwent a negative affect induction had an increased recall for negative, but not positive affect words. In this regard they state that negative affect *"acts like a stringent filter, leading to selectively focusing on negatively tinged memories".* Another study showing that positive, and no feedback at all, derive in a better recall of personality strengths than liabilities; whereas induced negative mood decreases recall (Isen, *et al.*; 1970). Interestingly, the authors claim: *"it appears that the content of the material to be recalled may be a critical factor with affect relevant words and interpersonal content showing effects on mood. Whereas neutral stimuli do not necessarily show an effect"*

Some of these techniques to manipulate and measure affective states or mood have been previously used in AHP as well. For example, as mentioned in the third chapter, AHP patients rated deficit-related sentences as less self-relevant than controls (Fotopoulou, *et al.*, 2010), which demonstrates implicit denial of their deficit. Another study cited in the same chapter, that used verbal feedback paradigms, found that negative, self-referential emotion induced by feedback from another person temporarily improves awareness of left hand hemiplegia (Besharati, *et al.*, 2014). Some psychoanalytic perspectives cited in this thesis propose relevant ideas as to why could awareness of deficit increase in the presence of negative feedback. By providing a patient with a *negative* feedback, we are providing an extraneous negative 'sign' that can be cancelled along the negative sign implied in the patient's negation. Both negative signs would produce a positive (i.e. awareness of deficit under the reality principle), as referred by Ferenczi (1926/1994).

There is nonetheless more to be said regarding the cognitive arrest hypothesis of denial (Dorpat, 1983) and the induction of negative affect. As previously explained, the hypothesis proposes that painful affect (which emerges from the preconscious appraisal of threat, and is essentially what the person is defending against) comes about due to information processed by the senses about a

threatening situation or object. In the case of the experimental paradigms aimed at manipulating mood and affect in an experimental situation, the role of negative feedback is precisely to intervene the otherwise neutral (or stable) environment to generate a painful affect. Then, the effects of this affect on cognition may be later analysed behaviourally. It could be thus said that providing negative feedback to some extent places the patient in a past position: that of the child that is being restricted or limited by the caregiver.

An experimental proposal that could contribute to existing evidence on whether induced negative emotions affect the report of hemiplegia in AHP patients will be included in this work as a way to illustrate these premises in the context of the cognitive arrest hypothesis of denial in AHP. Positive, neutral, and negative feedback of AHP patients' performance in some tasks will be given whilst a video-replay shows the failure. The goal of this experiment is to investigate if induced negative emotions whilst watching a video-replay of another patient's motor failures can affect the report of motor awareness in AHP patients. Implications of video-replays in the context of this thesis will be addressed later, when perspective taking and self-other referential processes in AHP are considered.

As for negative affect, it is precisely the restrictions of the caregiver that prompt a wish of independence in the child and that are considered an important milestone in the apparition of the first *No* (Ver Eecke, 2006; Nathanson, 1989, Spitz, 1957). Similarly, just as the child is conflicted by the fact that the source of threat is an object that is also affectively meaningful (i.e. the caregiver), and therefore does not wish to break the attachment, so is the researcher meaningful for the AHP patient tested. The patient wishes to 'keep' good impressions of his/her skills or performance in the eyes of the experimenter, and/or the link to a pre-stroke identity that has expired in reality. The developmental milestone implied in coping with these complex developmental demands underlies the next phase, whereby the negative affect generated begins to alter cognitive processes.

According to the cognitive arrest hypothesis, the negative or painful affect triggers a shift of focal attention from the painful situation to something less

threatening, which biases secondary processes that link the person with the painful object. As revised, the hypothesis proposes that the shift of focal attention from the painful object or negative affect to a less threatening object interrupts integrative and regulatory functions of consciousness related to the object that is being denied. This shift blocks secondary process cognition of the painful object. Those secondary processes include, for example, the role that cognition has on regulation of emotions. As previously discussed, it has been argued that in AHP a cognitive mechanism that normally regulates emotional responses to threatening stimuli may be impaired, increasing the influence of emotion on cognitive processes (Turnbull, Fotopoulou, & Solms, 2014).

Self and other: Interactional perspectives

The developmental views of denial in psychoanalytic theory analysed in chapter 4 did not only bring into attention the importance to consider the early stages of the development of cognition (Spitz, 1957; Ver Eecke, 2006), but also opened the possibility to expand psychoanalytic theory first into object relations theory and then to intersubjective, or interpersonal aspects of defence that emerge in everyday interactions (Nathanson, 1989; Dorpat, 1983; 1987; 1989). This is due to the fact that developmental approaches give a greater role to the caregiver, the first ever experience of an *other*, in the development of cognitive and psychological functions.

In chapter 3, evidences from AHP research on the role of the cognition of the self and of the other were presented. In the light of the cognitive arrest hypothesis, the topic acquires relevance as it implies three different 'social' aspects (inasmuch as they involve others) that have been found to be important in the aetiology of AHP and in the overall manifestation of denial according to some psychoanalytic views: i) perspective taking (1st person perspective, 3rd person perspective); ii) online (i.e. live, moment-to-moment interaction) and offline (i.e. perception of a copy of an event in the past) modes of cognition; and iii) dynamic

relation between affect and cognition of the self and the other, both developmentally and senso-perceptually) in the aetiology of denial.

In terms of perspective taking, evidence showing that AHP patients overestimate their manual skills when asked in the 1st person perspective, and that 3rd person perspective tasks may increase awareness of hemiplegia in some patients (Marcel, *et al.*, 2004; Fotopoulou, *et al.;* 2009; 2011) was covered in chapter 3. Other relevant cited evidence includes the finding that many AHP patients are capable of recognising left hand hemiplegia in another patient, but not in themselves, or are unable to recognise the deficit in the self or in the other (Ramachandran, 1996). This relates to some aspects of the developmental theories of denial in psychoanalysis. As explained in chapter 4, the first *No* reflects with certainty that the child is fully conscious (i.e. can now verbalise) of being a separate person from the caregiver. Thus, once the child finally renounces omnipotence for the sake of adaptation to the reality principle (Ferenczi, S.; 1913/2018), the child is ready to conceive the existence of an *other* individual. Spitz introduces the concept of *distance communication* (Spitz, 1957), as the child must now communicate over a distance that was created in the endeavour of individualisation. That distance exists both physically and psychically, but the child can only now form an internal representation of that distance and of the object. It is moreover argued that around 2 years of age, the child acquires the skill to say *No* to himself during play just as the caregiver (a third person) does, prompting assumptions that the capability to see oneself from a 3rd person perspective is acquired at this stage (Ver Eecke, 2006).

The relevance of the cognitive arrest hypothesis here is not limited to the psychoanalytic premises it considers, but also because there is a visuospatial element to that communication with the other over a distance, that brings about the importance of intact senso-perceptual input for optimal cognition. In stroke, these issues may as well be hindered by the damage to neuroanatomical structures and networks. As revised in chapter 3, some cases of AHP have a strong element of sensory and perceptual deficits avoid left hand hemiplegia from

being ‘discovered’ (Levine, *et al.*, 1990; 1991). These cases can henceforth also be accounted for on the basis of the rationale behind the integration of sensory and perceptual aspects to the psychoanalytic-based model of denial, including the role of sensory receptors and perception in the preconscious appraisal of a threatening or displeasurable event (Dorpat, 1983).
The internal representation of that distance brings us to another consideration in the context of the cognitive arrest hypothesis of denial. These aspects that are being understood as *self* and *otherness* in light of both AHP research and psychoanalytic observations, are not included in any particular stage proposed by the model. The author of the model rather considers that interactional contexts are the main scenario where all the phases leading to cognitive arrest, denial, and the resulting screen behaviour take place.

The relational nature of denial brings attention to another important aspect that both AHP research and psychoanalytic theory are interested in, and that is inherent to all interpersonal interactions. Detection of errors or incongruences between what is represented internally and what happens in objective reality (i.e. what happens in a video replay or a mirror) is capital for understanding everyday life interactions with the environment as it allows the person to correct and adapt to dynamic demands. Detection and correction can be undertaken in *online* modes of cognition (Robertson, 2010). As revised in chapter 3, detection of errors and means of correction have been investigated in AHP by means of the use of mirrors to provide immediate visual feedback of the patient’s behaviour (Fotopoulou, *et al.*, 2011). The use mirrors has demonstrated temporary improvement in awareness of hemiplegia, as opposed to video-replays of the failure in a task shown to the patient *offline*, which has been reported to permanently remit the syndrome in a case (Fotopoulou, *et al.*, 2019), or to have longer-lasting effects in improvement of motor awareness using video-replays than when using mirrors (Besharati, *et al.*, 2016). The role of physical and figurative mirrors, or of *mirroring* processes, has been proposed in psychoanalysis as providing an experience of structuration. Mirroring processes

allow the child not only to integrate a congruent senso-perceptual representation of the body, but also to understand his own conflicts and emotions (Lacan, 1949; Ver Eecke, 2006). From this view, it could be assumed that mirrors and videos provide the AHP patient with transient experiences of structuration in the face of all the predicaments they find themselves in after stroke, including physical, cognitive, and social issues. In AHP, brain damage has disrupted the normal mechanisms by which a non-AHP patient (or almost any other patient to that effect) can update previous representations to what happens in reality, not without having to deal with both defensive and coping mechanisms that would in this case be considered normative.

Maurice Merleau-Ponty articulated from a phenomenological standpoint the principle of the 'primacy of perception' (Merleau-Ponty, 1964), placing the act of perception (which cannot occur without a physical body) as a foundation of the understanding of the world and the way in which we engage with it. Thus, the body and what the body perceives cannot be dissociated. The author statesthat a "pre-reflective, bodily existence" is the base of higher mental functions. Furthermore the existence of two related views of oneself and his/her body are proposed: the 'body for me' and the 'body for others' (Merleau-Ponty, 1962). He elaborates: *"…'for me'* and *'for others'* coexist in one and the same world, as is proved by my perception of another who immediately brings me back to the condition of an object for him*"* and adds that *"*through others' eyes we are for ourselves fully visible*"* (Merleau-Ponty, 1968). This conceptualisation is specifically interesting when viewed in light of the particularities of AHP as manifested in visual feedback (mirror, videos) experiments and in negative verbal feedback provision paradigms following a task, both instances in which awareness of hemiplegia increases.

As mentioned earlier, offline observation of paralysis from a first-person perspective, offline view has not been previously investigated. A proposal for a research study intending to assess whether offline view of the motor deficit from a first-person perspective under self and other-reference conditions (i.e. patient acknowledging it's his/her own view, and by requiring him/her to suppose it is

someone else's first person perspective view), facilitates an increase of self-awareness in an AHP patient, will be included in the annex of the present work. The rationale behind the idea of using a first person perspective in reference to another person is that such a task provides the patient with an opportunity to displace the threatening event onto another hypothetical person, whilst keeping his own, real person perspective in a 'safer' environment. In light of the cognitive arrest hypothesis, it could be assumed that displacing the threatening object in that way would allow focal attention to shift back to the demand made by reality to which the patient should adapt (i.e. acceptance of deficit). In that way, inhibition, compromise, or *arrest* of a vast array cognitive functions, could be avoided along screen behaviours and denial reactions that present as a result. If this compromise is avoided, then a stable relationship with the threatening object could remain, leading to acceptance, recognition, or awareness of hemiplegia.

Subjectivity

As previously covered in the present work, exploring the subjective experience that patients have of their illnesses provides very rich insight into the nature of the phenomenon that is being studied. With increasing emphasis in individually tailored clinical approaches, an understanding of the phenomenon from the patient's own point of view is ever more relevant. Qualitative research methods have allowed the exploration of key components of the patients' understanding and experience of the illness in ways to complement empirical research, and have thus been increasingly accepted in the scientific community.

It is important to mention that the approach of subjectivity from psychoanalysis and from qualitative research has several things in common. Psychoanalysis is a theory and a practice that has always insisted on the individual specificity of each case, and has thus always given the right to the patient to 'use the microphone', which is exactly what qualitative research aims to do. Both approaches are therefore inclined to let the version of the patient count.

This work covered some insights from patients' experiences of different illnesses, including the experience of different consequences of stroke in survivors (e.g. Klinke, *et al.*, 2015; Barker & Brauer, 2005). However, no study has addressed the AHP patient's experience of denial and of the painful object. Therefore, a sketch for a first-ever qualitative investigation on the subjective experience of denial and unawareness in chronic AHP will be annexed to this work. This intends to illustrate clear and practical ways to advance the understanding of subjective experience in AHP, and how could it potentially contribute to all other relevant 'objective' aspects with the ultimate goal of deepening knowledge about this unique disorder. The objective of the proposal is to explore the subjective experience of follow-up AHP and hemiplegia only control patients of changes in awareness, motor and cognitive functions following a right-hemisphere stroke and of perspectives on coping with adversities and rehabilitation. An important element for the design of the proposal is the 'painful object' as proposed by the cognitive arrest hypothesis (Dorpat, 1983). The interview schedule is designed in a way that a narrative of the progression of phases that precede stroke, throughout the day when the interview takes place, arrives at the point where report of the 'painful object' (i.e. hemiplegia, anosognosia) could be expected. Strategies used by the patient to disavow, confront, or deviate from the painful object should be analysed. More specific procedures for this proposal can be found in the annex of this work.

Conclusions

The cognitive arrest hypothesis of denial (Dorpat, 1983) is a psychoanalytic approach that offers an optimal framework to discuss evidences and observations on the mechanism in AHP stemming from neuroscientific research, and from the theoretical debates within psychoanalysis. As the model takes into consideration aspects of denial that have been found to be of aetiological value by some neuroscientific approaches, a dialogue with psychoanalytic conceptions that stress the same or similar aspects can be established. The establishment of such dialogue has the potential to contribute to the understanding of the syndrome and the mechanism of denial, as can be reflected by the research proposals included in this work. These research proposals show how distinct evidences from some current approaches in AHP research, viewed in the light of the cognitive arrest hypothesis of denial, can derive in practical steps to advance knowledge in the field. On the other hand, empirical evidence yielded by AHP studies may assist psychoanalytic approaches on denial in clarifying the internal debates explored in this work. Psychoanalysis and neuroscience–including the approaches in which this work focuses –are similar in that they are heterogeneous and plural. The origins of both may be tracked to diverse sources and it is along their trajectories that they converge with different practices, knowledge, and disciplines.

It is important to mention that a review of the concept of denial from psychoanalytic approaches in the context of this work is complicated by the lack of reference to neurological cases in many available accounts. Neurological cases pose hard questions for psychodynamic theory at conceptual and technical levels, as they leave less space for interpretation inasmuch as the patient is suffering from physiological damage as well. Psychodynamic theory would nevertheless gain from analysing how its tenets and proposals apply in these populations and multi-disciplinary debates, like the one that shall be developed in the next chapter, are very needed.

The importance to stress the subjectivity of the patient with AHP was also addressed. Patient's personal, subjective experience of AHP provides valuable information for the overall understanding of the syndrome and of denial. Exploring these issues can contribute to better diagnose and treat not only AHP patients, but also any type of hospitalised patient. The present work therefore proposes a qualitative study to address these issues for the first time in a follow-up, AHP patient population.

ANNEX
Experimental Proposals

OBJECTIVE

The target of this study is to assess the influence of viewing a motor deficit in oneself from first person, self and other-referential perspectives on denial of the deficit; and evaluate whether motivational processes play a role in the self awareness of stroke survivors that present AHP and HP as sequelae of right brain damage.

MATERIALS AND METHODS

Patients

Admissions to a stroke unit rehabilitation unit are consecutive and medical notes are produced for each patient and screened to identify eligible patients. According to the experience gained by the research team in the last 7 years, it is calculated that 9 patients will match the inclusion criteria and consent for participation during the period of recruitment. This will be undertaken in seven London-based acute stroke wards: King's College Hospital, St. Thomas' Hospital, Homerton University Hospital, University College London Hospital, St. George's University Hospital, Royal Free Hospital and the National Hospital for Neurology and Neurosurgery.

Inclusion criteria

(i) Right hemisphere stroke, as detected by MRI, CT scans and confirmed by subsequent neuropsychological assessment.

(ii) Less than 4 months after onset.

(iii) Contralesional hemiplegia.

(iv) Anosognosia for hemiplegia.

Exclusion criteria

(i) Presence of generalised brain damage.

(ii) Psychiatric history.

(iii) Less than 7 years of education or an estimated premorbid Full Scale Intelligence Quotient (FSIQ) of 70, based on the Wechsler Test of Adult Reading (WTAR).

(iv) Acute confusional state (forward digit span <5, abnormal sleep- wake cycle).

(v) Medication treatment with severe cognitive and/or mood effects.

(vi) Severe language impairments (unsatisfactory comprehension, expression or communication)

Neuropsychological assessment

A number of standardised neuropsychological tests will be applied: the Mini Mental State Examination (MMSE) (Folstein, *et al.*,1975), assessment of proprioception (Vocat, *et al.*, 2010), the 'confrontation' technique (Bisiach, *et al.*,1986), the WTAR (Wechsler, 2001), and the digit span task from the Wechsler Adult Intelligence Scale III (Wechsler, 1998). Also: the Cognitive Estimates Test (Shallice and Evans, 1978); the Frontal Assessment Battery (FAB; Dubois et al., 2000); the Medical Research Council scale (MRC; Guarantors of Brain, 1986); the Behavioral Inattention Test (BIT), and the 5-item test from the Montreal Cognitive Assessment (MOCA) (Nasreddine, 2005). The One Item Test (Bisiach, *et al.,* 1986), the Comb/Razor Test (MacIntosh, *et al*., 2000) and the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) will be used to assess depression and anxiety symptoms related to hospitalization.

Testing for anosognosia and associated disorders

The Berti Assessment (Berti, *et al.,* 1996) will be used to diagnose anosognosia for left hand hemiplegia and to discriminate participants who meet the inclusion criteria for the study into patients and controls. This assessment includes general questions (e.g. 'why are you in the hospital?'), specific questions concerning motor ability (e.g. 'can you move your left arm?'), and 'confrontation' questions (e.g. 'please touch my hand with your left hand. Have you done it?'). The interview is scored on a 3-point scale where:

0 = the patient answered correctly, to the first group of questions (normal); 1 = the patient acknowledged being in the hospital and/or being affected by a stroke, but denied his or her upper limb impairment; however, the patient acknowledged that the left arm did not reach the examiner's hand (indicative of mild anosognosia);
2 = the patient claimed that he or she had reached the examiner's hand (indicating severe anosognosia). Patients scoring 1 or 2 will be classified as anosognosic.

In addition to this test, the results of the different assessments of anosognosia as measured in the same patients by other members of the team, will be considered to confirm presence and extent of unawareness. This will avoid repetition of tests or adding information that does not apply directly to the current research.

Experiment 1: Negative affective modulation

Aim

The goal of this experiment is to investigate if induced negative emotions whilst watching a video-replay of another patient's motor failures can affect the report of motor awareness in AHP patients.

Design

Recent studies on the role that affective, motivational and emotional factors play in AHP yielded data showing increased interference (response latencies) for emotionally threatening words in these patients (Nardone, *et al.*, 2007) and that, among two emotion induction procedures (positive and negative), only the latter increased awareness of the deficit (Besharati, *et al.*, 2014). These findings point at the relevance of further evaluating the degree to which affective modulation of denial of paralysis is possible.

In addition, the use of paradigms considering perspective and referential processing has been employed to gather evidence on their role in the recognition of deficits in the self as well as in other people. In this line, Moro, *et al.* (2011) asked AHP patients to report how capable they are to perform a series of actions (i.e. cutting meat, hammering a nail) and, after a short interval, answer the same questions, but referring to the performance of another hemiplegic patient that was seated in front of them. The results revealed that seven patients were anosognosic for both self and other-referred conditions, whilst four others showed lack of awareness only in the self-referred interview. However, this study does not consider the effects that such a manipulation could have on awareness if presented under an offline perspective condition, that is, in the absence of moment-to-moment, online cognitive processes.

Recent case studies have nevertheless provided preliminary data supporting the use of offline, video replays to increase motor awareness in AHP patients. For instance, Besharati, *et al.* (2015) investigated their use in a study involving two AHP patients. An acute patient went through multiple sessions of video-based self-observation (self-reference) of his/her performance in the Berti, *et al.* (1996) interview, which includes instructions to move the paralysed hand among other questions to measure awareness. The same questionnaire and video procedures were used for a second, chronic stage post-stroke onset AHP patient. In this case, the intervention was based upon a single session in which, in addition to the self-referent video, the experimenter showed an equivalent video of the performance in the same interview of another age and gender-matched, hemiplegic patient without anosognosia (other-reference). Both patients showed increases in self-awareness immediately after the re-plays, even if the changes did not persist into complete recovery. The authors conclude that video-replay seems to be what could be called a "first step" towards rehabilitation of awareness within a more elaborated programme.

To gather further evidence for the arguments presented above, the goal of this experiment is to investigate whether inducing negative mood by supplying negative feedback on motor deficits in offline mode can increase online awareness of deficits in the self and others. These factors are to be analysed by manipulating the provision of negative or neutral remarks on the performance of some instructions of another person with left-hand hemiplegia in a video replay. This will allow a 1 (Group: AHP) X 2 (Feedback: Ng, Nt) mixed factorial design, in which neutral (Nt) and negative (Ng) feedbacks are the within-subjects factors.

<u>Independent variables</u>

(i) Verbal feedback of performance (Ng, Nt).

<u>Dependent variables</u>

(i) Report of other person's performance.

(ii) Emotional state scores.

(iii) Online motor awareness.

A small sample, changing intensity design will be used to increase the generation of data for each participant with the goal of reaching higher levels of validity, and to frame the timing of the intervention and other measurements throughout the experiment. The experiment could be expressed with the following formula:

PreG → A * B^1 A * B^2 A → PostG

Where:

PreG = Global measure of awareness before experiment

A = Baseline awareness for experiment

B^1 = Intervention (video re-play, neutral feedback supply, performance rating)

B^2 = Intervention (video re-play, negative feedback, performance rating)

* = Measurement of current mood status.

See below in *Experiment* for details on each of the above factors.

Procedures

Video production: Another person's deficit

Firstly, a clip will be elaborated during the preparatory phase of the study. The content of the video includes the performance of an age and gender-matched actor in 6 different instructions. The actor will be seated as the patient sits presently at hospital and will be at the centre of the screen from the waist upward in a way in which both naturally stretched arms and hands are visible. Like a mirror, the experimenter will sit in front of the actor with the camera.

The left hand of the actor will perform unsuccessfully in all instructions where it is

involved. A space of 3 seconds will be allowed after the performance of the participant before proceeding to the next instruction.

1. Make a fist with your right hand.
2. Touch your left arm with your right arm.
3. Can you move your right elbow?
4. Can you twist your wrists simultaneously?
5. Make a fist with your left hand.
6. Touch your right arm with your left arm.

See below in *Intervention* for detailed N and Ng statements.
Additionally, this clip will be edited in a way in which the last three instructions are presented before the first three instructions. This is to control for possible order effects in the presentation and consequences of a particular feedback as will be explained below in *Intervention*.

Pre and post-experiment general awareness (PreG, PostG)

In order to obtain a global measure of explicit and implicit awareness of deficit prior to the first experiment and after a second experiment to compare changes, a set of 4 items extracted from previously validated questionnaires and adapted for the purposes of this investigation will be asked to the patient. Two questions from the Feinberg, *et al.* (2000) Anosognosia for Hemiplegia Questionnaire will assess explicit knowledge about the deficit; one instruction (not to be performed) from the Experimental Bimanual Task (BMT) (Della Sala, Cocchini, *et al*., 2010); and one estimation from the Della Sala, Cocchini, *et al*. (2009) Visual Analogue Test for Anosognosia of Motor Deficit (VATAm) will assess behavioural awareness, as follows:

<u>Explicit awareness</u>

1. The doctors tell me that there is some paralysis of your arm. In a scale from 0 to 5, where 0 is ‘don’t agree at all’ and 5 is ‘totally agree’, can your left arm move like before?
2. There is some paralysis according to the doctors. In a scale from 0 to 5, where 0 is ‘don’t agree at all’ and 5 is ‘totally agree’, do you think the same?

Behavioural awareness

1. Are you able to clap your hands? (Yes/No)
2. Are you capable of using a stairway? (Yes/No)

The examiner will code ‘No’ as 0 and ‘Yes’ as 5 and will add the scores to the ones of the first two questions in order to find the global awareness score.

Experiment

A) *Baselines*

Two questions to assess the current status of awareness before starting and after finishing the first experiment will be asked. The goal is to measure changes in awareness before and after the intervention, taking into account the nature of the feedback that will be provided. The questions are extracted from the Structured Awareness (Marcel, *et al.*, 2004) and will change phrasing each of the two times they will be employed to avoid repetition:

Unimanual awareness

- In a scale from 0-5 (where 0 is ‘not at all’ and 5 is ‘very well’) how well can you presently drink from a glass of water with your left hand compared with your normal ability?

Alternative phrasing: In your present state, compared with your normal ability, how well can you drink from a glass of water with your left hand? Use a 0-5 scale (where 0 is 'not at all' and 5 is 'very well').

Bimanual awareness

- Compared to your normal ability, how well can you wash your hands at present? Use a 0-5 scale (where 0 is 'not at all' and 5 is 'very well').

Alternative phrasing: In a scale from 0-5 (where 0 is 'not at all' and 5 is 'very well') how well can you currently wash your hands compared with your normal ability?

B) *Intervention*

The clip in which the actor performs instructions given (see above in *Production of a video*) will be ready to play in a laptop. The laptop will be placed on the participant's lap moved and turned slightly to the right of the hemifield to minimise potential left hemineglect. The experimenter will ask whether participants have a full view of the image on the screen and can describe everything that they see.

The researcher will explain: 'We are now going to watch a video of the performance of another person in some instructions that we recorded earlier. We will see the performance and you will rate how successful it was. Then you will try to perform each instruction yourself and you will tell me how well you did.'

When ready to start, the frame of the clip before the first instruction will be frozen and shown to the patient.

The experimenter will proceed: 'I am going to push play and we will hear my instruction in the video. Then, we will see X's performance and you will tell me how successful it was after I pause the clip. Are you ready?' The experimenter will push play and pause the clip after the actor performs the first instruction and

then ask ‘did X make a fist? How successful was X?’ (‘Unsuccessful’ will be scored as 0; statements such as ‘kind of’ or ‘a bit’ will be computed as 0.5; ‘succesfull’ will be scored as 1). The experimenter will tell the patient: ‘Can you show me how you make a fist with your right hand?’ and after the instruction is followed: ‘How successful were you?’ (‘Unsuccessful’ will be scored as 0; statements such as ‘kind of’ or ‘a bit’ will be computed as 0.5; ‘succesfull’ will be scored as 1).

At this point, the experimenter will provide a feedback. In the case of the first three instructions (which involve intact right hand skills), neutral remarks will be provided, whilst negative feedback will be provided for the last three instructions.

Neutral feedback

- I can see how you… (e.g. make a fist)
- You… (e.g. touched your left arm with your right arm)
- That’s it.

Thus, after a neutral remark is given to the patient after his/her performance, the video will be re-played to continue to the second instruction. After the actor performs it, the experimenter will ask ‘did X touch his/her left arm with his/her right arm?’ followed by ‘Can you show me how you touch your left arm with your right arm?’. After performing, the patient will be asked ‘How successful were you?’ (These items will be rated as above in the first instruction). The same procedure will be followed until the last instruction.

After allowing for enough time to debrief, the last three instructions of the video will proceed like the first one, with the exception that the randomised feedback provided after following the instructions will be negative.

Negative feedback

- That was unsuccessful.
- X did not do very well on this task.
- You did poorly this time.
- You did not perform very well.

Current mood status

The current emotional state will be measured to evaluate the influence of the type of feedback on the mood status after each set of three questions and before the baselines (A). Participants will be required to provide a subjective rating of their current emotional state on a 6-point Likert-type scale. The experimenter will say: ‘Using this scale from 0 to 5, 0 being ‘unhappy’ and 5 being ‘very happy’, how do you feel right now?’. The scale will be read to patients and presented vertically on an A4 sheet of paper (0 at the bottom and 5 at the top), positioned in the patient's right visual field in order to control for possible unilateral visual neglect effects.

Controlling for order effects

To control for possible order effects in the provision of neutral and negative stimuli, half of the cohort will be given the instructions as described above, whilst the second half will be given the second set of three instructions (the ones corresponding to negative feedback) first, followed by the instructions corresponding to neutral feedback.

Experiment 2: Self as Other (SaO) and Self as Self (SaS)

Objective

This study is meant to assess whether offline view of the motor deficit, from a first-person perspective under self and other-reference conditions, facilitates an increase of self-awareness in AHP. The patients will participate in this experiment once experiment 1 concludes and enough time is allowed for rapport and debriefing. This is meant to reinforce the patient's and the experimenter's alliance and hence their overall engagement with the study.

Design

This experiment is based on the premises previously revised (see *Design* in Experiment 1). References on the use of offline observation of a motor deficit from a first-person perspective are nevertheless not to be found in existing literature. Manipulation of self "as if it was another" has not been previously used at this level in AHP patients. Henceforth, the present experiment aims to assess whether showing the patient an offline video-replay of his/her own performance from a first person perspective, and viewing the actions from different self-referential standpoints, has an influence in awareness of the deficit. This will allow for a 1 (Group: AHP) [between-subjects factor] X 2 (Reference: Self as Self, Self as other) [within-subjects factor] mixed factorial research design.

Independent variables

(i) Reference (SaO, SaS).

Dependent variable

(i) Online motor awareness.

A small sample, alternating treatment research design will be employed to frame the timing and the patterns to run the experiment. Such design could be expressed using the following formula:

PreG → A B A C A → PostG

Where:

A = Baseline awareness for experiment.
B = Intervention (video re-play, SaO)
C = Intervention (video re-play, SaS)

To control for order, fatigue or carry-over effects, half of the cohort will participate according to the following order:

PreG → A C A B A → PostG

The intervention will further require them to judge whether the instruction was performed or not according to what the patient sees, if the view in question (patient's 1PP) was somebody else's (the patients will be asked to choose a different name for that hypothetical person) (Self-as-Other), and then according to what they see from that same perspective but as themselves (Self-as-Self). To control for possible effects of the order of Self-as-Other (B) and Self-as-Self (A) conditions, the sample will be counterbalanced and analysed using a small sample number research technique. In the specific case of this experiment, 50% of participants will follow SaO – SaS and the remaining will follow SaS – SaO.

Procedures

Video production: Self-Other reference

Once participants consent to participate in the study before commencing Experiment 1, the experimenter will film a video of the patient for further use whilst the patient performs a set of instructions (see below in *Design* for Experiment 2 for complete details).

To proceed with filming, the researcher will position him/herself behind the right side of the participant and hold the camera over the shoulder, in line and as close as possible to the right eye without touching, during the performance of the instructions. The camera will thus be positioned in a first person perspective with its focus on the participant's midline and in accordance to the focus of the eyes and will record the experimenter's instructing voice as well as the performance of the hands, which should be visible from 3cm above the elbow to the tips of the fingers. An object will be placed to the left of the hospital table at a reaching distance from the right hand. When filming, the patient will be asked to reach that object in two separate trials with their right hand to establish initial image processing and self-recognition in the video. The first instruction is planned to be one that the patient can successfully follow as a warm-up for detecting movement in the video, whilst the patient is meant to fail in the remaining three instructions due to left hand paralysis. The instructions include:

1. Use your right hand fingers and show a number 3.
2. Use your left hand fingers and show a number 5.
3. Shake your left hand.
4. Turn your left hand palm-up.

When the video production ends, the clip will be kept until the first intervention phase of the second experiment, when it will be shown to the participant.

Experiment

A) *Baselines*

Two questions to assess the current status of awareness will be asked before

and after each intervention. A global measurement of awareness after the experiment (PostG) (see *PreG and PostG* in *Design* of Experiment 1) will be undertaken in order to compare changes in respect to the PreG measurement undertaken before Experiment 1. The questions for the baselines of the experiment are the same that will be used for baselines in Experiment 1.

B) *Self as Other (SaO)*

The frame of the clip before the first instruction will be frozen and shown to the patient. Before continuing, the patient will be asked: 'do you recognise yourself in the video?' after being shown his/her attempts to reach the object with their right arm when the video was filmed as explained before. The goal of this action is having a mechanism at this point of the procedure for the patient to recognise himself in the video and to bypass possible neglect. After successful recognition the researcher will say: 'Now, let's imagine these are not your hands, they are somebody else's. Let's choose a name for this person to whom the arms belong', plus 'any particular reason why you chose that name?'. The experimenter will continue: 'I am going to push play and we will hear my instructions in the video. We will also see X's performance and you will pay attention to X's left arm. After I pause the clip, you will judge X's performance in the video as if you were watching X from the outside. You will also state whether the left hand was successful or not after I pause the clip. Do you understand? Are you ready?'

The first scene of the video will be frozen and ready for re-play once the laptop has been placed on the participant's lap or hospital table. After the first instruction is performed, the video will be paused and the experimenter will ask the patient 'did X's left hand perform the instruction successfully?' (Negative will be coded as 0, statements like 'partially' or 'a bit' as 0.5, and affirmative as 1).
The other instructions will follow the same procedure. The lower the total score, the more awareness of left hand paralysis.
At the end, the experimenter will ask: 'If someone else other than you was

watching X's performance, how successful would that person say was X's overall left arm performance during the video according to that person's view?' ('Unsuccessful' will be scored as 0; 'partially' and alike as 0.5 and 'successful' as 1).

C) *Self as Self (SaS)*

After allowing some minutes for debriefing and rapport, the researcher will say: 'We are going to watch the same video again. You might feel by now that it is too repetitive, however, the tasks are slightly different every time'. After a brief pause, the experimenter will add: 'This time you should judge your own performance from your own perspective'.

After successful self-recognition as previously described, the frame of the clip before the first instruction ('Make a fist with your right hand'), will be frozen and shown to the patient. The experimenter will say: 'I am going to push play and we will hear my instructions in the video. We will also see your performance and you will pay attention to your right and left arms. After I pause the clip, you will state, from your own perspective, whether your left hand was successful or not. Do you understand? Are you ready?' The experimenter will then push play and pause the clip after the patient reports his views on the first instruction, and successively until the last.

It is important to note that, as aforementioned that the order of SaO and SaS conditions will be changed every second participant to control for possible order effects on the responses, which means that in half of the cases, the SaS condition will precede the SaO condition.

Post-experiments general awareness (PostG)

As mentioned elsewhere, post experiments measure of general self-awareness will take place after every experiment. This last assessment is meant to measure the global state of self-awareness as preceded not only by the last intervention, but by the two experiments proposed in this study.

Body and self after right hemispheric stroke: An AHP follow-up study

AIMS AND METHODS

The objective is to explore the subjective experience of follow-up AHP and HP control patients of changes in awareness, motor and cognitive functions following a right-hemisphere stroke and of perspectives on coping with adversities and rehabilitation.

This study aims to analyse from a phenomenological standpoint the process of integration or continuity of the subjective lived experience of embodied self before, during and after the stroke. Additionally, expectations about the future in will be inquired. Interpretative Phenomenological Analysis (IPA) (Smith, *et al.*, 2009) will be the method used in this study. This qualitative research method allows patients to evoke their own thoughts and feelings regarding the stroke and to lead the process of meaning making.

It is important to consider that the population participating in this study does so in the context of a stroke history, meaning that the subjective account narrated by the patients is influenced by the specific brain damage. Participants' responses should be analysed and interpreted in light of this clinical context.

Patients

Previously screened and tested patients as part of a larger, neuropsychological; study on AHP will be followed-up and in the current study new patients will be recruited and followed-up in similar intervals.. Inclusion and exclusion criteria, as well as neuropsychological assessments at baseline will be the same as for the overall study as specified above in the experimental investigation

The Berti Assessment (Berti, *et al.,* 1996) (with alterations corresponding to the location of the interview) will be used to diagnose potential chronic anosognosia for left hand hemiplegia. This assessment includes general questions (e.g. 'why are you in the hospital?'), specific questions concerning motor ability (e.g. 'can you move your left arm?'), and 'confrontation' questions (e.g. 'please touch my hand with your left hand. Have you done it?'). The interview is scored on a 3-point scale where:

0 = the patient answered correctly, to the first group of questions (normal); 1 = the patient acknowledged being in the hospital and/or being affected by a stroke, but denied his or her upper limb impairment; however, the patient acknowledged that the left arm did not reach the examiner's hand (indicative of mild anosognosia);
2 = the patient claimed that he or she had reached the examiner's hand (indicating severe anosognosia). Patients scoring 1 or 2 will be classified as anosognosic.

Additionally, the Cutting, *et al.* (1978) Anosognosia Questionnaire will explore the current sense of ownership and feelings towards the paralysed arm.

Procedure and data collection

A standard explanation of the study will be provided to the patient before starting a semi-structured interview that will take place at the patient's home and that will be recorded for further transcription. The goal of the interview is to evoke the patient's subjective experience of changes in awareness, cognition and capabilities and perspectives on coping, rehabilitation and the future and compare the outcomes of veteran AHP patients and HP controls.
The interviewer will be able to directly refer to terms related to the illness (e.g. paralysis, weakness, unawareness) only after allowing the patient enough time to

evoke these issues spontaneously. It is however important to mention that within the spontaneity needed to freely evoke material, the interviewer needs to secure that stroke remains the central topic of the interview.
The interviewer will ensure the patient acknowledges he/she may withdraw from the interview at any time. Other conditions under which the interview may be interrupted include fatigue, lack of compliance or issues concerning environmental factors (e.g. family concerns, patient's routine schedule, potential cultural restrictions). The duration of the interview should not exceed 1 hour and is to be adapted as necessary to the conditions of the patient.

As recognised in IPA literature, as the interview progresses, the patient is 'warmed' (sic.) until capable of evoking the specific experiences and associated thoughts and feelings needed for the study (Smith, *et al.*, 2009). The authors mention that this develops usually during the first stages of the interview, however, in order to achieve this as early in the conversation as possible and to procure the elicitation of more elaborated and meaningful answers at the outset, the interviewer will make sure that rapport is established and will ask three warm-up introductory questions not directly related to the study that will demand from the patient: a description, a request for additional details, and to choose which would be the most important ones for him/her among the ones mentioned.

To facilitate further discussion, the interviewer will suggest using a tree as an analogy to the history and accompanying subjective experience of the patient that comprehends from the time before the stroke until the present day. A standard drawing of a tree will be shown to the patient in a vertical A4 sheet of paper. Each part of the tree, from the roots to the fruits at the top, corresponds to a different phase in the life of the patient, each of which will entail a set of specific questions. As conversation progresses, the experimenter will point with his/her finger to the part of the tree that corresponds to the phase that will be discussed next. It is the task of the interviewer to detect any resistance shown by the patient as a result of the presentation of the drawing and/or the use of the tree as an

analogy. In such a case, the interview can still proceed as planned, only without the drawing and with no mention of the tree or it's parts.

It is pivotal to maintain stroke as the main topic around which the conversation revolves and to start the interview from present perspectives. Hence, the order of the phases with their respective tree parts and questions will be as shown in the at the end of this section.

Each interview will be followed by debriefing, during which the interviewer will assess whether the conversation elicited emotions requiring further attention or containment. The interviewer will summarise the points that were covered and will emphasise the positive coping skills and achievements of the patient throughout the process.

Data analysis

As mentioned elsewhere, the IPA qualitative research method (Smith, *et al.*, 2009) will be used to analyse data yielded by the participants.

The interviewer will elaborate a fieldwork diary in order to register personal impressions and interpretation following each interview. This will help minimising interpretation bias by the interviewer as it is considered in further data analysis.

The interviewer will listen to the whole recorded interview twice before writing a full transcript, that will be further read and re-read to find salient units of meaning and to detect emergent themes, both of which will be summarised separately for each patient. A chart summarising this information across patients will be made and similar themes will be grouped under topic-specific clusters and will allow a hierarchical classification of themes according to degree of salience across patients. Moreover, each case and the complete process will be carefully supervised and discussed by the laboratory team in order to achieve a higher degree of validity and of attachment to the protocol.

Item	Phase of Self	Description	Rationale	Questions / Prompts
Roots	Before stroke	*Past:* Memories, self-defining achievements, failures, ambitions.	Gain deeper understanding of patient's context, subjective experience of previous behaviour, possible sources of motivational conflict and compensatory behaviour.	→Tell me a little bit about how were you like before your stroke. Hobbies, family? →What ambitions or expectations of life did you have? →Can you tell me about an important achievement? →Can you give example(s) of how you coped with any failures?
Trunk	Immediately before, during and immediately after stroke	Experience of self, body, others in right hemispheric stroke.	Produce a narration of events and symptoms from the patient's perspective; learn about habits, culture, surrounding environment (family, community, staff), knowledge and beliefs regarding illness.	→ How did you arrive in the ward? What were you doing? How were you feeling that day? Who helped? → How would you describe your contact with hospital staff, family during that time? → What do you remember about your stay in hospital? Food menus, smells, noises, touch. → What do you know about your stroke? (Explanations, physiological understanding, stroke location)
Branches	Rehabilitation, defense and compensation	Discuss problems and obstacles encountered, ways and resources used to cope with them and feelings around it. Explore the impact of changes in the body, and ways in which the patient has tried to compensate.	Elicit the 'Painful Object' (i.e. left arm paralysed) in the conversation. Produce patient's narrative, perspectives, subjective experience. Direct 'confrontation' with the trajectory of denial. Evoke the subjective experience of denial of paralysis. Elicit material to further compare against previously employed defensive and coping strategies.	→Which would you say have been the most difficult issues to cope with since your stroke? (i.e.: what happens, how do you feel, how do you cope?) (i.e.: Abilities, body, sensation) (is deficit in left arm spontaneously mentioned?) → How about your left arm? → What do you remember about your left arm during your stay in hospital and during rehabilitation? (i.e.: what happens, how did you feel, how do you cope?) (i.e.: Abilities, body, sensation) → What attitude did you have regarding your left arm during your stay in hospital until now? → Do you remember denying or underestimating the effects of paralysis in your left arm? → How do you think that your family/friends perceived the paralysis in your left arm? →How well have you coped with your left hand paralysis compared to previous adversities in your life? (i.e. death, pain, work, family) → Which were your sources of help during this time?
Foliage	Outcomes	Result of strategies applied, what is the present state of things, degree of satisfaction.	Elicit patient's subjective perspective of how physical and emotional challenges unfolded and to which degree he/she overcame them.	→ How would you describe the results of the rehabilitation of your left arm until today? Physical, emotional. → Has your relation with friends/family changed in any way during the process? → What has been achieved Vs not achieved regarding the paralysis in your left arm?
Fruits	Prospective	Desired goals (physical, emotional) and views about the future.	Patient's subjective views on desired attainments, capability to undertake specific activities in the near or far future. Assess how realistic is the patient regarding his/her current state. Self Vs Others views.	→ How do you feel about your left arm now? And about the stroke more generally? → What do you think is the perspective of your family/friends regarding your stroke now? → How do you think they feel about your future? → More importantly, how do you feel about your own future?

Interview schedule

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