Abstract

Social psychological research into adjustment and adaptation to brain injury has revealed "unrealistic" self-appraisal as problematic for people with brain injuries and the people in their social environments. This unrealistic self-appraisal can be expressed as reduced awareness of physical, cognitive and/or emotional difficulties, which occur following neurological damage. However, the development of a realistic self-appraisal is seen as important if people with brain injuries are to engage in rehabilitation and live fulfilling and meaningful lives.

In this thesis this point of view will be challenged. Instead, awareness of difficulties will be linked to social interaction. It will be suggested that the discursive environments of people with brain injuries may be beneficial for the development of awareness of difficulties after a brain injury. A concept of self-knowledge is introduced to guide the collection and interpretation of the data. The concept derives from an integration of a social symbolic interactionist theory (Mead, 1934) and a social constructionist theory of consciousness (Burns and Engdahl, 1998). It emphasises that self-knowledge is constructed during social interaction and that the information exchanged during this interaction is assimilated, internalised and used in self reflection. In addition, the concept also recognises that self-knowledge involves selection from multiple sources of information used to form a united sense of self.

The empirical work includes three studies. Study One consists of two parts. Part One of the first study examined the salience of the brain injury and the difficulties that follow the brain injury in the narratives of people with brain injuries. It was found that people with brain injuries referred equally to their brain injuries and to their physical difficulties. Cognitive and emotional difficulties were referred to in second and third place. The results gave little indication that the participants understood the implications of their difficulties for their everyday lives. In Part Two of the same study, significant others were interviewed and asked to talk about their knowledge of the difficulties experienced by the people with brain injuries they supported. The
significant others were also asked about the ways these difficulties were explained by them to the people with brain injuries. It was found in this part of the study that significant others made more complaints about difficulties than people with brain injuries did but were reluctant to talk about these difficulties to the people with brain injuries. This was due to the physicality of some of the difficulties, in favour of protecting the person they supported and as a caring practice. Study Two examined the construction of knowledge of their difficulties by people with brain injuries. It was found in this study that people with brain injuries equated the acquisition of knowledge about their difficulties to a process of discovery which was the product of actor, social and physical environment. Study Three explored the discursive practices of non-expert health professionals and the ways in which this discursive environment was involved in the constructions found in the second study. The third study showed that some of the non-expert health professionals' lay theories of brain injury mirrored those of people with brain injuries.

The findings are discussed in relation to the integrative social constructivist theory of consciousness introduced in this thesis. Research into awareness of difficulties in brain injury cannot assume that any particular difficulty is problematic for any given individual or that a particular level of awareness should be imposed on people with brain injuries. Such an assumption, erroneous in some cases, would imply that people with brain injuries should construct their worlds in the same manner as the researcher. It is concluded that awareness of difficulties following a brain injury is too complex a phenomenon to be investigated from only one perspective.
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Chapter One - Introduction to the thesis

CHAPTER ONE

INTRODUCTION TO THE THESIS

1.1. INTRODUCTION

Social psychological research into adjustment and adaptation to brain injury has revealed "unrealistic" self-appraisal as problematic for people with brain injuries and the people in their social environments. This unrealistic self-appraisal can be expressed as reduced awareness of physical, cognitive and/or emotional difficulties, which occur following neurological damage. However, the development of a realistic self-appraisal is understood in the literature to be important if people with brain injuries are to engage in rehabilitation and live fulfilling and meaningful lives. This thesis challenges this point of view. Instead, it investigates the self-knowledge of people who have been affected by a brain injury. It aims to answer questions relevant to rehabilitation staff, carers of people with brain injury, families, researchers and clinicians in the field of rehabilitation after brain injury. It also aims to introduce a new theoretical perspective from social psychology to the study of brain injury. The investigation concerns the ways in which people with brain injuries construct knowledge of their difficulties and the challenges they have to face following the brain injury. Explanations of the findings are presented at an intrapsychic and social level.

One of the salient features of the process of reviewing the literature on awareness of difficulties following a brain injury was the emergent dominance of a research paradigm that gave neurological, neuropsychological or psychological interpretations of people's behaviour and resultant rehabilitation practices. Apparent deviance from the norms of acceptable behaviour came to be constructed as symptomatic of a disorder. Memory loss was interpreted not as lapses of concentration or selective memorising, but as indicative of a specific syndrome associated with pathological defects or injuries. It was noted that despite the absence of any neurological,
neuropsychological or psychological research evidence capable of explaining the aetiology of lack of awareness of difficulties amongst people with brain injuries, contradicting rehabilitation practices were recommended for lack of awareness of difficulties in people with brain injuries. The theory or theories which prompted such an approach appeared to be derived from a fairly simplistic analysis of individuals as part human, part machines amenable to repair once the cause of the problem had been isolated. Therefore, one of the main concerns of the thesis is the lack of any robust theoretical basis for the research and rehabilitation of people with brain injuries, who are assumed to have lack awareness of their difficulties.

The thesis thus asks whether this lack of awareness can be explained by a neuropsychological or neurological or psychological diagnosis only. As human beings are not machines many different factors might combine to lead to an apparently confused state of mind. In short, an alternative conceptual framework is needed to explore the phenomenon of awareness of difficulties following a brain injury.

This thesis presents such a framework. The research introduced here is moulded around a conceptual framework of self-knowledge developed from an integration of social interactionist theory and a social constructionist theory of consciousness (developed in Chapter Three). Social constructionism asserts that the apparent scientific basis on which neurological, neuropsychological and psychological practice is founded is only one way of interpreting the world. The paradigm of scientific knowledge is one in which reality is depicted as facts waiting to be discovered "out there". Yet, some writers argued, these facts are mental constructs that are influenced by social and cultural values. What is a hard fact today may be denied tomorrow. The portrayal of knowledge as value free is questioned by those who would argue that epistemologies gain acceptance and authority only by the merit of their being compatible with prevailing beliefs and value systems.

Thus, this initial foray into social constructivism led to the writing of this thesis, for under this umbrella it is understood that self-knowledge is constructed during social interaction and that information exchanged during social interaction is assimilated, internalised and the basis of self-reflection. In addition, the conceptual framework
recognises that self-knowledge involves selection of external and internal sources of information which are in turn constructed to give the person a unified sense of self. Understanding self-knowledge in this way not only recognises that the self develops from complex processes but it allows the research to explore the awareness of the self from other perspectives. That is, without assuming for example that people with brain injuries are motivated by a desire to protect the self from the negative implications of having been affected by a brain injury.

Integrating these theories of self-knowledge also allows the research to question the usefulness of other research paradigms, which quantify awareness of difficulties following a brain injury and treat the subject as a static phenomenon. McGlynn and Schacter (1989) and other workers in the field, call for more efforts to be devoted to the development of theoretical models and conceptualisations of unawareness phenomena. A notable feature of the literature is that there has been little attempt to make use of relevant concepts from other domains of psychological inquiry. This is then, as far as the researcher is aware, the first work on the social construction of awareness of difficulties following a brain injury. The introduction of this conceptual framework into the area represents therefore, its major theoretical contribution. The thesis will argue that awareness of difficulties after brain injury may be socially influenced, and that the major players in this construction are the individuals in the social environment of the people with brain injuries.

1.2. SUMMARY OF THE CHAPTERS

Chapter Two defines brain injury and introduces the problem of lack of awareness of difficulties as observed during clinical practice, during rehabilitation and in community settings. Evidence that lack of awareness of difficulties is observed in people with brain injuries is offered in the chapter from clinical, social and health psychology observations and research. The chapter reviews the theoretical explanations encountered in the literature, and outlines the development of awareness of difficulties following a brain injury. It is underlined in the chapter that researchers assume denial of difficulties to be a coping mechanism used by people with brain injuries leading to problematic rehabilitation. This assumption is questioned in the chapter and some methodological issues are discussed.
In Chapter Three, a theoretical perspective that allows the thesis to gain a non-neuropsychological understanding of lack of awareness of difficulties is established. This theoretical background is an integration of symbolic interactionism theories and a social constructionist theory of consciousness. The chapter develops the symbolic interactionist tenet and discusses questions of agency. Evidence for and limitations of the theory are also addressed. A social constructivist theory is introduced to widen the scope offered by the symbolic interactionist perspective. This position allows awareness to be understood as a defining form of consciousness. It argues that human consciousness results from the development of collective naming, classifying, judging, reflecting and talking applied to individual members of a collective. Individuals acquire the capacity to engage in self-reflectivity not only through the acquisition of language and collective representation but through the capabilities of discussing conceptions, observations and assessments of the self. It is suggested here that self-knowledge is constructed during social interaction through a process of assimilation, internalisation and self-reflection. In addition, the theory recognises that self-knowledge involves selection from multiple sources of information and that this information can be the content of communication. The chapter discusses the different ways the body, cognition and emotion can be the object of this communication. Reviews of the literature on the self in brain injury follow this discussion and the role of the other in brain injury is defined. The end of the chapter outlines the main research questions and summarises the studies. The introduction of the theory to the study of lack of awareness of difficulties after brain injury is then the main theoretical contribution of the thesis and is used to steer the research and the interpretation of the data.

Chapter Four considers the assumptions and implications of some methods commonly used to study lack of awareness of difficulties after a brain injury. It then describes the philosophical framework within which the research in this thesis has been undertaken. The constructivist ontological and epistemological positions are outlined to demonstrate the congruency of the methods used during the investigation within the chosen paradigm. The choice of exploring awareness of difficulties after brain injury by talking to the people affected by it is justified and the analytical procedures are explained.
The three studies in this thesis are described respectively in chapters five, six and seven. These studies investigated knowledge of own difficulties in people with brain injuries (Chapter Five), communicative practices in the social, everyday environment of the participants (Chapter Five), the constructions of self by people with brain injuries (Chapter Six) and communicative practices in the social environment of the participants (Chapter Seven). Chapter Five describes the first study of the thesis. The study is divided into two parts. Part One is an interview study in which people with brain injuries were asked to talk about themselves and their everyday activities. The study found brain injury and the physical difficulties of the participants to be predominant in the narratives of the participants. Cognitive and emotional difficulties were found to be of low salience. Explanations in terms of the visibility of the difficulties, the level of abstraction of some difficulties, memory loss and self-presentation are offered.

Part Two of Study One is an interview study with people appointed by the participants in Part One as their significant others. Significant others were asked here to talk about their knowledge of the difficulties being experienced by the people with brain injuries whom they supported. Significant others were also asked about the ways these difficulties were explained or talked about between themselves and the people with brain injuries. The patterns found in the data are explained in terms of lack of communication.

Chapter Six examines the construction of knowledge of their difficulties by people with brain injuries. It describes a second round of interviews in which the difficulties mentioned by participants in the first round were addressed directly by the researcher. This study found that people with brain injuries construct the knowledge of their difficulties in a manner resembling the sorting of a puzzle. The understanding of these difficulties is described then as a struggle involving their ability to control their own behaviour and their ability to remember.

Chapter Seven investigates further the discursive environment of the participants and the ways in which local discourses are involved in the constructions found in Study
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Two. Non-expert health professionals were interviewed as to their communicative practices in relation to cognitive and emotional difficulties which (coincidentally) were found to be of low salience for the people with brain injuries in Part One of Study One. This study found that the lay theories about lack of awareness of difficulties following a brain injury of non-expert health professional did not correspond to the clinical or academic theories of lack of awareness of difficulties following a brain injury. Non-expert health professionals' theories attributing behaviours to brain injury however, mirrored those of people with brain injuries and those held by academics, other health experts and the general population.

Chapter Eight summarises the findings of the three studies and considers the application of the social constructivist theory of consciousness to the study of awareness of difficulties after a brain injury. The chapter points to some limitations of the research, the implications of the research for rehabilitation practices and suggestions for future research. The chapter ends with some concluding remarks.
LACK OF AWARENESS OF DIFFICULTIES FOLLOWING A BRAIN INJURY: A REVIEW

2.1. INTRODUCTION
The last few years have witnessed a growing interest in the study of brain injury. The literature is replete with studies of its epidemiology, physiology, neuropsychology and outcome, together with a large number of comprehensive texts written about it. Despite this abundance of literature rehabilitation professionals and families of patients remain uncertain about how to deal with the challenges and complex problems presented by those who have sustained a brain injury. Further, recent studies point to the fact that in spite of rehabilitation and family efforts, people with brain injuries remain severely handicapped many years after the injury. The reasons for this lie largely in the unique epidemiological, physiological and neuropsychological characteristics of this population.

Before focusing on one of these characteristics though, it is important to remember what it is meant by the term "brain injury". The clinical and research literature can be very confusing because, all too often, the same word is used to define different phenomena and vice-versa. For example, brain injury and brain damage seem to be used interchangeably for any kind of insult to the brain or a malfunction of the brain. The effects of tumours (or their removal), stroke, haemorrhage, multiple sclerosis and other trauma are included in this description. Other descriptions talk about closed-head injury, described by Martin (1998) as an insult to the skull or any of the meninges. Closed-head injury has primary consequences such as bleeding, or swelling of the brain; it has also secondary effects such as cell death. This type of injury contrasts with penetrating head injury, which involves penetration of the skull and/or
meninges. Traumatic brain injury is a term that is used by some writers indistinguishably with the term acquired brain injury. The National Head Injury Foundation (NHIF) (1989) has described a traumatic brain injury as an insult to the brain caused by an external force that may produce reduced or altered states of consciousness, which results in impaired cognitive abilities or physical functioning. Traumatic brain injury can also be described according to the degree of severity of the injury as: mild, moderate or severe. In some instances, usually amongst carers of people with brain injuries and by some authors, the term acquired brain injury has been differentiated from that of its twin, traumatic brain injury and has come to refer, in their everyday parlance, cases of brain injury referring to stroke, tumours, aneurysms, haemorrhages and so on. By the term traumatic brain injury, these carers mean any brain injury that is the outcome of "a heavy blow to the head". In this thesis however, the term brain injury will be used in a global sense as it is the most widely used in the literature and it will refer to any damage to the brain ranging from heavy blows to the head, strokes, tumours, aneurysms, haemorrhages to ME and Alzheimer's. Distinctions will be made as and when the need will arise.

Having defined brain injury, the attention turns now to introducing one of the problems that affect rehabilitation and reintegration into the community of people with brain injuries, namely, lack of awareness of difficulties. The chapter proceeds with a review of theoretical explanations and evidence encountered in the literature, and outlines the development of awareness of difficulties following a brain injury. It then incorporates an alternative explanation to the phenomenon and underlines some methodological issues encountered in the research literature. The chapter concludes with a summary and limitations encountered in this literature.

2.2. LACK OF AWARENESS OF DIFFICULTIES FOLLOWING A BRAIN INJURY: THE PROBLEM

Lack of awareness of difficulties following a brain injury or, "unrealistic" self-appraisal, has been pointed out by a number of researchers in the field of brain injury (Ponsford, 1995, Prigatano and Fordyce, 1986a) as problematic at the time of social psychological adjustment and adaptation to brain injury. This problematic self-appraisal can be understood as reduced awareness of changes in cognition, behaviour
and personality. These changes which, allegedly, occur as a result of neurological impairment reduce motivation for rehabilitation, result in unrealistic decisions regarding work and produce conflict with family members. In general, however, the neuropsychological literature reflects widely on the consequences of brain injury. Attentional difficulties, perception, planning, action, memory, spatial orientation and language disorders have been analysed and documented. The debilitating and often dramatic effects of brain injury are well known and yet, it comes, as a surprise that a significant proportion of afflicted people are, unaware of their difficulties.

Lack of awareness of difficulties has important theoretical and clinical consequences (McGlynn and Schacter, 1989). Theoretically, lack of awareness of difficulties amongst people with brain injuries poses questions concerning the nature of the mechanisms that allow people in normal circumstances to be aware of their own overall functioning. Clinically, because unawareness of difficulties poses a difficult obstacle for rehabilitation purposes: if the patients are not aware of their difficulties they are unlikely to do anything about them. Setting the problem in context and a review of the literature will help illustrate the point.

2.3. THE PROBLEM IN CONTEXT: CLINICAL, REHABILITATION AND FAMILY SETTINGS

Lack of awareness of difficulties is a problem that was first observed and studied in clinical settings. Clinical observations such as those of Schilder (1934) and Ota (1969) state that brain injured patients are frequently unconcerned about their injuries, are unaware of their psychological disturbances and do not spontaneously complain of physical disabilities. Patients that seem somewhat aware of their difficulties only complain of minor physical problems or vaguely mental difficulties. Ford (1976), also in clinical observations, includes lack of insight as a primary change following brain damage.

Similarly, psychological rehabilitation research (e.g. Prigatano, 1986) has found that many severely brain injured patients will continue to minimise the severity of residual neuropsychological difficulties for several years following trauma. Groswasser, Wendelson, Stern, Schechter and Najenson (1977) reported that all the patients that
exhibited unawareness of behavioural disturbances when evaluated 6 months post-injury continued to do so at a 30 month evaluation. Similarly, Tyerman and Humphry (1984) note that although severely head injured patients might exhibit some awareness they often lack full insight into their condition and continue to hope that they will return to their former past.

Lack of awareness of social and behavioural changes following brain injury has also received the attention of social psychological research. By examining patient's own accounts in relation to relatives' accounts, Thomsen (1974) reported that patients did not complain about post-traumatic disabilities but close relatives acknowledged the changes in personality of the patient. Along these lines, Santos, Castro-Caldas and Sausa (1998) investigated the long-term consequences of brain injury for patients and families. Their examination of spontaneous complaints in people with brain injuries and the comparisons with the impressions of relatives concluded that relatives mentioned more complaints about the injured subjects than the injured subjects mentioned about themselves. This occurred in several domains: somatic, physical, cognitive and behavioural. Memory problems were highly reported by both groups but somatic problems were more frequently reported by patients while behavioural problems were more often reported by the relatives.

Memory impairment, attention difficulties and impaired judgement, as well known cognitive difficulties that follow head injury, have been investigated as possible contributors to the observed discrepancies between patients and relatives. McKinlay and Brooks (1984) asked 55 patients and their relatives to assess patients degree of impairment on various psychometric tests. The authors concluded that unawareness of difficulties appears to be unrelated to cognitive difficulties as measured by the tests. Mackinley and Brooks reported that the discrepancies between patients and relatives could be attributable to distorted perceptions on the part of relatives. More recently, Port, Willmott and Charlton (2002) found that the level of awareness in significant others was limited during the early stages of recovery from brain injury. However, relatives of patients with brain injury have been shown to learn to accept social, behavioural and personality changes in the patients as primary coping strategy. Willer, Allen, Durnan and Ferry (1990) described the integration problems faced by
13 young men who had experienced traumatic brain injury and the coping strategies used by their mothers and siblings. Willer et al. (1990) reported that despite physical and cognitive disabilities, these young people identified problems in living as having highest concern. Mothers identified acceptance of the change in their sons as the most important coping strategy.

In reference to rehabilitation, lack of awareness of difficulties in people with brain injuries represents a problem. The psychological literature acknowledges that unaware patients may lack motivation for treatment (Prigatano and Fordyce, 1986a), fail to benefit from therapy (Ford, 1976) and make no use of compensation strategies (Brooks and Lincoln, 1984). Prigatano and Fordyce (1986b) studied unawareness of difficulties in 23 patients who underwent rehabilitation after traumatic brain injury. The authors found that patients tended to rate themselves as more competent than did family or staff members. Discrepancies between patients and staff members were positively correlated with patient's degree of neuropsychological impairment and negatively correlated with patient's extent of emotional distress. Furthermore, Ranseen and Bohaska (1987) examined the relation between staff-patient rating discrepancy on the Patient Competency Rating Scale (used in Prigatano and Fordyce study) and lesion site following traumatic brain injury. In this case, 32 patients with focal left, focal right and diffuse damage were studied before rehabilitation and one month after it. The three groups rated themselves more competent than did rehabilitation staff at both periods. Patients showed improvement after one month of rehabilitation but continued to overestimate their competency. The staff rating discrepancy was significantly greater at both periods of time for the group with focal right damage than for the other two groups. The authors concluded that right brain damaged patients have a greater unawareness of difficulties because their cognitive impairment involves perceptual problems and difficulty organising information in relation to one's self.

Thus, the evidence shows that people with brain injuries can lack awareness of their difficulties. Although observed in clinical settings, lack of awareness of difficulties has been described as a problem by psychological rehabilitation research and continues to be considered a problem by social psychological research by the time the individual
affected with the brain injury returns to a family or community environment. Therefore, it is to this lack of awareness of difficulties and to the different explanations found in the literature that the discussion turns now.

2.4. THEORETICAL EXPLANATIONS

Lack of awareness of difficulties following brain injury has been conceptualised as a failure to gain consciousness or "explicit access to information regarding the state of a perceptual, cognitive, or motor function: the patient is not consciously aware that a once-intact function is currently impaired" (McGlynn and Schacter, 1989, p.194). As such, most investigations into the phenomenon have tried to provide evidence for this loss of consciousness and a few have tried to offer more specialised theoretical interpretations and explanations.

McGlynn and Schacter (1989) in an extensive review of the literature on unawareness of difficulties in neuropsychological syndromes classify theories of anosognosia (lack of knowledge, awareness or recognition of disease (Babinski, 1914)) into neuroanatomically based theories or motivational theories. A more recent classification however, proposed by Ownsworth, McFarland and Young (2002), divides these theories into neurological, psychological and integrated theories of awareness. These theories will be discussed here as to follow this, more recent and expansive, categorisation.

2.4.1. Neurological theories

Neurological based theories attribute lack of awareness of difficulties to focal brain lesion, to diffuse brain damage or to a general disorder of the brain. These will be considered in turn.

_Focal brain injury_

Proponents of this theoretical position have suggested that lack of awareness of difficulty results from damage to the right hemisphere of the brain (Koehler, Endtz, Te Velde, & Hekster, 1986). However, the idea that lack of awareness is exclusively the outcome of lesions of the right hemisphere has been questioned by several researchers who observed lack of awareness in patients with left hemisphere damage.
(Cutting, 1978; Prigatano and Altmant, 1990; Grotta and Bratina, 1995). However, relative to lack of awareness resulting from right hemisphere lesions these cases are rare.

Advocates of the focal lesion explanation often view lack of awareness as a disorder of cognition arising from particular lesion sites. In 1985 for example, Bisiach, Meregalli and Berti proposed a model that emphasised the domain-specificity of the defect in patients with brain injury. The authors viewed anosognosia and related phenomena as "modality-specific disorders of thought" and resulting from disruption of specific mechanisms that normally monitor the output of individual perceptual and cognitive modules. In applying the model to visual anosognosia patients, Bisiach et al. (1985) stated that patients who become blind following peripheral lesions acknowledge their deficit and behave in a realistic manner. Patients with more central lesions of the visual system resulting in blindness were described as having visuo-specific cognitive dysfunction manifesting itself in a disordered monitoring of the disability, therefore these patients deny their blindness or act as if they can see. The first type of blindness is seen as a failure of the "sensory transducer", which transmits impulses from the retina to the brain and the second as a breakdown of a "sensory processor" that mediates between the transducer and the neural regions where visual input is processed. Messages flowing from modality specific sensory processors travel along independent paths in the direction of various "response systems". Thus, Bisiach et al. (1985) argue for a modular structure of central processing to account for the domain specific nature of anosognosia and reject the notion of a central, higher order monitoring system as such a system could not explain the specificity of anosognosia. In other words, if a single monitoring system were responsible for lack of awareness, it could not be expected of the patients to be aware of one difficulty and unaware of another. Lack of awareness of difficulties could then be accounted for by postulating disruption of multiple monitoring mechanisms. This model, which according to McGlynn and Schacter (1989), is consistent with many clinical and empirical findings provides insight into possible mechanisms underlying lack of awareness relating to physical, sensory and language difficulties. However, some unawareness phenomena are not easily described in terms of disruptions of individual monitors associated with specific modular functions. For instance, brain injured patients may lack awareness of
personality changes and behavioural difficulties. It is not clear how Bisiach et al.'s model would account for lack of awareness of such global functions, which are not easily identified with individual modules.

Another model that defines this position and is perhaps more comprehensive than the one postulated by Bisiach et al. (1985) is the anosognosia model of Stuss and Benson (1986). These authors argue that regions of the frontal lobe are involved in self-awareness and monitoring of one's own cognitive functioning, and as such, view anosognosia as a deficit in self-monitoring. Empirical evidence that unawareness of memory difficulties is observed in cases of amnesia caused by damage which includes the frontal lobes suggests that frontal malfunction contributes to unawareness of difficulties. Frontal lobe involvement is further supported by the literature on brain-injured patients who also exhibit frontal malfunction as well as unawareness of difficulties. For example, Leduc, Herron, Greenberg, Eslinger, Grattan, (1999) investigating the relative contribution of different frontal lobe regions in the process of social self-awareness demonstrated a crucial role for orbital frontal regions in monitoring social self-awareness. These authors compared five patients with focal, orbital frontal lobe damage to six patients with restricted posterior ventromedial (PVM) frontal lobe damage on a self-awareness measure. Results indicated that the orbital frontal group had difficulty estimating their social and emotional competencies compared to cognitive or instrumental abilities. In contrast, the PVM group demonstrated no alterations in any form of awareness. Thus, on the basis of this type of evidence, Stuss and Benson (1986) postulated that lack of awareness of difficulties probably results from simultaneous lesions of several cerebral areas, with varying degrees and combinations producing different forms of the disorder. The authors argue that particular types of lack of awareness may be dependent on a specific combination of brain deficits.

Other investigators have associated anosognosia to an affective disturbance resulting from lesions in particular neural regions. Bear (1982) for example, described lack of awareness of difficulties as a decline in emotional surveillance. After observing the critical involvement of right-hemisphere damage in lack of awareness, especially right parietal and dorsal frontal lesions, Bear stated that these patients do not detect a
severe threat and therefore, cannot exhibit emotional concern. Heilman, Watson and Valenstein, (1993) also proposed that the right hemisphere of the brain is dominant for attentional arousal. When the left hemisphere is damaged, the right hemisphere is still capable of full attentional focus, whereas when the right hemisphere is damaged attention is restricted to the right hemispatial field of the intact left hemisphere. Along these same lines, the theory proposed by Gainotti (1997) argues that the right hemisphere is dominant for negative emotions. Lack of awareness is explained by suggesting that if the right hemisphere is damaged the patient has access to the intact positive emotions from the left hemisphere, therefore the victims will have inappropriate positive feelings about their condition. This theory however could not possibly explain the negative character of some behaviours displayed by some patients with a brain injury. In addition, McGlynn and Schacter (1989) have pointed out that to view anosognosia as secondary to a neurologically based affective disturbance offers more problems than it solves. First, it does not account for the domain specific of anosognosia (if lack of awareness is lack of concern then such indifference should be displayed for all difficulties). Second, this theory does not explain the persistence of lack of awareness of some difficulties: patients that are not concerned about their difficulties should acknowledge them upon confrontation.

**Diffuse brain injury**

A second group of neuroanatomically oriented theoretical positions consists of those who explain lack of awareness of difficulties as a manifestation of a general mental disorder that can be associated with diffused brain pathology. Sandifer (1946) for example, argued that severe cases of anosognosia are the consequence of intellectual impairment resulting from diffuse brain damage. Weinstein and Kahn (1955) considered that a general alteration in brain function is important in order to produce lack of awareness of difficulties although the brain itself does not cause anosognosia. Weinstein and Kahn (1955) reflected that "the effect of the brain lesion provides a milieu of function in which any incapacity or defect may be denied whether it is hemiplegia or an unfortunate life situation" (p.96).

More recently, Levine (1990) suggested that lack of awareness of physical difficulties is not a phenomenon automatically experienced by people with brain injuries. Levine
assumes that interruption of a sensory path at any level, from peripheral nerve to primary sensory cortex, is not associated with any immediate sensory experience that uniquely specifies the difficulty. Instead, Levine argued, these difficulties have to be discovered by a process of self-observation and inference. In other words, sensory loss is not sufficient to experience lack of awareness. Sensory loss combined with general cognitive dysfunction impedes victims of brain injury from discovering their difficulties. From a similar perspective, Heilman (1991) argues that a person needs to want to move a limb to discover that it is not in working order. If the desire is lost, then the belief that the limb is in working order goes unchallenged.

A number of studies have investigated if indeed lack of awareness of difficulties is associated with severity of brain injury or general intellectual decline. The results of these studies indicate that although severity of brain injury is not associated with lack of awareness of difficulties (Allen and Ruff, 1990) longer duration of PTA (Post-traumatic Amnesia) is indeed associated with lack of awareness of difficulties (Prigatano, 1999). With respect to general intellectual decline, some studies have found an association between general cognitive decline and lack of awareness (Prigatano and Fordyce, 1986a). Other studies however, have found that patients with intact IQ still exhibit lack of awareness of their difficulties (McGlynn and Schacter, 1989). Further, evidence for Levine's theory of discovery of difficulties is supportive. Chatterjee and Mennemeier (1996) investigating patients' retrospections on their resolution of anosognosia found that patients' reports were compatible with Levine's claims that difficulties are not perceived automatically. In general though, the empirical evidence offered for the diffuse set of theories suggests that other neurological factors such as the nature of the injury and specific aspects of neuropsychological impairment play a more significant role than severity of injury or general intellectual decline.

"General disorders" (Internal control) theories

This group of theories suggest that there is a monitoring or supervisory control function (usually attributable to the frontal lobes) providing direction to posterior systems or subordinate cognitive skills (Mesulam, 1985). A significant disruption then of higher order cognitive control systems such as monitoring and regulation of
behaviour may lead to lack of awareness. Empirical evidence has shown some support for this theoretical position (Allen and Ruff, 1990) by demonstrating that impairments in executive functioning are associated with lack of awareness. However, in general, research has failed to develop a specific neuropsychological profile associated with lack of awareness of difficulties. Prigatano and Altmant (1990) argue that assessing IQ and memory are unlikely to sample the cognitive disturbance underlying lack of awareness.

2.4.2. Psychological theories

In contrast to neurological based theories, psychological theories of lack of awareness of difficulties bring to relevance the psychological defence mechanism of denial, pre-morbid personality of people with brain injuries, personality of people with brain injuries and cultural factors.

Weinstein and Kahn (1955), from a psychodynamic point of view and based on their clinical observations, argued that unawareness of difficulties following brain injury is due to pre-morbid personality factors, not a consequence of brain damage. Patients with anosognosia, they explain, have always regarded illness as an imperfection; they tend to deny their perceived inadequacies, suffer from compulsive drives and have a strong need for prestige and the esteem of others. Therefore, unawareness of difficulties following brain injury is interpreted as a manifestation of the patient's drive to be well or as a coping mechanism, a way of avoiding anxiety (Goldstein, 1942).

Similarly, other psychological theories view denial as an adaptive coping mechanism in response to trauma and stress (Gainotti, 1993). Brain injury is considered an unfamiliar stressful experience, which the patient appraises and copes with in a manner similar to previous coping experiences. For example, Godfrey, Partridge, Knight, & Bishara (1993) suggest that coping mechanisms such as denial play a role in patients' appreciation of the extent of their difficulties. However, a number of studies have also demonstrated that the development of awareness of difficulties increases levels of emotional distress. Therefore, denial may serve as a buffer from emotional reactions. An implication of this view is that the availability of accurate,
relevant feedback and other life experiences during rehabilitation would serve to promote realistic self-appraisals of the difficulties.

In addition, some theories have proposed personality characteristics of the individual as influencing the degree of awareness of difficulties. On the one hand, patients with brain injury come from a predominantly male cohort with a higher than usual incidence of drug and alcohol abuse and developmental and psychiatric disabilities and lower than usual educational attainment. All of which are given as reasons to explain why patients with brain injury show such impairment in awareness (Gruvstad, Kebbon and Gruvstad, 1958). On the other hand however, Prigatano (1999) offers striking pieces of evidence based on subjective accounts of three experienced individuals, a neuroanatomist, a psychiatrist and a neurosurgeon, who had all experienced alterations in self-awareness following their brain injuries. These individuals were all trained and familiar with the phenomenon of lack of awareness of difficulty. Yet when their brain was injured, they could not apply previously learned technical knowledge to their own cases. Their memories were just not there. They underestimated their impairments in the same manner that their less educated brain injured cohorts did.

Although this evidence is contradictory, it is not considered enough to exclude personality characteristics out of the equation of lack of awareness. The tendency to underestimate difficulties which appears to be a direct consequence of brain injury is still thought of by some workers as influenced by the individuals personalities in their self-reports about their neuropsychological disturbances. In fact, Prigatano (1999) observes that personality and cultural factors appear to influence brain injured individuals' perceptions of their difficulties. For example, Fordyce, Rouche and Prigatano (1983) carried out neuropsychological testing on a population of 160 brain injured patients and found that emotional functioning of the patients was independent of the level of neuropsychological impairment experienced by the patients. With respect to the cultural influences in the reports of people with brain injuries cross-cultural studies conducted by Prigatano and various other workers add to the view that self-awareness is indeed influenced by cultural contexts. In general, Prigatano's findings reflect the tendency to underestimate or overestimate difficulties following a
brain injury depending on the patients' cultural background. For example, Japanese patients underestimated their difficulties and overestimated their abilities to perform self-care abilities (Prigatano, Ogano and Amakusa, 1997). Reflecting the fact that in Japanese culture, modesty is a virtue and the ability to perform self-care is important socially. Another study conducted with a brain injured Maori population showed that Maori of English ancestry, like American brain injured underestimated their difficulties while Maori patients did not (Prigatano and Leathem, 1993). A further study conducted on a Spanish population of brain injured patients showed that consistent with other Western cultures many Spanish patients also underestimated their difficulties. The findings were similar to those of the American and patients with traumatic brain injury of English ancestry from New Zealand (Prigatano, Bruna, Mataro, Munoz, Fernandez and Junque, 1998). Thus, personality characteristics and cultural factors were found to influence patients' reports of their difficulties and have been shown to be independent of the brain injury.

More recently, Solms (2000) illustrates with clinical examples another psychoanalytic contribution. Solms, observing five cases of right hemisphere damage uses the psychoanalytical term of resistance to explain that these patients seemed unaware of and indifferent to their difficulties not because they cannot attend directly to these difficulties but because they do not want to attend to them. Solms claims that the attention is not directed at difficulties because it is actively diverted away from them. This is to say that the victims of brain injury know very well what has happened to their bodies, but "they do not want to know". Solms' account tries to synthesise psychoanalytical interpretations with neurobehavioral theories of lack of awareness following a brain injury. Arguably this explanation centres only on physical difficulties and does not seek to explain the lack of awareness experienced about cognitive and emotional deficits which are also experienced and are more problematic following a brain injury (Fleming and Strong, 1999). Further, and in more general terms, psychodynamic explanations of lack of awareness of difficulties have been criticised for not accounting for the specificity of lack of awareness, the relation between lesion site and unawareness of difficulties, the short duration of some unawareness (McGlynn and Schacter, 1989) and the fact that they do not explain how a defence
mechanism that is prevalent amongst the general public becomes a syndrome in certain people and not in others (Stuss and Benson, 1986).

To summarise, psychological explanations seem to suggest that the qualitative differences between patients who lack awareness of their difficulties can be attributed to psychological factors such as, personality characteristics, cultural context or coping styles as opposed to different patterns of neurological impairment. However, psychological factors do not seem to provide comprehensive enough answers to satisfy all the questions, and hence, the emergence of more integrative approaches (below). Arguably, what psychological explanations seem to be hinting at, and some of the evidence seems to point this way, is the independence of awareness from purely neurological impairment. This point is one of the main concerns of this thesis and will be elaborated further in the next chapter.

2.4.3. Integrated theories of lack of awareness

As indicated by the above discussion, no single theory provides an entirely satisfactory account of lack of awareness of difficulties in neuropsychological syndromes. More recently however, researchers have developed theoretical models, which suggest that a contribution of both psychological and neuropsychological factors influence the manner in which patients adapt and interpret their difficulties. These theories recognise the high degree of variability in the clinical presentation of awareness of difficulties (Prigatano, 1999) and acknowledge that it is unlikely that a single theory can explain the mechanisms underlying lack of awareness of difficulties. Therefore, some researchers have identified that the relative contribution of psychological and neurological factors may vary according to the levels of processing. Allen and Ruff (1990) for example, propose that three levels of processing may influence patients' awareness of their difficulties. The first level involves awareness per se and requires the ability to attend to, encode and retrieve information relating to the self. The second level of this model involves appraisal of the ability of the patient to compare information of the present self with that of a pre-morbid self. The third level of processing involves disclosure, that is, the willingness of the patient to report self-perception to another person.
The Hierarchy of Brain Injury Model (Stuss, 1991) is a second example of an integrated theoretical framework that considers self-awareness as the highest form of brain activity that mediates and interacts with other brain processes. This model considers psychological processes like attention, language and memory as complex functional systems with their own inherent organisation that works at an overlearned, automatic level. The systems are fixed in that they are relatively constant across the adult population (Stuss, 1991). Such systems are also integrated in the sense that they involve various cortical and subcortical regions in both hemispheres in the working of one function, different regions participating in their own specialised way. The frontal lobes interact with these posterior/basal regions, appearing to play a unique role. Furthermore, the model describes two frontal functional systems that provide the posterior/basal systems with the capacity to sequence and integrate information; they also serve as an integral part of drive or motivation. A second control function is hypothesised as depending on frontal brain regions which provides conscious direction to the posterior/basal and frontal function systems. Self-awareness is posited then as the highest psychological attribute of the frontal lobes.

Stuss' model is important because it is one of the few that most clearly emphasises neurological and psychological processes as interactive functions underlying self-awareness. In addition, the notion of interactive processes has also been used to redefine other existing models. For example, Schacter and Prigatano (1991) observed that different forms of unawareness of difficulties seemed to emerge after different types of brain injuries. That is, depending on the part of the brain that is damaged, different forms of unawareness may emerge. Prigatano (1999), following this observation and following the new anatomical model of Mesulam (1985), suggests four syndromes of awareness: frontal heteromodal, temporal heteromodal, parietal heteromodal and occipital heteromodal. Prigatano explains that when the frontal heteromodal regions are damaged, patients often exhibit unawareness of socially inappropriate actions, disorders of planning, initiation and so on. When the parietal heteromodal region is damaged, patients often are unaware of a limb (like in hemineglect) or apraxic disturbances. If the temporal heteromodal region suffers an insult, individuals may be unaware of language dysfunction and memory impairments while damage to the occipital heteromodal is associated with unawareness of loss of
vision. Prigatano adds that when a cerebral dysfunction is bilateral it produces syndromes that are "complete" while in unilateral impairment these syndromes are "partial". It is during partial unawareness that coping mechanisms begin to emerge (Prigatano, 1999). Furthermore, these coping mechanisms can be described as defensive or non-defensive. Non-defensive coping mechanisms are those that the patient used pre-morbidly to deal with life problems. Defensive mechanisms are defensive manoeuvres, including denial and projection, that can lead to substantial distortions of reality and development of delusional syndromes years after the original brain damage.

Evidence for this group of theories, although sparse, seems to suggest that neuropsychological factors have more direct effect on awareness of difficulties than psychological factors. For example, Ownsworth, Mcfarland and Young (2002) examining the theoretical models proposed by Allen and Ruff (1990) and Stuss (1991) on a population of sixty-one participants with acquired brain injury found that the relative contribution of neurological factors to an outcome of difficulties in self-awareness and self-regulation was more direct than psychological factors for intellectual awareness, anticipatory awareness and strategy behaviour. Furthermore, the authors conclude that the use of denial as a coping strategy for individuals with impaired executive functioning may disturb successful adjustment to acquired brain injury because of interference with the development of emergent and anticipatory awareness.

**2.4.4. Summary**

It is clear from the observations discussed in this section that in the recent past there has been a good deal of interest in lack of awareness of difficulties following a brain injury. It is also clear that no single theory provides a satisfactory account of lack of awareness. In other cases, like with the integrated theories, the theories are so recent that there is still not enough evidence to support them. It is with this in mind that the present work attempts to outline a theoretical framework that, it is believed, can integrate a range of relevant phenomena. This framework does not attempt to account for defensive denial; although a clinically significant phenomenon, it lies outside the grasp of this theoretical discussion.
However, and before this approach is introduced, the discussion turns now to how awareness of difficulties develops in people with brain injuries. Close attention is paid here to research indicating how the phenomenon progresses through various stages and to why alternative explanations have been sought. The chapter concludes with a brief review of the methodological issues encountered in lack of awareness research. A further discussion of these methods can also be found in Chapter Four.

2.5. DEVELOPING AWARENESS OF DIFFICULTIES FOLLOWING A BRAIN INJURY

Research into lack of awareness of difficulties following a brain injury, regardless of its aetiology, recognises the disruption that brain injury causes to the integration of thinking and feeling in the individual (Prigatano, 1999). This disruption appears in a few cases irreparably truncated due to "bona fide" organic impairment although there are a good number of cases where the process of awareness of difficulties develops after the trauma of brain injury. For example, and in the words of Prigatano (1999) patients go from having "complete" syndromes to "partial" syndromes. To understand the development of awareness of difficulties after brain injury it would be helpful to explore the different stages of the syndrome as revealed by the literature (Fig. 1) to appreciate this development (please note that Figure 1 is entirely speculative).

In acute stages of brain injury and during hospitalisation, (a) unawareness of difficulties or anosognosia is dramatic and transient (Prigatano, 1999; Newman, Garmoe, Beatty, and Ziccardi, 2000), it affects awareness of physical injury, cognitive and emotional difficulties. In post-acute stages of brain injury, during rehabilitation (b), unawareness of difficulties is problematic in that it represents the deciding factor between successful rehabilitation or unsuccessful rehabilitation (Schacter and Prigatano, 1991; Prigatano, 1999). Concrete deficits (i.e. physical disability, memory impairments) are, at this stage, more readily acknowledged than more abstract cognitive and emotional disabilities (i.e. information processing difficulties or verbosity) (Fleming and Strong, 1999).

As time goes on, and once the individual is back into the community (c), awareness of concrete deficits improves while unawareness of some cognitive and emotional
deficits may persist. For example, in a longitudinal study carried out by Fleming and Strong (1999) it was found that over the first year post-injury there were gains in self-awareness. These gains covered most areas connected with daily living. Other areas like judged competence for driving, managing finances and recognising when
something one said or done had upset someone else reflected the self-centred
behaviour and deficits in self-monitoring and self-regulating characteristic of early
brain injury. Similarly, research carried out on victims of brain injury, and their
families, years after the patient's injury and after hospitalisation and rehabilitation,
showed supporting results. That is, once these patients had re-integrated into the
community, the gains made were towards awareness of cognitive difficulties. Lack of
awareness of emotional disabilities remained, especially when patients had suffered a

Nevertheless, this time progression seems to indicate that awareness of difficulties is
connected with normal, everyday, experience. After brain injury and the disruption
that this represents to the process of awareness, the individual may not commence
this process until difficulties (d) are experienced in naturalistic environments, and in
comparison with the person's pre-morbid abilities. Very often it is after the first year
of injury or later, when the individual tries to return to work or to social activities,
that awareness of persisting deficits emerges (e) (Prigatano and Fordyce, 1986b;
Prigatano, 1999; Brown and Vandergoot, 1998). In some cases, this awareness of
difficulties means that there is also an increase in emotional distress (f). Fordyce,
Roueche and Prigatano (1983) found that chronic head trauma patients were more
anxious and depressed than acute patient groups. In other cases, unawareness of
difficulties persists but the patients also show increased emotional distress (Fordyce
and Roueche, 1986; Ownsworth, and Oei, 1998). Both these reactions suggest that
lack of awareness is unrelated to the presence or absence of emotional reactions and
that defensive (h) and non-defensive mechanisms (g) may come into operation at this
stage (i.e. when re-integrating into the community) (Prigatano, 1999).

In addition, if non-defensive coping mechanisms are deployed and acceptance of
disability is reached rehabilitation methods or strategies to help the patients cope with
their new challenges can be beneficially implemented. The patients may be able to
return to productive activity. Melamed, Groswasser and Stern (1992) found, for
example, that acceptance of disability was significantly associated with work status. If
on the contrary, defensive mechanisms are used to cope with the brain injury and
acceptance of disability is not reached, rehabilitation efforts usually go to waste and
coping strategies ignored, what could be called the "Yes, but" effect. In other words, they appear to listen to rehabilitation efforts but these are not implemented.

Further, during rehabilitation, unaware patients often lack motivation, display uncooperative behaviour and show animosity. In contrast, some patients with more self-awareness are more willing to participate actively in the therapeutic process (Lam, MacMahon, Priddy and Ghered-Schultz, 1988). The recommendation of some researchers in this field is therefore, that self-awareness should be continually assessed and be made the target of rehabilitation itself (Kay and Silver, 1989).

This recommendation however, is one that is not supported by all workers in the field. Sohlberg, Mateer, Penkman, Glang and Todis, (1998) in a qualitative study that examined a variety of awareness indicators in three individuals with brain damage found a disassociation between behavioural and perceptual (caregivers' perceptions of the participants' awareness levels) indices of awareness. The authors argued that a prerequisite level of awareness is not necessary, as indicated by Kay and Silver (1989), to utilise adequate compensatory strategies following a brain injury. Sohlberg et al. (1998) suggest that people with brain injuries can be trained to use compensatory strategies even in cases where the patients do not understand why or believe that they need them. In fact, lack of awareness of deficits may indeed prevent them from inquiring why they need to use the strategies. The authors conclude that for some victims it may be more productive to tap into implicit learning than into declarative knowledge as to why these strategies are important.

Nevertheless, and although Sohlberg et al. (1998) seem to offer a pragmatic solution for patients showing lack of awareness of their difficulties, the authors do not really address the problem. If the development of awareness of difficulties, as illustrated above and as extrapolated from the research literature, leads patients to either adopting defensive (denial) and non-defensive mechanisms (acceptance) the question of how patients reach this outcome goes unanswered. Further, suggesting denial, as the defensive mechanism adopted by the affected patients does not explain why some difficulties are denied and not others. In addition, the interpretation of denial is one that cannot be proved wrong. Since denial, by definition, refers to concealed
mechanisms, any evidence that people with brain injuries do not show concern for
their difficulties can be interpreted in this way. Thus, if the interpretation of denial
creates more questions than can answer, there is a need to seek another interpretation
to the one already illustrated here. This explanation, given in social constructivist
terms and which is introduced below and expanded in the next chapter, constitutes
the core of this thesis.

To summarise, the latest research into lack of awareness of difficulties following a
brain injury acknowledges the problem as a disruption to the integration of thinking
and feeling in the individual caused by a brain injury. People with brain injuries
experience the acute stages of their injuries in hospitals, they undertake official
rehabilitation following the acute stage and finally, they reintegrate into the
community. This reintegration into the community often means either the resolution
or continuation of the problem. In a majority of cases, lack of awareness of cognitive
and emotional difficulties continues to be a problem due to the patients adopting what
the literature calls defensive coping mechanisms. Defensive coping mechanisms, like
denial, have been seen as inadequate in explaining the problems posed by lack of
awareness. Therefore, there is a need to find alternative explanations to the ones
reviewed here.

2.6. LOOKING FOR THE ALTERNATIVE
As has been seen, physical difficulties are usually the first difficulties that a brain
injured person becomes aware of, usually during hospitalisation (Fleming and Strong,
1999). Cognitive effects include a range of difficulties that often take some time to
make themselves felt. These can include problems with language and communication
skills, intellectual difficulties, memory and learning difficulties, attentional difficulties
and difficulties in executive function (McKinlay & Watkiss, 1999). Emotional effects,
which have been studied under the term of psychosocial changes, emerge in the
weeks and months after the injury (McKinlay, Brooks, Bond, Martinage and
Marshall, 1981). The most frequently reported are irritability and impatience,
slowness and tiredness, bad temper, verbosity, lack of inhibition and change of
personality (McKinlay & Watkiss, 1999). The frequency in which these problems
arise varies according to injury severity and the problems themselves can vary over
time (McKinlay, et al., 1981) plus they may be exacerbated by problematic social interactions.

Recognition of physical, cognitive and emotional difficulties tend to emerge during rehabilitation and come into focus once the brain injured person reintegrates in the community. Prigatano (1995) notes that at this stage the patients want to return to work or school or to pre-injury activities. In the cases where they do return to previous activities, Prigatano observes, more often than not, they fail. This failure may illustrate the difficulties to the patients and to those around them. Reactions to this discovery, not surprisingly, are manifest in an increase in emotional and behavioural difficulties during the first year post-injury.

Neurological explanations for this increase could have been suggested here but appear unlikely due to the nature of brain injury. Brain injury is not a degenerative disorder and recovery, or some recovery, of function is possible (cognitive functions in particular). Instead, explanations turn to the role of the family in pointing out these difficulties as time goes by and to stop making allowances for the patient, or to the secondary nature of these problems, i.e. the patient exhibits these problems as secondary reaction to limitations (McKinlay and Brooks, 1984). Empirical evidence seems to support these increases in emotional difficulties and emphasises the role of awareness of these difficulties, as well as awareness of physical and cognitive difficulties, as the necessary ingredient for adjustment to brain injury (Ponsford, 1995). These findings have led some researchers to point to the role of denial on the part of the relatives (Romano, 1974) as a coping mechanism and as part of a process in coming to terms with dealing with a brain injured relative (Port, Willmott and Charlton, 2002).

This state of affairs is highlighted further by research into short-term rehabilitation (Fordyce and Rouche, 1986; Prigatano, 1991; Port, Willmott and Charlton, 2002) and long-term rehabilitation (Kinsella, Ford and Moran, 1989; Krefting, 1989; Willer et al., 1991; Gan and Schuller, 2002). The problems encountered by the brain injured person and their family, years after the injury, are due to the cognitive and emotional sequelae, as opposed to the physical sequelae of the brain injury (Blyth, 1981). Lack
of awareness into some cognitive difficulties and lack of awareness into emotional problems continue to be a cause of concern. Furthermore, and as already mentioned, some researchers have observed that denial may have been adopted as a negative defence mechanism by some patients (Prigatano, 1999). However, the adoption of this defence mechanism does not explain why not all people with brain injuries react to the injury in the same way. An alternative explanation can be offered which does not assume that the brain injured person is responding to the difficulties caused by the injury in this way. This explanation, extrapolated from studies with people with learning disabilities (Todd & Shearn, 1997; Finlay & Lyons, 1999), refers to the discursive environments and the ways in which these may affect the understanding of difficulties and their implications in the brain injured person. It is this explanation which is the focus of this thesis and for which the theoretical framework is provided in Chapter Three. Before proceeding however, the review will underline a few methodological issues encountered in the literature. A deeper, more comprehensive discussion concerning methodological issues in this area is offered in Chapter Four.

2.7. METHODOLOGICAL ISSUES IN THE RESEARCH

Most investigations into lack of awareness of difficulties following brain injury to date have been based on clinical observations, experimental or psychometric testing. Although successful in their different ways as means to research into a difficult phenomenon, their failure to offer clear answers or to develop an acceptable theoretical framework emphasises the need for new theoretical frameworks and the development of new methodology. Crisp (1992) and Fleming, Strong and Ashton (1996b), for example, suggest that new methods for assessing self-awareness are required to increase the understanding of the phenomenon. These methods would then be the point of departure from which to formulate strategies for clinical interventions with patients who lack such self-awareness.

The methodological difficulties encountered in the existing literature start with the definition of awareness. Schacter and Prigatano (1991) have highlighted the fact that there are no clear definitions of the term awareness. Most research has tended to view awareness as a static concept. Herbert and Powell (1989) for example, operationalised the construct as the ability to perceive one's present state and its
implications, while Malia, Torode and Powell (1993) understood awareness to be the ability to predict one's future state. Other authors however, have given definitions of awareness that regard the phenomenon as a process. As such, awareness is defined as the integration of information from external reality and inner experience, or as Schacter and Prigatano (1991) explain, the capacity to perceive the self in objective terms whilst maintaining a sense of subjectivity.

Definitions apart, the strategies used to form a quantitative evaluation of self-awareness of difficulties in patients with brain injury have also been found wanting. Researchers have used comparisons of patients' self-ratings of their functions with another measure that is considered more objective. Deaton (1986) for example, has identified three such strategies: comparisons of patients self-ratings and those made by their families, patients' self-ratings and those of rehabilitation staff, and patients' estimates of their abilities and performance on neuropsychological testing.

Studies comparing patients' self-ratings and those made by their families have been criticised on the grounds that although head injured patients generally tend to under-report difficulties compared with their relatives, relatives themselves may demonstrate varying levels of denial and decreased awareness (Fleming et al., 1996; Port, Willmott and Charlton, 2002). The accuracy of relatives reports has been known to depend on factors such as stress levels, fatigue, personality type of the relative and the length of time post injury. Cavallo, Kay and Ezrachi (1992) found that families do not always respond in the same way and argued against the convention of depending on family reports for reliable information about the performance of the person with traumatic brain injury. Furthermore, in a study carried out by McKinlay and Brooks in 1984 to investigate the possibility that relatives' personality could influence the perception of changes in the patients, it was found that relatives' high score in neuroticism in the Eysenck personality scale was correlated with their report of emotional/behavioural changes in the patients.

Similarly, comparisons of patients' self-ratings with ratings made by health professionals have also been criticised. Fleming et al. (1996) argue that the judgement of health professionals can be coloured by interpersonal factors, and may be limited
by the fact that health professionals may not have first hand knowledge of patients' pre-morbid personalities. Furthermore, mood, attitude towards the patient, expectations of the patient's performance and interpretation of poorly defined items on scales (Ponsford, 1988) can also distort rehabilitation staff judgements.

The third approach, comparisons of patients' reports of abilities on certain tasks with actual task performance on neuropsychological tests, eliminate the problems associated with relying on relatives or rehabilitation staff accounts but are costly and time consuming (Fleming et al., 1996). Additionally, a number of recent articles warn that the intellectual consequences of head injury may not be reflected sufficiently in standard test of intelligence (Walsh, 1982). Part of the problem, in this third instance, lies in the nature of the tests used. If intellectual abilities in people are characterised by their fluidity and their crystallised nature (Walsh, 1985), these tests only measure one type of intellectual ability. That is, if fluidity is the general ability to discriminate and perceive relations between any fundamentals, and crystallised abilities are discriminatory habits established in a particular field (primarily through the operation of fluid ability, but no longer requiring insightful perception), then it becomes apparent that neuropsychological tests are very good at measuring mainly crystallised ability as stored information. Developed skills are known to be resistant to all forms of cerebral impairment (Walsh, 1985). In a similar vein, Crosson, Barco and Veloza (1989) propose that intellectual awareness of difficulties is only the first step towards full self-awareness. Patients first gain the ability to acknowledge intellectually that certain difficulties exist. Further along in the development of self-awareness, patients start recognising problems related to difficulties when they are actually occurring (Crosson et al., 1989), call this emergent awareness) and finally they begin to anticipate when a problem is likely to occur because of difficulties (anticipatory awareness). Psychological tests evaluate intellectual awareness only.

One further methodological criticism concerns the use of questionnaires and structured interviews to quantify self-awareness of difficulties. Fleming et al (1996b) in talking about the limitations of using such quantitative methodology point out that, these techniques rely mainly on the patient's ability to understand verbal or written questions and to verbalise their understanding of difficulties. As such, a number of
Chapter Two - Lack of awareness of difficulties following a brain injury: a review

patients suffering from language and speech disorders are excluded from any assessment that utilises such methodology. In addition, emphasis on verbal aspects may result in neglect of behavioural manifestations (Deaton, 1986), as some patients may deny verbally the existence of any problems and still participate adequately in treatment.

2.8. SUMMARY AND LIMITATIONS OF PREVIOUS RESEARCH

So far, the literature reviewed above reveals different theoretical positions and explanations that fail, overall, to account for lack of awareness of difficulties following a brain injury. Empirical research in the field does however, offer a time progression of gains of awareness of difficulties from the acute stages of the brain injury to the time when individuals with a brain injury re-enter the community. Empirical work carried out during rehabilitation or sometime thereafter points to lack of awareness of some cognitive and emotional difficulties as continuing to be a cause of concern for both people with brain injuries and their families. In reviewing this literature, however, some limitations were noted.

First, theoretical and methodological difficulties encountered in the existing literature start with the definition of awareness. Schacter and Prigatano (1991) point out the fact that there are no clear conceptualisations of the term awareness. Some authors however (Schacter and Prigatano, 1991), have given definitions of awareness that regard the phenomenon as a process. Awareness is then defined as the integration of information from external reality and inner experience. That is, the capacity to perceive the self in objective terms whilst maintaining a sense of subjectivity. This thesis, following on Schacter and Prigatano's understanding of awareness as a process, conceptualises awareness under a social constructionism theory of consciousness. Awareness is, then, defined as the process of monitoring, regulating and self-reflecting of bodily experiences, cognitive activities and emotional processes emanating from concrete social interactions settings (Burns and Engdahl, 1998).

Second, the almost exclusive use of quantitative methodologies to explain a subjective problem has meant a reliance on others' perceptions as sources of information. This thesis addresses this limitation by following a constructionism mode
of enquiry and therefore adheres to Kelly's (1955) words that "If you want to know what is going on for an individual, ask him". In other words, the person experiencing something is the only authentic source of knowledge of that person's experience.

Third, the use of quantitative methodology has also meant reliance on questionnaires, structured interviews and standardised tests. Such instruments help measure different functions (i.e. cognitive functions) but do not reveal an accurate picture of how a brain injury affects individuals living in the world. The present thesis suggests qualitative methodologies as an alternative and more effective means of gaining an in-depth understanding of lack of awareness of difficulties. Qualitative psychological paradigms investigate phenomena from an insider's perspective, as opposed to an outsider's perspective (Crisp, 1992).

Fourth, the use of qualitative methodology in brain injury research has grown in the last few years. Willer, Allen, Durnan and Ferry (1990) and Willer, Allen, Liss and Zicht (1991) used nominal group techniques to explore problems and ways of coping in traumatic brain injury. Karpman, Wolfe and Vargo (1985) used in-depth discussions for similar purposes. Grotta and Bratina (1995) used directed interviews to examine subjective experiences after recovering from stroke. Coehlo, Liles and Duffy (1991) used discourse analysis to provide evidence for differing patterns of deficit in closed head injured adults. Nochi (1997) used life narratives to collect the experiences of people with brain injuries, to mention but a few. To date, there are few qualitative studies researching lack of awareness of difficulties following a brain injury. Jacobs (1993) used phenomenological methods to investigate lack of awareness of difficulties in children. Sohlberg, Mateer, Penkman, Glan and Todis (1998) used a grounded theory approach to investigate the phenomenon. Chatterjee and Mennemeier (1996) used subjective accounts to investigate anosognosia for hemiplegia. The present work builds on these studies and explores lack of awareness of difficulties with the help of qualitative methodology as discussed in Chapter Four.

Fifth, the terminology employed by the literature is unclear and needs some specification. Most writers in the field of awareness of difficulties following a brain injury refer to anosognosia to describe lack of awareness of physical difficulties. This
term has been passed down to describe a more general lack of awareness of physical, cognitive and emotional difficulties immediately after a brain injury. This thesis recognises, however, that anosognosia may be an appropriate term for lack of awareness of physical difficulties encountered immediately after a brain injury but it is not an accurate term to refer to the present work. While, the literature points to anosognosia as a temporal phenomenon that refers mainly to unawareness of physical difficulties, lack of awareness of cognitive and emotional difficulties are still problematic years after the injury has happened. It is this two lack of awareness that the present work addresses.

A final limitation, and perhaps the most severe, is the unidirectional sense in which research in the area proceeds. That is, most research and theorising either starts with the assumption or implies that lack of awareness is caused by organic impairment. The evidence, as has been seen, has not corroborated this assumption. Empirical work however, has offered evidence for organic impairment of the brain to explicate organic impairment of the body. The questions of how much self-awareness the person had pre-morbidly or how much self-awareness the brain injured individual should have, have never seemed to have risen in the area. This perhaps is more to do with the understanding of science and of how science should proceed than with researching awareness in particular (for a more specific discussion see Chapter Four). However, and while it is assumed that science should be intent in demonstrating the causality relationship between the brain and awareness, other non-causal possibilities go unnoticed. For example, Manicas (1986), calling for an integration of psychological explanations incorporating social, cultural and structural influences with more conventional models of human cognition, argues that neurological mechanisms may themselves be shaped by different social environments. Similarly, Gillett (1992a) suggests that the brain, for human beings, is the case of meanings in that it serves as the physical vehicle in which mental content is realised and plays a part in the social activities of human beings. In this respect, Harré (1994) argues, the brain is no different from the neuromuscular system. The brain is like a muscle in the body, which is shaped by its use. Therefore, the brain is plastic in the face of experience. Throughout life, Harré (1994) explains, the brain stores experience in terms of the meanings that have been given to that experience and the responses made
by the person to aspects of the events experienced. The meanings given to experience
draw on rules that have been shaped during social interaction. This implies that there
must be a relation between the language that a community speaks and the
categorisations that members of that community use to unify stimulus presentations
and group them into meaningful patterns.

Harré (1994), drawing on his description of the brain as a muscle and drawing from
the work of Penfield (1958), says that the brain develops the processing structure
required to underpin the discursive skills evident in perception, action and problem
solving and also holds some kind of "record of past experience" that can be used to
retrieve past events. Because of these properties of the brain, humans are provided
with a narrative resource that is built out of their own individual history. The
structure of this "record" and the skills that enable the subject to make use of it are a
function of language but the brain is the substrate for the requisite mental activity.

This argument, which has received considerable support from recent cognitive
neuroscience (see Harré, 1994, for a review) is essential to this thesis. Manicas,
Gillett and Harré emphasise the pre-eminence of the brain in relation to the social
contexts of human beings and thus facilitate placing the development of self-
awareness in an interactive context. It is this which constitutes the core argument of
this thesis and which will be discussed in the next chapter.
3.1. INTRODUCTION
This chapter will be concerned with establishing the theoretical perspective, which will allow this thesis to gain a non-neuropsychological understanding of lack of awareness of difficulties following a brain injury. Social constructionism is the chosen tool in helping develop a theory of "what is it like" to be unaware of difficulties following a brain injury, for social constructionism examines how people make their worlds and are in turn made by their worlds. That is, the work suggests that awareness of difficulties is primarily the result of a psychological process rather than of the neurological impairment depicted in the brain injury literature reviewed in the previous chapter.

It is not the purpose of this thesis to deny the importance of the biological aspects of a brain injury. In social constructionism, the issue is not whether biological processes are important, but whether their contribution to action is pre-eminent in the remarkable diversity of human actions. In social constructionism, whatever the constraints of biological processes, the world and how it becomes known is presumed to be a construction. Indeed biological processes themselves become social constructions when the understanding of how they will affect individuals determines how they will act in response to them.
3.2. WHAT DOES THE TERM SOCIAL CONSTRUCTIONISM REFER TO?

This question is not one that is easily answered. For example, for Waters (1994), constructionism is a kind of sociological theorising build on the assumption that the social world is subjective and consists of the creations and interpretations, meanings and ideas of acting individuals. These individuals are seen as competent and communicative agents who actively create or construct the social world. Waters places the origins of social constructionism in the work of George Simmel and the German sociologist Max Weber. Equally, Burr (1995) points to the symbolic interactionist work of Mead in America, amongst others, and to some British and continental writers of the late 19th century and the early 20th century as the predecessors of this movement.

The definition of social constructionism although not as clear cut as it appears is confused by its influences, which are sociological and psychological. Both however, form part of a general constructionist mode of thought in sociological theory. In this thesis, the theme developed is that social constructivism is derived from symbolic interactionism and post-modernism (for a definition of this term and an introductory reading on the subject please see Sarap, (1993)). Where symbolic interactionism focuses primarily on the way in which individuals build self-identities from the meanings they bring to categories of experience, social constructionism examines critically how those meanings are formed and then reflect on to and into the individual. Thus, the boundaries between symbolic interactionism and social constructionism are somehow ambiguous. (As an aside, it is necessary to clarify at this point that the terms constructionism and constructivism will be used throughout the work indistinguishably). This chapter will therefore first discuss the symbolic interactionist perspective of the self and will explain some limitations of the perspective. Then, a social constructivist theory of consciousness will be introduced from which the experiential states of the body, cognition and emotions will be discussed. Finally, the topic of the self in brain injury and the role of the other in brain injury will be explored.
3.3. DEVELOPING AWARENESS OF THE SELF

The topic of self as a product and reflection of social life was introduced to social psychology by James as early as 1840. Cooley (1902), who is often described as the first symbolic interactionist, advocated that our self-concept develops from childhood. According to Cooley, this development occurs when we see how others respond to us or "when in the presence of one we feel to be of importance" (p. 175). Mead in 1934, expanded Cooley's view of the development of the self. For Mead, essential to the development of the self was the ability to take the role of the other and to perceive the attitude of the other towards the perceiver. His looking glass included not only a significant other, as Cooley had argued, but a generalised other, that is, the individual's sociocultural environment. Vygotsky (1962), also from a socio-cultural perspective, complemented and gave this position a more developmental flavour. According to this author's view, human development of higher order cognitive capacities, including the ability to think about one self, come into being during the course of interactions with others. Individual human beings, Vygotsky explains, acquire a repertoire of discursive skills in symbiosis with those already skilled in speaking. An unskilled infant attempts some intentional act and an adult supplements his or her efforts. By the age of three a human being is beginning to develop the capacity for private discourse, and is thus enabled to perform complex cognitive acts for him/her self. According to Vygotsky, this skill facilitates higher level cognition by making possible retrospective and anticipatory comments first upon overt acts of public life and then on its own discursive practices, modelled on the commentaries to which his or her speaking and acting have been subjected by others. In other words, the human being starts to recognise his or her own point of view as well as many other attributes.

In contrast, self-perception theorists like Duval and Wicklund (1972) argue that the self can be "discovered" without the need to internalise the view of the other. Duval & Wicklund suggest that the elements of self-consciousness are indigenous to psyche structure, while Mead maintains that the self arises from society. These authors explain that the child has a self and the self is, in itself, an object. The child's consciousness can focus on any object but the child needs to be in society for the self to develop, or in other words, he/she needs to become aware of the distinctiveness of...
the other to achieve knowledge of the subjectivity of the self. As experience with
different points of view accumulates, the child, systematically, will become aware of
his/her causal agent self as a distinct entity in the world. Further, with repeated
situations that cause the child to examine different dimensions of the self, he/she will
come to build up a unified conception of the self. Once he is aware of the concept of
the self, he/she will then come to focus on those dimensions of the self that happen to
be salient in a situation.

In general though, Duval and Wicklund seem to recognise an essential step in
becoming aware of the self which does not appear in Mead's theory, the
differentiation of the causal agent self. For Duval and Wicklund, taking the point of
view of the other (or the perception of being observed) is just a stimulus that causes
the individual to focus attention on the causal self. Contact with the ideas of others is
another stimulus that will cause objective self awareness (objective because the
authors consider the self as an object) as far as these ideas are different.

3.3.1. What, no agency?
Arguably though, it could be said that while Cooley, Mead and Vygotsky locate the
self in the social (as a function of communicative interactions), Duval and Wicklund
locate the self in the psychological (as a function of internal psychic processes). This
opposition has been seen as problematic by some authors, especially in the realm of
moral psychology, where assuming responsibility and accountability for one's actions
is seen as key to attaining moral maturity (Tappan, 1991a). From a dialogical
perspective, for example, Tappan (1999) argues that the self, and by this he means the
moral or causal self, is located dialogically. This perspective looks at the self as a
function of the linguistically mediated exchanges between individuals and the social
world (Tappan, 1999). It is based on three assumptions: 1) all so called higher
psychological functioning is mediated by language and forms of discourse, 2) such
mediation can also happen during inner speech and 3) processes of social
communication and social relations are the base of causal functioning (Vygotsky,
1987). Thus, the idea that the causal self develops, as the words of others become
one's own words as social speech becomes inner speech, resolves the opposition
between the social and psychological theories.
However, how social words become a person's own words is not clear from Tappan's argument. To clarify then, and according to Bakhtin (1981), a person appropriates words when these are infused with the speaker's intention, the person's accent and the person's semantic and expressive intention. Bakhtin argues that a speaking individual is always, in varying degree, an "ideologue", because language is a particular way of viewing the world. To gain an insight into an individual's ideology, therefore, one must consider the processes by which the individual appropriates and assimilates other's words and discourses as the individual constructs his or her ideological perspective of the world.

Thus, to answer the question heading this section, there is agency to the self that Mead describes. The argument places the agency of the self in the words that individuals use in their linguistic exchanges between selves and society.

3.3.2. Empirical evidence and limitations of the symbolic interactionist theoretical perspective

Duval and Wicklund (1972, 1973) and others (Swart, Ickes & Morgenthaler, 1978; Buss and Scheier, 1976; Davis and Brock, 1975), offer wide empirical evidence to support the idea that perception of being observed and encounters with the different ideas of others do indeed increase self-awareness. Meanwhile, empirical evidence to support Mead's ideas is not so clear. According to Shrauger and Schoeneman (1979) and Waters (1994) research into the looking glass self suffers from "ahistoricity" or as they explain, little sense of cumulative development of information. Evidence for influence of others' actual appraisals on self-appraisals has been found in some cases (Cast, Stets and Burke, 1999; Ichiyama, 1993) but reviews of earlier research (Shrauger and Schoeneman, 1979) indicate that this evidence has not always been supportive. Stronger evidence is found to link reflected appraisal (i.e., a person's perception of the appraisal of significant others) and self-appraisals (Felson, 1989), although the relationship seems to work better when it involves the generalised other rather than the significant other. Furthermore, some reviews (Kenny and DePaulo, 1993) examining the extent to which people know how others see them, indicate that people determine how others view them not from the feedback that they receive from others but from their own self-perceptions.
This lack of consistency in the research has been attributed to a variety of factors. Ichiyama (1993) has pointed out that which others are considered as influential, the self’s agency in protecting self views and the person’s openness to change may all have an effect on the self-concept process. Methodologically speaking, experimental studies have been criticised because of their short-term nature and the demand characteristics of the tasks, longitudinal studies for not accounting for change of knowledge over time, and cross-sectional studies because of the possibility of reciprocal causation and the influence of a third variable (Shrauger and Schoeneman, 1979; Felson, 1989; Ichiyama, 1993).

Generally speaking, the symbolic interactionist tenet, that we come to see ourselves as others see us, has received only inconsistent support and has been found to be dependent on the status of the individuals (Cast et al, 1999), the type of communication (Felson, 1981; Shrauger and Schoeneman, 1979), the type of relationship between self and the other (Cole, 1991) and the tendency of the self to attend to other’s information (Cooley, 1902). In addition, the importance of others’ views for the self has been evaluated (Cast et al, 1999; Felson, 1989; Ichiyama, 1993) and the agency of the self in attending to and influencing others’ views of the self has been underlined (Cast et al, 1999; Felson, 1989). The importance of others in increasing self awareness has not been examined. This thesis suggests that one important influence on the development of awareness of difficulties following a brain injury is the extent to which significant others talk about the brain injury and how sequelae to the injury are explained, and made sense of in everyday discourses, to the brain injured person. Thus, symbolic interactionism deals with the way in which individuals build awareness of the self through messages given by others in the individual’s immediate surroundings. However, what this theory needs now is to be widened to incorporate the understanding of how messages that may not originate in a social context, like bodily perceptions, are constructed by the self and how the self can access the contents of awareness. Therefore, the discussion will turn to social constructionism per se and will introduce a "weak" social construction theory of consciousness. The term "weak" is referred to here because the theory about to be introduced postulates the pre-eminence of the body, cognition and emotion to social interaction.
3.4. A SOCIAL CONSTRUCTION OF AWARENESS

In this section the term social constructionism will be explored further as the basis on which this analysis of awareness of difficulties following a brain injury is built. Social constructionism is understood here as following symbolic interactionism in suggesting that:

- Social objects do not have their own objective existence
- They do, however, exist, and if they are not objective they must be subjective
- If social objects are subjective, they must be constructed out of the perceptions of individuals, that is, they must be constructed in the social realm, subjective realm
- Individuals are social objects, and they construct their selves, their perceptions of themselves and the self they portray to others (Harding and Palfrey, 1997).

However, symbolic interactionism is not enough to describe the influences of an inner life in the individual. That is, all the thinking, feeling, and bodily perceptions which may be carried out in the privacy of the self and which the individual may bring into open communication. Therefore, a theory, which retains the core of symbolic interactionism, but allows for the inner influence of the self to be felt and known, will be developed here.

3.4.1. Conscious awareness of the self

The definition of awareness used in this thesis is part of a comprehensive social construction theory of consciousness proposed by Burns and Engdahl in 1998. This theory suggests that individual's awareness, as a defining form of consciousness, derives from collective processes. It argues that "human consciousness results from the development of collective naming, classifying, judging, reflection, and discourse applied to individual members or participants in the collective" (p. 166). Individuals acquire the capacity to engage in self-reflectivity not only through the acquisition of language and collective representations but through the capabilities of discussing conceptions, observations and assessments of the self, among other objects defined and discussed within the collectivity. Such reflectivity, propose Burns and Engdahl, is one of the many mental processes that are encircled by the term awareness.
Chapter Three - Social constructionism: the theoretical perspective

To develop this theory further the authors pinpoint three tenets:

1. The individual self is seen as a collective representation and an object of collective reflection and discourse.

The argument here is that individual reflectivity, as a form of consciousness, derives from collective processes. Language, language-mediated collective representations and a cultural cognitive frame enable individuals to participate in communicative and reflective processes and to become objects of attention and representation themselves. Individuals learn to give accounts of themselves, their actions and performance results; they explain and justify themselves. They learn to regulate the self according to particular collectively defined role conceptions, norms or policies. In a few words, they develop an awareness of the self, a sense of self.

Burns and Engdahl make several key points on the self as collective representation and object of reflection:
- The self is not only involved in collectively defining and using collective representations, but is itself a collective representation in reflective processes and internalised dialogues. Self-reflectivity on the individual level entails self-observation as object and as agent. An I with desires, intentions, orientations and a will, which can be analysed in terms of values, goals, aims and beliefs. Furthermore, the individual experiences the own self in ways differing from the ways the individual is aware of other selves, albeit still capable of identifying with others.

- Self-monitoring and regulating activities, within a particular socio-cognitive frame, work to constrain activity in particular ways, through organising conceptions of reality, classifying states of the world, assigning values and making judgements on the basis of the principles specific to a social order or institutional domain.

- Self-conceptions are originated and sustained or changed through social interactions, in particular, communicative activities with others. A person's self image is largely the result of interactions between self and significant others when it comes to interpretations, classifications, enactments, assessments and judgements in relation to the individual self.
2 - **Complexity of human mental life and the multiple modes of individual awareness and consciousness.**

According to Burns and Engdahl (1998) human beings experience a variety of sensory states in respect of their bodies, mental activities, etc. Their awareness of some of these conditions and processes is considered a phenomenological fact and as such, it should be distinguished from purely material aspects of a physical and physiological nature. In addition, Burns and Engdahl note that sentience and cognition entail some organising mechanisms that are non-conscious. In some instances, they explain, individuals become aware, recognise and respond to certain patterns of data. Furthermore, in some modes of mental activity, states, events and processes are named and are brought into dialogues and reflective processes within a collectivity. Analysis of individual mental processes, including awareness and consciousness, indicates that there are multiple processes within a mental process, biological, neurophysiological, mental, symbolic, and that some of these take place in parallel. On other occasions, the multiple processes are interlinked and translations take place transforming the information contained in one process into another. Some of this interlinks happen between physical-biological processes and linguistically mediated processes that make up higher-order forms of awareness. For the authors the individual mind consists of multiple, interrelated processes, with a number of transformations that go on between processes. This transformation of data from one encoding to the other is a fundamental type of process in the complex of mental life. The interrelationships between sentience, cognitive processes, and language based representation and reflectivity entail both, internal and external interactive and feedback effects. The processes of data selection and organisation, in part through anatomical and physiological mechanisms, in part through subconscious structuring, and in part through language and culture mediated structuring of experience and cognition, makes humans active cognisers within an established cultural cognitive frame which, in turn, make communication and social sharing of experiences and definitions of reality possible.

The individual reflective mode, Burns and Engdahl suggest, originates and develops with respect to the complexity of mental processes. These mental processes depend on the interrelationships of the sensory experience of the body, cognitive processes
and the symbolic interactionism of communication with others. Via such processes, other mental processes can be reflected on, and even these reflections can be in their turn, reflected upon and so on. The explanation of how this takes place is broken down by Burns and Engdahl into:

**Sentience**

Sensations relating to the body are many and diverse. Smells, chemical processes, sounds, are seen as primitive phenomenological processes, position, movement and functioning are essential in monitoring and regulating the body. Although many of these processes are non-reflective or automatic, some are conceptualised and can be brought into a communicative interaction. The person is aware and reacts to experience based on multiple pieces of information. If the person hears, sees, smells, feels his/her body, the person reacts to these data and uses it to orient and regulate his/herself.

**Cognitive processes**

Experiences, images, memories, representation of objects, concepts, and processes of self, among others, are conceptualised with the help of language or without it, although language helps articulation and elaboration of category systems. Burns and Engdahl explain at this point that complex, parallel and linked information processing is a characteristic of advanced beings. They see the developed brain as capable of recording, experiencing and organising multiple sensations into multiple cognitions and maintain that representations are not uni-dimensional, "but complex and multi-faceted" (p.171). Information processed in a cognitive framework is integrated into holistic experiences, which are the basis for experiencing patterns rather that just bits of data. Mental states maybe investigated not only at a physical level but at a phenomenological level. In humans this phenomenological level is enhanced by language and so internal monitoring is possible. Without language these processes remain unelaborated.

**Self reflectivity**

This is what Burns and Engdahl call "consciousness proper". Consciousness is based on language-mediated representations and inner dialogue. The person by internalising collective representations and skills of social dialogue gains the basis for individual
reflectivity. Such individual reflectivity can be reported to others depending on language and communicative interactions.

What is essential in reflectivity, the authors claim, is not only the noticing of a change but the translation of such change into language-based representation processes. Thus, one's state of awareness can be discussed with self, in inner dialogue, as well as with others.

Thus, Burns and Engdahl recognise the complexity of the human mind and explain how it can categorise, discriminate and react to environmental stimuli. Also, it can reflect, judge and alter these discriminations, categorisations and reactions to the environmental stimuli. Awareness of self-processes requires, according to the authors, a representation of the self's states and this depends on memory. The enduring self, they say, is a variety of social and cognitive mechanisms, which stabilises representations, cognitions and memories.

3 - Different levels of awareness and reflectivity.
Within the individual mind, there are multiple levels of awareness and consciousness:
- processes, states, events and developments that are outside of human sensory experience (without aid)
- processes, states, events, developments which humans experience but of which they have no developed conceptions
- processes, states and developments that make up sensory experience: some sensory inputs (perhaps qualitatively different aspects: whether visual, motor or emotional) are framed, conceptualised and understood as being connected
- experiences of the body, movements, habits, perceptions, and sensory inputs are encoded in language. They can be discussed and reflected on.

Although Burns and Engdahl stress that these levels are not hard and fast in an empirical way, analytically speaking, they emphasise the need to differentiate types and qualities of awareness and these are explained below:
a) Signals outside sentience and direct awareness
These are signals that are not accessible to the individual and even if they were, the individual would not be able to attend to all possible sensory data. Factors that explain this unawareness can be biological, cognitive and emotional.

- Biological - there are numerous bodily processes and states that are outside awareness. Making use of medical instruments, a doctor may be able to measure and analyse some of these conditions.
- Cognitive - some cognitive processes are ignored while the individual focuses on other cognitive conditions; other processes are taken for granted by the individual and are not cognised or perceived (like seeing something out of the corner of the eye or certain, well rehearsed activities).
- Emotional - certain emotionally threatening or destabilising sensations, experiences and cognitions are ignored or forced out of awareness, re-framed and so on.

b) Awareness and primary reflectivity
The authors state that the individual may be aware of states and processes of self, self-sensation and self-awareness, without being able to verbalise and discuss these conditions; primitive forms of primary reflectivity may be present at this stage. The individual or agent engages in primary reflective mode to monitor, assess, describe and re-orient activities, to exercise a will or control of behaviour and influence the environment.

This self-regulation implies self-referentiality. The individual's goals, values and intentions that derive from a position or role in a social organisation are tested against relevant observed states, actions, developments and results. In turn, these states may or may not have anything to do with actions taken by the agent. But if they are perceived as connected with actions, the self-reference becomes obvious: in the individual's conception of the situation, the actions of the individual are different from those of others or from other factors in the situation.

c) Higher order reflectivity
Burns and Engdahl consider that consciousness is different from just being awake. Wakefulness entails a type of awareness or experiencing, but not necessarily
reflectivity. That is, the individual may be aware of the self, may be experiencing the self but may not be reflecting on one's own awareness or type of awareness. However, if the individual enters the reflective mode and applies it to the self, Burns and Engdahl explain, by assessing it and re-orienting it, then the individual enters a higher order awareness or reflection on self-awareness. At this stage, the experience of states and processes of the self are named and can be verbally thought about. Therefore, if awareness is attending to the self, higher order awareness implies that the individual can observe and analyse that very attending to the self.

3.4.2. Summary

Under this framework, it is recognised that humans experience a variety of sensory states to do with their bodies, their cognitions and their emotions. Although a certain number of these sensory states may be unconscious, individuals become aware, on occasions, and recognise and respond to stimuli. When this awareness takes place, the sensory states are named and brought into dialogues and reflective processes within a collectivity. Reflective processes can be biological, neurophysiological, mental, symbolic, etc. and can take place in parallel or interact with each other. There are processes of data selection and organisation. In part through unconscious mechanisms, in part through anatomical and physiological mechanisms and in part through language and culture mediated structuring of experience and cognition, or to the same effect, humans can be seen as active cognisers. They can structure data and organise perceptions within established cognitive and cultural frames. Thus, communication and social sharing of experiences and definitions of reality becomes possible (Burns and Engdahl, 1998).

Furthermore, the person's reflective mode "emerges and develops" from the complex of mental processes. This means that it emerges not only from sensory experience of the body and cognitive processes but also from the symbolic, representative processes involved in communication and interactions within a collective. Through such processes, emotions, cognitions and sensations of the body can be reflected on or communicated (Burns and Engdahl, 1998).
However, and even though Burns and Engdahl recognise the body, cognition and emotion as objects to be reflected on and/or as the objects of communication, the authors do not seem to emphasise enough the role of the body, cognition and emotion as agents. That is, Burns and Engdahl explain that self-reflectivity entails self-observation of the body, cognitions and emotions as objects and agents but do not make this distinction sufficiently clear. This distinction is important however for two reasons. First, because the body, cognition and emotion as agents can also be the subject of communications. Second, to regard the body, cognitions and emotions as agents helps to understand the self as active and not as a mere passive recipient of feedback from the social world. Therefore, the discussion will focus now on this distinction and will see the difference between the body, cognition and emotion as objects and as agents.

3.5. THE BODY AND AWARENESS

From a social constructivist perspective awareness emanates from the interaction between the private self and the social self. Both selves are related to the body. Bodily sensations provide the initial way of knowing about the world and provide the first experiences from which self-awareness can develop (Piaget, 1959). Mead (1934) argued that awareness of the body as a separate object is an essential prerequisite to the development of the social self, while Dewey (1963) argued that to view the body as a causal agent is also crucial. Things happen to the body but the body, in turn, can also make things happen. Both ways of viewing the body, it is argued here, are essential to understanding awareness of the body. Let us consider first the body as an object.

The body as object

From the theoretical perspective offered by Burns and Engdahl (1998) it is understood that the human body is both an object of knowledge and a knowing, sentient being. Humans sense, touch, feel, hear and see ourselves as individuals in space and time, and so experience ourselves as continuous beings. However, through relations to others and in the establishment of a relationship to our own self, we can see ourselves from a distance and also act and perform differently in different contexts. Some authors have divided this experience into the body located in time and
space which experiences itself as a unified entity (Self) and the various selves that humans display in various social contexts (Person) (Harré, 1983). The person is the public being, the self the subjective, private being which has no physical referents. The distinctiveness of one's own body serves as the basis of the identification of one self by others, and the basis of one's personal sense of identity has also to be, at least in part, referred to bodily considerations. For Harré, both senses of self are produced through discourses of the local moral order, pertaining to the rights and obligations one has as an individual within one's community. That is, within local moral orders individuals are held accountable for their actions by others, and these accounts must be framed in terms of local moral principles. Harré explains that individuals do this because they have a basic desire for respect and honour within their communities, and this is achieved by being known as a morally good member of society.

Adding to Harré's view, Burkitt (1999) argues that the embodied location of the individual, in both its spatio-temporal context and in social interactions, can be seen as the person, upon whom is conferred rights and duties, along with particular marks, names and numbers. Burkitt says:

"It is around these symbolic markers (including the ethical codes and norms), as well as through our own sense of bodily location, that we identify ourselves as a person." (Burkitt, 1999, p.62)

Furthermore, perhaps the most obvious way in which the physicality of the body influences awareness is by shaping this social identity (Stone, 1962). The shaping of identity, according to Kelly and Field (1996), happens in three different ways. First, being aware of the body helps the person to be acknowledged as competent social performer by giving the impression of control, use and presentation of the body. This becomes more clear when our bodies let us down as in the case of brain injury. In this instance, a brain injury may affect self and social identity by inhibiting the capacity of each individual to play a social role/s. Instead, the body becomes central to the social process (Kelly and Field, 1996) and central to the coping task of having a brain injury. This occurs because the individual has to deal with the physical manifestations of the injury, if any, which precedes having to cope with relationships, disruptions to daily
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life activities and social reconstruction of events (Kelly, 1991). The physical aspects of living (eating, washing, etc.) become then the focus of the experience of having a brain injury for the individual and the carers of the individual (Anderson and Bury, 1988). Second, in many cases, after a brain injury especially, bodies change and this change often creates tension between the physical appearance (i.e. cripple) and the individual's self-conceptions based on the actual identity of what they are able to do (Goffman, 1963). Third, the enduring quality of the body itself. Although after a brain injury the body can change just as the self and social identity can do, the body is the same body as it was premorbidly, just as the self and social identity are part of the same person. It is the same person who has endured the brain injury, the same body. What is different is that after the brain injury, the awareness of the body is greater, in the self and in others. This awareness stops the body being taken for granted. The changes suffered during brain injury have to be incorporated into the self and become the basis for the imputation of identity by others.

Thus, the arguments emphasise how central the body is to the identity of the person and how this identity is shaped by the presentation of the body, especially when presented as disabled. As an object, the body is ascribed meaning in its own right. However, to come to grips with awareness of difficulties in people with brain injuries as individuals that have bodies of flesh and bones and do not just have a body as a cluster of meanings attached to it, the body as a communicative device or as a meaning-producing device needs to be understood and it is to this that the argument turns now.

The body active

Social constructivists argue that knowledge of the world is produced during social interactions, which actually construct the objects we take to be the things in the world. Lately, Danziger (1997) has observed that social constructivism can be divided into "strong" or radical and "weak" positions. The strong position links knowledge to power, while the weak versions link knowledge to everyday relations and communicative interactions (Gergen, 1994a). Both positions, however, claim the uncertainty of the existence of objects beyond their construction in social interchange.
In other words, individuals can never know with certainty the existence of a world beyond their linguistically formulated knowledge of it.

It could be argued though that it is the weak social constructivist position that facilitates placing individuals not as objects but as communicators in relationships and conversations, and therefore, as active agents. This argument can be clarified with some ideas suggested by the phenomenological studies of Merleau-Ponty (1962). For this author, thinking is not the consequence of a disembodied mind located somewhere outside the material world, beyond time and space. Nor is it just the product of a body reacting to its surroundings. Thought, for Merleau-Ponty, is part of the active relationship between individuals and their worlds. Before thought and ideas, the author argues there is a co-existence between the body and its world. This co-existence is what makes it possible for individuals to develop conscious awareness and knowledge. Space and time are not dimensions that the body is situated in, but body, space and time are seen as a unity. This concept of unity draws attention to how the self is conscious of always being in a particular location, and that, because of other perspectives, there are always other points of view on the world.

According to Merleau-Ponty humans can never gain an objective knowledge of the world that exists outside individual subjectivity, for, the author explains, there is no such knowledge to be had. That is, a disembodied perspective of the world is a perspective from nowhere and is therefore impossible to achieve. All knowledge is embodied and placed, created in the fundamental unity between subjects and objects, which is the consequence of having an active body. Action, for him, is the clue to understanding human beings and this active perspective involves not only the fundamental and variable relation between the body and its objects, but between different human bodies as well. Therefore, the human world is primarily a social world. For Merleau-Ponty this relational unity, this being in the world, is the context for human thought and knowledge.

Merleau-Ponty (1962) speaks of the sentience of the body in a similar way as Burns and Engdahl (1998) speak of sentience of the body. With reference to the human body and the way in which the body is embedded in the various natural settings.
Sentience is understood here as the body's sympathetic and responsive relation to its environment, which is regarded as mindful even though it is not rational and pre-linguistic. Thus, the body can be described as a thinking body and having intentionality before the emergence of language and self-consciousness. Grasping for an object, for example, is a basic form of intentional action and no cognitive representation of grasping is needed for such action. Thinking and intentional activity are then seen as pre-linguistic and pre-cognitive, and prior to the self-conscious individual there exists the bodily individual which is its foundation.

Merleau-Ponty's view of this bodily individual pre-existing the self-conscious individual is in direct opposition to the cognitive subject described by Descartes. If for Descartes the person was a spectator, viewing the world from an intellectual distance, for Merleau-Ponty, humans are always enmeshed in a lived relation with the world, grounded in the activity of the body, which engages all the senses. In other words, humans not only look at the world but live the world through their bodies. Further, the senses are not understood as a set of bodily pre-givens. Merleau-Ponty thinks that sense data in themselves cannot be the base of thought for there is no initial distinction between the senses. The senses have to be differentiated and organised for them to have any meaning for the individual, a process that takes place in bodily action, that is, through active perception. A body that is active in the world brings together the senses in a coherent way (Merleau-Ponty, 1962), and the formation of habits plays a part in this process of perception. Yet this distinction and differentiation of the senses is never complete and absolute, for the senses continue to infuse one another to varying degrees. For example, there is always some taste sense when looking at an attractive meal, and vice-versa.

Empirical evidence does indeed seem to support this idea. Wong (1975) for example, explored the relationship between visual and tactile perception, using the Necker cube and the Schroeder staircase as visual stimuli. The study attempted to elucidate experimentally how pre-reflective (i.e. non-verbalised) perception integrates the other sensory modalities (i.e. touch) in comparison to reflective (i.e. verbalised) sensory experience. Wong divided 24 participants into 4 experimental groups. Her findings showed significant differences between the verbal and non-verbal groups indicating
that the reflective condition group lowered the degree of relationship of visual and tactile perception. The author concluded that in spontaneous perception seeing and touching are "inseparable".

Therefore, the body and its habitual actions are not mechanical process, such as simple physical reflexes, but are forms of knowledge or ways of carrying on effectively in the world. Thus, while this body knowledge is not mechanically produced, neither it is constituted as self-reflective and fully articulated understanding (Merleau-Ponty, 1962). However, it could be argued that the body can be placed in a self-reflective mode if an anomaly, such as brain injury, affects it or disrupts the habitus. Then the signs of a malfunctioning body need to be differentiated and interpreted after the injury. This interpretation is then open to communication once and only once the person has the intention of making something public. Furthermore, the person has to make use of a socially shared signal or code in order to make this possible. In cases where these conditions are not met, bodily conduct should be considered as symptomatic of a certain bodily state rather than communication. Paralysis of an arm, for example, may be symptomatic of having had a brain injury, but should not be considered as communication about feeling the arm not moving. In this sense, the body is active in interpreting sense data and formulating interpretations of these data. These interpretations are open to communication and are, in part, the subject of this thesis.

3.5.1. Summary
In this section, the body has been considered under two different lights: as an object and as an agent. As an object, the body has been described as creator and receptor of identity. This identity is shaped by the presentation of the body (injured or intact) which in turn, is the basis for imputation of identity by others. As an agent, the body and its habitual actions, have been described as forms of knowledge or ways of carrying on effectively in the world. Thus, each perspective allows the body to be both object of knowledge and a knowledgeable object and therefore, the possible subject of communication. The same distinction will now be attempted for cognition and emotion in the subsequent sections.
3.6. AWARENESS AND COGNITION

It is a well known fact that the variety and quantity of social and environmental stimulation available to the individual at any one time is too great for the individual to be able to be aware of, process or attend to (Spinelli, 1989; Markus, 1977). People need to be and are selective in what they attend to. This selectivity is not random but it is said that depends on internal cognitive structures that allow the person to process incoming information with some efficacy (Markus, 1977). These structures have been called "schemata" (Tesser and Conlee, 1975), "scripts" (Abelson, 1975) or "frames" (Minsky, 1975).

According to Markus (1977) these cognitive structures are more apparent when we process information about ourselves. Research on self-perception (Bem, 1972) and self-monitoring (Snyder, 1974) supports this idea and indicates that the individual takes an active role in the information processing construction. Markus argues that when an individual explains his or her own behaviour in a particular field, what is communicated is information about the self or what Markus calls self-schemata. Markus defines self-schemata as "generalisations about the self, derived from past experiences, that organise and guide the processing of self-related information contained in the individual's social experiences" (p. 124). The author argues that self-schemata can be specific (derived from personal experiences) or general (derived from repeated categorisations and evaluations on the person's behaviour made by the individual and others) and constructed by the person from information processed in the past. Self-schemata then represent the way the self has been differentiated and articulated in memory.

This point brings to relevance the important role that memory plays in the process of awareness. Tulving (1985) for example, claims that "there is no such thing as awareness without remembering" (p. 5). Individuals, he argues can behave and learn without awareness but they cannot remember without awareness. They may know something about an event but they may not remember such an event. Such knowledge, Tulving argues, can be created and be of the same quality as the knowledge about the spatially and temporally extended world. The difference between knowing and remembering is then, the phenomenal experience that
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accompanies the recovery of episodic knowledge. This difference can be made manifest by asking people to recall an event and enquiring whether they remember the event or know about it. Empirical evidence for this distinction (Tulving, 1985) does indeed support the idea that people can retrieve information about personally experienced events without remembering the event. Indirect empirical evidence is also offered from a narrative perspective. Nochi (1997), in a qualitative investigation of individuals with traumatic brain injury, describes how these individuals on recovering awareness of themselves and their environments, found that they could not remember their accident. This not knowing lead them to what Nochi calls "finding the void" (p. 539). Finding the void is a term used to describe how four brain injured patients searched for information from medical staff, relatives, newspapers and other sources, about the accident, in and effort to fill the absence of this particular memory. When they were talking to the researcher, their narratives were not about their memories of their accidents but about what they knew of their accidents.

The difference between knowing and remembering that Tulving derived from his observations of amnesia patients has various implications. It emphasises the phenomenological nature of awareness on one hand and on the other, puts a stop to simply equating awareness with knowledge often found in common parlance and unawareness of difficulties research. The evaluation of the phenomenological nature of awareness is dealt with below. Deconstructing the equation knowledge/awareness helps understand why, in brain injury in particular, some individuals who know the facts about their disabilities don't do anything about them (Stuss, 1991). If the disability involves memory difficulties, they may know about it but they may not be able to remember it. Therefore, knowing is not enough for awareness to be activated, according to Burns and Engdahl (1998), knowing needs to be accompanied by reflectivity or be "illuminated" by consciousness (Zahavi and Parnas, 1998).

3.6.1. The phenomenological nature of awareness

Traditionally, and from a dualistic perspective, consciousness and its contents exist in an immaterial realm that has no location or extension in space. From a materialistic perspective, consciousness and its contents is nothing more than selected states or functions of the brain. And yet, from a phenomenological perspective the contents of
normal phenomenal consciousness define and fill three dimensional space as they are none other than the everyday world, as experienced (Velmans, 2000). What one experiences at a given moment depends on how one directs one's attention. Consciousness contents differ depending on what a person attends to and they include not only inner and body experiences, but what it is conventionally known as the physical world. Thus, consciousness involves, among others, references to one self and self-awareness is a necessary part of any instance of this consciousness.

Although there is disagreement among theorists concerning the process by which inner awareness or self-awareness is accomplished, it is rare for psychologists to deny that humans possess the ability to be directly aware of some of aspects of the inner self (Natsoulas, 1998). From a philosophical perspective, the idea of reflection or the ability of the mind to turn its view inward upon itself is one (Locke in 1975) hinted as a way to knowing the contents of consciousness. Equally, Armstrong (1993) advocates that there is a close analogy between perception and introspection. A perception is a mental event whose intentional object is a situation in the physical world (i.e. bodily perceptions, visual perceptions, etc.). An introspection is a mental event whose intentional objects are other mental happenings occurring in the same mind. Armstrong claims that it is only by becoming the object of introspection that a mental state becomes conscious or manifests itself subjectively.

This account of knowing about the contents of consciousness however, has been criticised on two accounts. Firstly, Nisbett and Wilson (1977) proposed that when people attempt to report on their cognitive processes, that is, on the processes mediating the effects of a stimulus on a response, they do not do so on the basis of any true introspection. Instead, their reports are based on a priori, implicit causal theories or judgements about the extent to which a particular stimulus is a plausible cause of a given response. This suggests that though people may not be able to observe directly their cognitive processes, they will some times be able to report accurately about them. This would imply, in turn, that giving accurate reports of the contents of consciousness is a bit of a fluke anyhow. Nevertheless, the evidence presented by Ericsson and Simon (1980) has refuted Nisbett and Wilson's objections. These authors argue that the inaccurate reports found by Nisbett and Wilson in 1977
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were the result of requesting information from participants that was never directly heeded, thus forcing participants to infer rather than remember their mental processes. In other words, in some of the studies presented by Nisbett and Wilson, the questions presented to the participants contained considerable background information that would make it feasible for participants to generate answers without consulting their memories of the cognitive processes.

Secondly, using introspection to acquire knowledge of the contents of consciousness implies understanding the self as object of thought only. Natsoulas (1998) for example, argues that this understanding stops psychologists from considering awareness as part of the stream of consciousness (James, 1890). Psychologists fail to realise, Natsoulas explains, that in the absence of inner awareness humans would be ignorant as they went along with their seeing, feeling, thinking or intending whatever they may be seeing, feeling, thinking, or intending. If there was no inner awareness, humans would be, with respect of mental life, like people who possess only "blindsight" over the entirety of their field of view (Weiskrantz, 1993). In a similar vein, Zahavi and Parnas (1998) argue that regarding self-awareness as an object is to regard consciousness as aware of itself not as aware of the self. Zahavi and Parnas (1998) explain that the object of perceptual experience is intersubjectively accessible in the sense that it can, in principle, be given to others in the same way that it is given to an individual, the perceptual experience itself is given directly only to the individual. It is the first personal "givenness" of the experience, which makes it subjective. In contrast to physical objects, which can exist regardless of whether they appear, de facto, for a subject, conscious experiences are essentially characterised as having a subjective feel (Nagel, 1986; James, 1890). However, while we cannot ask what it feels like to be a something, we can ask what does it feel like to be a human being because human beings are taken to be conscious. To undergo a conscious experience necessarily means that there is something it is like for the subject to have that experience. This is true for bodily sensations, perceptual experiences and intentional feelings. There is also something it is like to contemplate the problem of self-awareness. Therefore, if there is something it is like to experience self-awareness, there must be some awareness of these experiences themselves or in other words, there must be self-awareness.
Nevertheless, if there is self-awareness how is this self-awareness known? According to Zahavi and Parnas, this state is known because consciousness, like a flame, illuminates itself and other things. That is, Zahavi and Parnas, like Burns and Engdahl (1998), understand self-awareness as part of consciousness not as a secondary act or reflex but as a constitutive moment of the conscious experience itself. Thus, they argue, there is only one component in self-awareness, which means that the experience is and is present to itself and it is this self-presence which constitutes the self in its most original and fundamental form.

This "experience" has also been described by Natsoulas (1998) who complements his argument by defining the conditions for self-awareness to take place. According to Natsoulas for self-awareness to happen a person must be witnessing oneself, the oneself needs to be appropriated, there needs to be "retrowareness of oneself", inner awareness and consciousness extended backwards. The concepts, which are explained briefly below, and as described by the author seem to relay on one important cognition, namely, memory. Natsoulas observes, and as noted by most philosophers, that consciousness cannot be about anything. Rather, a person is or has been at some point, aware firsthand, on the spot, at the time of its occurrence, of a certain relevant piece of one's own behaviour or a certain relevant part of one's stream of consciousness (James, 1890). This behaviour or the particular part of one's stream must be suitable for serving as evidence about one's cognitions, beliefs, abilities, traits, dispositions or tendencies. The evidence cannot pertain instead to merely social or material factors because awareness is always about oneself, although in evaluating evidence concerning an aspect of oneself, one may take into account social and material factors. For example, one may acknowledge one or more of these factors as determinant of one's intellectual performance. However, it is not these factors that one has awareness of or about; rather, it is the relevant outcomes to which they may have contributed, such as a habitual way of thinking about the world or treating other people. This is how Natsoulas defines witnessing of oneself.

Further, self-witnessing cannot happen of its own accord. Natsoulas suggests that the self-witnessing must "appropriate" to oneself that which is witnessed. One must not only be aware firsthand of the particular piece of one's behaviour or part of one's
stream of consciousness that would serve as evidence, but also one must be aware of that piece or part as being one's own. In this sense, self-witnessing must be personal. Natsoulas explains that it is possible for one to have, instead, inner awareness of one's stream of consciousness whereby one's stream of consciousness seems to have been taken over by another agent or at least, seems not to be one's own. Reed (1972) pointed out that behaviours, as well as parts of one's stream of consciousness, may suffer a loss of personal attribution, either transiently, as a result of stress situations or more consistently, as part of neurological pathology such as schizophrenia or brain damage.

To explain retrowareness of oneself Natsoulas observes the instances of consciousness that sometimes take place at a temporal distance from the specific self-witnessing that provides evidence for them. For instance, something of oneself that was witnessed at a certain, perhaps early point in life may repeatedly serve one as evidence for judgements regarding the kind of person one is. Therefore, remembering proper is a part of being conscious and all instances of such remembering, whether or not they take place as part of consciousness, necessarily involve occurrent awareness now of a past happening or state of affairs. In being conscious, one now remembers something that one previously did or experienced. In other words, consciousness usually involves a kind of self-awareness that is a "retrowareness". For instance, one can apprehend in thought right now, and not for the first time, how one behaved in a particular instance in a particular occasion.

However, for an occurrent awareness to qualify as an instance of remembering proper, the awareness must be a retrowareness of a special type. It is not enough that one was originally aware first hand of the object of the particular retrowareness. In an act of remembering something in particular, one must be occurrently aware now of oneself as now apprehending that which one had earlier apprehended. Therefore, necessarily involved at the point of remembering is inner awareness of one's present self-retrowareness. Further, according to Natsoulas, there is also a kind of retrowareness that resembles inner awareness. There occurs a present retrowareness of one's past experience. For example, one's perceiving, emotion over, thinking about, planning, remembering or expecting something or other in particular that was taking
place or was going to take place. Thus, in those cases of consciousness whereby one remembers witnessing the relevant evidence, there occurs both inner awareness of present components of one's own stream of consciousness that are retrowareness of the evidence witnessed and inner awareness of present components of one's stream of consciousness that are retrowareness of some of the mental acts that took place as part of one's witnessing the evidence.

However, there is more to consciousness than remembering the right sort of item. For Natsoulas, one is conscious not simply because one is remembering one's act of witnessing about oneself but one is conscious because one puts to use what one remembers. It becomes evidence by being brought to bear on something that one already believes or may come to believe. In addition, to one's undergoing retrowareness of particular past events as being occurrent parts of oneself, one must have thoughts regarding one or more characteristics that may belong to the intellectual, moral or belief dimensions of one's personality, and one must make judgements regarding how the remembered evidence bears on whether those characteristics do so belong.

Thus, Natsoulas avoids focusing, while not denying it, on the individual gaining knowledge of the contents of awareness, via self-reflection or introspection, in favour of an immediate or direct awareness of present and past events. This immediate awareness, in turn, places a necessary emphasis in the role memory plays in awareness based on past evidence. However, Natsoulas argues that the processes of awareness described above take place in the same manner in the present. They can occur on the spot, that is, while one is engaged in witnessing a behaviour or a part of consciousness. The conclusion then, and by implication, converges with Tulving's empirical studies in that, in the absence of memory, humans may still be conscious but not aware of some or all the behaviours witnessed or parts of consciousness. The distinction, which will be explored further below, is important because it may help to explain knowing without remembering.
3.6.2. Memory or knowledge

If self-schemata, as has been seen, are understood as cognitive representations derived from an individual's social experiences then, they can be conceptualised as representations that have been articulated and differentiated in memory (Markus, 1977). Cognitive science has classified these representations in memory into two types of knowledge: semantic personal knowledge and episodic personal knowledge (Tulving, 1989). Semantic personal knowledge refers to information that has been abstracted from memories of the self in specific events (Tulving, 1989). Semantic personal knowledge of traits may include the facts that a person is generous, active, disabled or lazy. Episodic personal knowledge refers to memories of specific events involving the self (Tulving, 1989). Episodic personal knowledge of traits includes those instances in which behaviour was generous, active, disabled or lazy.

Empirical studies have examined the relationship between these two kinds of trait knowledge about the self. This research has consistently supported the view that in the field of trait knowledge, semantic personal memory and episodic personal memory are functionally independent. In other words, functionality of semantic personal memory does not require the functionality of episodic personal memory (Kihlstrom and Klein, 1994). Klein, Loftus and Plog (1992) for example, utilised the concept of transfer-appropriate processing in a study of recognition memory of own traits to show that different processes are involved in accessing the two types of memory. In addition, Klein, Loftus and Burton (1989) applied the principle of encoding variability in a study of recall for own traits and found that the type of information made available by accessing semantic personal memory was different from that made available by accessing episodic personal memory.

However, the problem with this type of research is that it tries to demonstrate the functional independence of two types of semantic and episodic trait knowledge of the self from the performance of individuals with no memory loss (Parkin, 1993). Research of this kind needs to demonstrate such independence owing to the fact that when participants have access to both memories it is very difficult to rule out interplay. Research carried out with people with brain injuries, specifically with participants with amnesia, provides a more effective way of testing the independence
of the two systems. Amnesia patients usually display intact semantic memory with impaired access to episodic memory (Tulvin, 1989). Tulving (1993), for example, was able to demonstrate this point with a patient who had experienced permanently loss of episodic memory. Tulving asked on two occasions from his participant to rate a list of trait adjectives for self-descriptiveness. Tulving also asked the mother of the participant to rate her son on the same traits. Tulving found that the participant's ratings were reliable (78% agreement across the two ratings) and consistent with the way he was perceived by others (73% agreement with the ratings made by the participant's mother). Thus, Tulving's participant appeared to have accurate, detailed knowledge about his personality despite the fact that he had no access to any behavioural episodes from which to infer this knowledge.

This remember-knowing distinction is of particular relevance to this thesis because it helps to underline that an individual may have knowledge of difficulties following a brain injury without having the memories from which to infer that knowledge. To illustrate, in a study carried out by Levine, Black, Cabeza, Sinden, Mcintosh, Toth, Tulving and Stuss (1998) the authors found that remembering episodes from one's personal past is not possible in the absence of awareness of one's self. Using the remembering-knowing paradigm on a brain injured participant, the authors found that the participant's behaviour was driven by generic information about how he should behave, rather than by the goals and intentions that could arise from his own identity. Furthermore, Cermak and O'Connor (1983) reported the case of another patient with amnesia who spontaneously provided what initially appeared to be descriptions of memories but which on further investigation turned out to be well-established narratives that the patient was in the habit of relating during social conversations. Thus, it is argued here, knowing about difficulties may indicate awareness of these difficulties but it may also indicate that some people with brain injuries may have learned to "narrate" their difficulties without remembering. Therefore, the attention focuses, once more, on the role of the social interactions of people with brain injuries. In addition, this would be an extension of Tulving's theory in that it shows that knowledge emerges from the social and not only from internal processes.
3.6.3. Summary

So far, cognitive structures have been discussed as being more apparent when people process information about the self. Self-schemata are constructed with the information that is differentiated and articulated in memory. Memory in turn has been discussed as an essential component for the process of awareness. That is, according to Tulving (1985), there is no awareness without memory. This is the equivalent of saying that people with an impaired memory had had the contents of awareness wiped out. The contents of awareness however, have been considered as objects and within reach of the individual through introspection. Using introspection to acquire knowledge of the contents of consciousness however implies understanding the self as an object of thought only. Therefore, to help understand the nature of the active self the phenomenological nature of awareness has been discussed as the ability of humans to be directly aware of some aspects of the inner self.

As with the subject of the body in the preceding section, the distinction emphasises that individuals can then access the contents of awareness and experience immediate awareness. In both cases, the contents of awareness and the experiences of awareness can be used as the subject of social interaction. However, in the absence of a functional memory, humans may still be conscious but not aware of the contents or experiences of awareness. In addition, a remember-knowledge distinction has been introduced in the section that helps explain why some people with brain injuries can narrate their difficulties without being able to remember them. On this note, and having discussed so far the body and cognition, the discussion continues to consider the role of emotion as an object and as an experiential state or agent.

3.7. EMOTION AND AWARENESS

Emotional difficulties is a term used in brain injury literature as a general label to encapsulate observed characteriological changes in individuals who have suffered a brain injury. These changes include: anger, depression, exaltation, altered mood, apathy, indifference, automaticity, incontinence, restlessness, euphoria, lack of motivation, lack of initiative, irritability, disinhibition, social withdrawal, lack of restraint, impulsivity, shallow affect, egocentricity, childish behaviour, to mention but a few (Stuss and Benson, 1986). These disparate statements collected under the
umbrella of emotional difficulties observed in people with brain injuries cannot be said to describe the behaviour of these individuals (Bedford, 1986). On the contrary, these statements are interpretations of behaviour made by researchers and caregivers to help define lack of awareness in patients showing such manifestations. The situation being that emotional behaviour is far from being homogenous and people who share the same information and expectations about another person's behaviour may possibly place different emotional interpretations on that behaviour (Bedford, 1986).

However, before elaborating further on this point it is necessary to underline a social constructivist perspective of emotion, question the understanding of emotion and define its role in awareness. This section therefore, will discuss these points and will lead, like the sections on the body and cognition to the distinction of emotion as a behaviour (object) and emotion as an experiential state (agent).

According to Burns and Engdahl (1998), emotions are reactions to threatening sensations, experiences and cognitions. This definition departs from the traditional understanding of emotion as an innate response elicited by natural features or from the theory of physiological arousal, proposed by Darwin (1872), involving innate instinctual drives such as self-preservation and pain avoidance. However, some critical features of what the constructivists mean by emotion are briefly described below (Armon-Jones, 1986):

a) Emotions are a socially prescribed set of responses to be followed by a person in a given situation.
b) Emotions are characterised by attitudes such as judgements, desires and beliefs, the contents of which are not innate but prescribed by the systems of value and cultural belief of particular societies.
c) The attitudes involved in emotion are culturally determined as these attitudes are learnt as part of the individual's introduction to beliefs, values, norms and expectations of the culture the individual is embedded in.
d) Emotions are functional in as much as the possession of culturally appropriate emotions serves to restrain undesirable attitudes and behaviour and to sustain and endorse cultural values.
This radical alternative to naturalist theories of emotion begs the question of how is it possible that emotions can be socio-culturally constituted. To answer it, it is necessary to understand first a constructivist theory of mind in which emotions, as instances of psychological states, are defined as cognition based. Culturally appropriate emotion attitudes are acquired by reference to those contexts for which the emotion is deemed to be desirable. This implies that once the emotion has been learnt then the individual’s further ability to respond appropriately will depend upon his or her ability to appraise a situation as warranting the emotion. Secondly, and under this theory of mind, emotions need to be world-dependent. That is, defining emotions as responses appropriate to cultural contexts implies some sort of connection between the emotion and the external world of affairs. Emotions are identified in part by behaviour and in part by those external situations to which the emotion is directed. The attitudes which constitute emotion are then, in principle, learnable and their external referents are either irreducibly or significantly socio-cultural in nature. Thirdly, emotions are seen as purposive in nature. The function of emotions is essentially socio-cultural and serves individuals only as members of a community.

This far the only objection that can be raised in the constructivist definition of emotion is concerning the functional role of negative emotions (see Markus and Kitayama, 1991, for a full response to this objection). Thus the need to provide an account on this socio-cultural function of emotion. Ready made explanations however, come from two different positions: strong constructivism and weak constructivism. Strong constructivism explains emotion solely as a socio-cultural product. From this position, no emotion can be an innate state, and therefore complex or sophisticated emotions cannot be regarded as cultural modifications of an innate state. The similarities between innate responses and emotions are incidental. However, the weaker position of social constructivism concedes a limited range of innate emotion responses. For example, Averill explains (1980) that to consider that there is an invariant core to emotional behaviour which remains untouched by socio-cultural influences is essentially a reification of emotion in to a biological given. This position clearly allows for the possibility that emotion responses could exist prior to and extra to socio-cultural influences.
Furthermore, the advantage of accepting the existence of innate emotions as opposed to just seeing emotions as socio-cultural products is that it escapes some of the difficulties of the strong position (Armon-Jones, 1986). For example, a brief look at the list of emotional behaviours given in the opening paragraph will suffice to identify anger as the only "genuine" emotion. Depression is not an emotion but a mood. Disinhibition is not an emotion neither is anxiety or any of the other terms describing emotional behaviours in brain injury literature. From the strong constructivist position it is difficult to explain why anger is not an innate response while the individuals that display such emotion exhibit much the same type of behaviour as some non-human species. Following this argument, if such a behavioural feature can be ascribed to non-human species, then it need not serve as evidence of socially constructed human emotions. In particular, the fact that humans often regard non-verbal behaviour as sufficient for the ascription of emotion such as anger to other persons suggests that the mastery by them of the concept of anger is not a necessary condition of their experiencing this emotion. Thus the strong position needs to explain the above points and it is in this respect problematic. Nevertheless, from the weak position it is necessary to specify what exactly is being proposed. Armon-Jones (1986) in her "Thesis of Constructionism" asks: Is it that some emotions, like non-innate emotions, are constituted socio-culturally? Or is it that all emotions are socio-culturally influenced to some extent? For Armon-Jones and this thesis, the second position seems preferable. This position enables the weak constructivist to demonstrate the extent to which both innate and non-innate emotions are socio-culturally influenced, a position which is compatible with there being instances of both types in which they are innate responses to natural situations. This is the position adopted in this thesis and from which emotional changes in people with brain injuries will be considered. However, to understand emotion as cognition based and as involving attitudinal components it is necessary at this point to delineate briefly the theoretical framework on which this weak constructivist position of emotions rests.

3.7.1. Cognition and attitudes in emotion

Traditionally, and as Armon-Jones (1986) remarks, philosophers through history have equated emotions with passions. Passions were seen as non-cognitive phenomena, like sensations and perceptions, impressions named by simple concepts. Like
sensations and perceptions, emotions were considered as inner feelings independent of their expressions in verbal and physical behaviour.

This traditional view of emotion was disputed by Wittgenstein (1980) by pointing out that this conception of emotion renders inner feelings as absolutely private. For Wittgenstein (1980) while not denying their existence, inner feelings are accessible since the terms people use to describe them depend upon objective criteria for their meaning and justification and hence form part of a shared public knowledge. Equally, he argued, emotions and sensations are not the same. Emotions, unlike sensations, are about external objects or situations. Expressions like, "I am afraid of something" or "I am angry with someone" whereby "something" and "someone" is the object, provide the extension of the emotion. Thus, and departing from the traditional view, emotions involve something beyond the person or the present state of the person.

However, while emotions may be dependent upon cognitions, the latter may not be enough to generate particular emotions because different emotions can be generated by the same cognition (Armon-Jones, 1986). For example, the belief that something is upsetting could provoke sadness in someone or anger in someone else. Therefore, evaluation and attitude are also involved in the generation of emotion. This point is crucial to the constructivist framework as it separates emotions as ontologically different to sensations or perceptions. As discussed previously, perceptions, for example, can be acquired, but as Merleau-Ponty (1962) indicated, perceptions are natural phenomena, which exist prior to the acquisition of any socio-cultural frame of reference within which it may be possible to explain them. Furthermore, explaining emotion as involving reference to an object or situation enables the constructivist to demonstrate the extent to which such situations reflect the beliefs, values and expectations of particular cultures and the way in which such situations are used as contexts for the acquisition of the culturally appropriate emotion attitudes.

3.7.2. Physiology, emotion, constructionism and self-awareness

Perhaps one of the biggest challenges to this constructivist framework is the one posed by the physiological argument (Perkins, 1966) and the body of knowledge presented by the brain injury literature. In the one hand, Perkins argues that
chemically induced autonomic arousal and increased motor activity are biological events understood to be basic, innate and involuntary. Thus if these events are necessary of a felt emotion, then this limits the scope of the constructivist thesis in that it reduces those components of emotion which could be explained as socio-culturally constructed. Nevertheless, the constructivist position would argue that even if emotion feelings amount to physiological events, this is not inconsistent with constructionism since it is the individual's attitudes, themselves socio-culturally constituted, which cause the physiological events in question.

On the other hand, this poses the question of what happens when the mechanisms that regulate physiological functions and cognitions malfunction, as it is the case in brain injury. To date, neuropsychological and brain injury literature is beset by empirical indications of the physiological correlates of emotion (and cognitions and perceptions and so on). From either a materialist or a dualist position, researchers work towards establishing these neurological correlates and, by implication, speculate about the nature of human awareness and consciousness. However, from a social constructivist perspective it is difficult to explain emotion in brain injury if the strong constructivist framework of emotion as radically constituted by socio-cultural influences is applied to the area. This perspective would deny drastically a possible role played by physiology in emotions. However, if the weaker position is considered, which this thesis subscribes to, the weaker argument being that some emotions may be innate, and therefore prior to socio-cultural influences, the physiological role in some emotions is not denied and it is then open to further analysis.

As an aside, it is also necessary to point out here that when the literature on brain injury reflects on emotions and the emotional changes observable in individuals who have suffered a brain injury, it is rarely the case that it is emotion per se that this literature is referring to. As mentioned previously, most of the emotional complaints listed in the literature on brain injury seem to refer to the characteriological or personality changes of the individual with a brain injury. This is perhaps more to do with the pragmatic side of research grouping complaints under one umbrella than to any conceptual reason. What is important here however, is that a weak constructivist perspective allows this thesis to differentiate between an innate emotion and changes
to the self with emotional overtones of a socio-cultural nature. Nevertheless, having defined emotion from a weak constructivist position, the question come to the fore of how is it that a person can lack self-awareness of his/her own emotions and/or his/hers own characteriological changes. Self-awareness of emotions will be dealt with here; self-awareness of characteriological changes will be dealt with at a later stage.

3.7.3. Self-awareness and emotion

The concept of self awareness introduces an element of subjectivity in emotions which some authors think is not reducible to belief, desire and judgement but may supplement these attitudes (Armon-Jones, 1986). This subjective element, which the literature recognises as qualia or feeling itself, is regarded as a distinct phenomenon which is evident in the experience of being moved by an emotion but can only be described through evocation and metaphor (i.e. what is it like to be ....) and so cannot be entirely captured through attitudinal analysis. For example, Leventhal (1980) explains that the conceptual system of emotions is a way of representing and communicating about feelings but not a representation of feelings themselves.

Although the concept of qualia may be difficult to integrate into a constructivist theory of emotion it cannot be rejected out of hand. Even if the concept of qualia casts doubts on the possibility that emotions may be socio-culturally constructed (Armon-Jones, 1986) qualia may be integrated into this perspective if they are considered as part of and not the sole constituent of emotion. From a philosophical perspective, Wittgenstein (1980) for example, remarked that terms for emotions and sensations were conceptually related to verbal and physical expressions to which they give rise. However, while sensations referred to inner processes, emotion words do not. For Wittgenstein, emotion words did not designate anything. In other words, neither inner feelings or outer behaviour provide sufficient conditions for interpreting emotions. In this way, Wittgenstein criticised theoretical reductions of emotion to either pure qualia or physical behaviour. Furthermore, the reason why sensation terms are understood as representing inner processes by Wittgenstein is that sensations are not perceived to be ontologically different to the expressions to which they give rise. Thus, feeling pain cannot be constituted by believing that a person is in pain and the
behavioural expressions of pain. Hence Wittgenstein’s remark that sensation feelings are conceptually related to outward criteria in the form of the appropriate verbal and behavioural expressions is a purely semantic remark concerning conditions of meaning making for sensation words, not an ontological remark about the existence of sensation feelings.

With reference to emotion words, individuals do not recognise their emotions as a consequence to observing their thoughts and behaviours. Rather, and as Wittgenstein implies, individuals simply think and behave in an emotional manner such that it is a recognition of an emotion and is part of the expression of that emotion. Further, and unlike sensations, emotions are identifiable with the experience of those emotions, hence these factors are ontologically constitutive of emotion feeling.

However, while Wittgenstein’s remarks seem to focus on outward verbal and expressive behaviour, emotions may not necessarily be openly expressed. For example, on one hand a person who is expressing anger can convey these feelings to the person or object responsible for that anger via spoken appraisals or can behave in a violent manner towards them. On the other hand, the person may not express anger, in which case the attitudes and behaviour remain undisplayed. This does not mean that the person does not feel angry. On the contrary, in this second instance linguistic and behavioural expression does not represent inner feeling as far as overt expression can be a refined version of the inner feeling. The covert expressed emotion is a mode of experiencing the emotion which shares the same features as the overtly expressed emotion (Armon-Jones, 1986). Furthermore, the overt expression of emotion can be regarded as a communicative act with particular consequences. Overt anger can lead to appeasement attempts from others and to assuming responsibility for feeling that anger. By comparison, covert emotion can remain ambiguous and consequently more amenable to self-deception. If the individual suppresses outwards signs of feelings of anger then it is easier to pretend or persuade himself/herself that these do not exist, or indeed, that he or she is not really feeling angry. Both modes though must be understood as constitutive of emotion just as the consequences of overt and covert emotion may enhance or diminish feeling. That is, overt anger may be intensified through, for example, provoking a fight or it may be “bottled up” and left to grow in
intensity. Overt anger can also diminish if for example, the agent responsible for causing the individual’s anger manages to reason the individual out of the emotion, "talk him out of it", while the individual can reason himself/herself out of it as well.

Nevertheless, if to feel these emotions is either to express overtly or entertain inwardly the relevant attitudes, then how can this account help explain emotions following a brain injury? To be more precise, how can this framework help explain the lack of awareness of emotional changes observed in people with brain injuries? To answer this question it is necessary to know first how individuals identify their own emotions. Some writers on emotion argue that people learn about their own emotions through the interpretation of behaviour and the use of psychological concepts (Bedford, 1986) thus denying the role of introspection in knowing emotional states. Bedford explains that it is hardly possible for an individual to be completely ignorant, as others may be, of the context of his/her own behaviour. Thoughts may cross the individual’s mind but these may not be made public. It is only in some respects, according to this author, that each of us is in a much better position to understand the self than anyone else is. Further, Bedford points to the fact that humans make mistakes about their own emotions. He exemplifies this observation with the case of individuals who feel jealous and how those who are jealous are often the last, instead of the first, to recognise that they are. In a similar vein, Laird (1989) assumes that feelings are a kind of knowledge about ourselves in the same way that others know about us. People know their own attitudes, desires and emotional feelings by a kind of nonconscious observation and interpretation of our action and the context in which we act.

However, while this may ring true for some emotions, like Bedford's jealousy, it may not be true of all emotions at all times. It is argued here that these explanations of how we know emotions need to take into account experiential (conscious and nonconscious) states as well. Emotions can be qualitative, experiential states to which an individual can turn his/her attention. Armon-Jones (1986) argues that emotions need to be vivid, serious and all consuming to induce the person to be moved by them. By vividness, the author refers to cognitive components of emotion, such as memory, as it is not possible to feel emotional about something that may be vaguely remembered.
In reference to seriousness, Armon-Jones explains this term as an attitudinal component of emotion and as the level of intensity to which the emotion refers. In other words, individuals cannot feel about something that just requires a passing acknowledgement. Finally, all consuming is the term used by the author to refer to the subjective element of emotion. In this case, the author argues that the collection of thoughts or memories and acknowledgements needs to occupy greatly or totally the individual's attention. Thus this inner array of events described constitute emotions which can be conveyed via language and behaviour, if they cannot be conveyed, the author argues, this is because "they are barely a feeling" (Armon-Jones, 1986, p.50).

Therefore, it could be argued, that for a person to know his or her own emotions the person's attention must be turned inwards. That is, towards the array of memories and acknowledgements with preoccupation. Then the object of attention, the emotion, can be interpreted and thus expressed overtly or entertained covertly. Empirical evidence for the effect of this attention or private self-awareness seems to support this process. Fejfar and Hoyle (2000) conducted a meta-analysis to examine the effect of private self-awareness on affect and attributions of responsibility to the self. The results showed that there is an association between private self-awareness and emotion and that private self-awareness increases rather than produces existing emotion.

Therefore, and having emphasised the role of experience, cognition, attitude and introspection in emotions this framework is used in this thesis to understand the lack of awareness of emotion observed in individuals who have suffered a brain injury. The thesis does not deny the possibility that physiological malfunction may contribute to this particular lack of awareness. Instead, it argues that the phenomenon, when emotions are not understood as being solely produced physiologically, may be explained in the same manner as emotions are explained in the non-brain injured. The fact that the brain injury may affect cognitive functions which, in turn, may interfere with emotions is a valid consideration. However, this consideration is one that does not stop the thesis from viewing people with brain injuries as knowing their emotions in the same way as non-brain injured individuals do.
3.7.4. Summary

Emotional difficulties is a term used in the brain injury literature as a general label to encapsulate a variety of observed characteriological changes in individuals who have sustained a brain injury. However, these observed characteriological changes do not always describe emotion. Emotions have been discussed here as a socially prescribed set of responses to be followed by a person in a given situation. This radical alternative to naturalist theories of emotion, from a weak position of social constructivism, concedes only a limited range of innate emotion responses. Equally, under this framework, emotions have been seen as generated by cognitions and attitudes and ontologically different to sensations and perceptions.

Further, emotions have been discussed as behaviours and as experiential states. As behaviours, emotions are a kind of knowledge about the self in the same way that others know about us. People know about their emotional feelings by a kind of nonconscious observation and interpretation of their own actions and the context of the actions. As experiential states, emotions are qualitative states, conscious and nonconscious, to which an individual can turn his or her attention. However, for an individual to know his or her own emotions, it has been discussed, the individual's attention must be turn inwards. In both cases, as with the body and cognition previously, emotion as behaviour and emotion as an experiential state can be the subject of social interchange.

3.8. OVERALL SUMMARY

So far, awareness has been seen as part of a weak social constructivist theory of consciousness derived from symbolic interactionism and accessible by self-reflection. The theory is weak because the body, cognitions and emotions are considered and have been discussed, in relation to their occasional pre-eminence to awareness and as both objects and agents. As objects, they can be used by the individual in self-reflection and communication. As agents, they can also be used as the contents of social interaction. In addition, regarding the body, cognitions and emotions as agents helps to understand the self as active and not as a mere passive recipient of feedback from the social world. The symbolic interactionist tenet of personal identity being negotiated during social interaction has then been widened to incorporate an inner or
self awareness that can help explain how it is that private individuals can emerge from socially created contexts. On this note, the discussion will turn to how the subject of the self has been treated in the brain injury literature and will emphasise the role of the other in brain injury.

3.9. THE SELF IN BRAIN INJURY

The scant literature that exists on the subject of the self in brain injury refers mainly to how organic impairment affects the self. While some authors seek to find the correlates of brain injury and personality changes (Stuss, Gow and Hetherington, 1992), others seek to address how the self is preserved after a brain injury (Morse and O'Brien, 1995), how the self interprets the brain injury (Nochi, 1997) or whether the self is lost when the individual suffers from a brain affliction (Tappen, Williams, Fishman and Touhy, 1999). For example, patients with Alzheimer's disease, who also experience lack of awareness of difficulties (Bohling, 1991), are said to experience a diminishing self (McGowin, 1993). Complaints from spouses about their Alzheimer's disease partners (Jenkings and Price, 1996) and the assumption of nursing staff in residential homes that the patients experience life as meaningless (Norberg and Asplund, 1990) all seem to support the idea of a lost self. However, Tappen, Williams, Fishman and Touhy (1999), in a qualitative study offer evidence for a persistence of self even into the middle and late stages of Alzheimer's disease. These authors observe that failure to recognise this continuing awareness of the self leads caring others to concentrate on task-orientating care and low expectations in therapeutic interventions. Furthermore, Tappen, Williams, Fishman and Touhy (1999), argue that the victims of Alzheimer's disease need to be told and be offered explanations about their condition.

Arguably, Alzheimer's disease is a degenerative disorder while brain injury is not and recovery or some recovery of function is possible (cognitive functions in particular) following brain injury. Comparisons may be limited here but the emphasis placed in the role of communication by Tappen, Williams, Fishman and Touhy (1999), in their study is also relevant to this thesis. Thus the need to account for the role of the other.
3.9.1. The other in brain injury

If the development of the self depends partly on the views of others the way these views are transmitted, received, interpreted and acted upon may be crucial for the development of awareness of difficulties following brain injury. The development of this awareness may be influenced by the accurate perception of how others see us which, in turn, depends on open communication. However, according to Shrauger and Schoeneman (1979), incongruences between self-appraisals and others' appraisals are often due to strong cultural sanctions against making direct appraisals, especially if these are of a negative nature. Goffman in 1955 had already observed that negative evaluations are only given when directly solicited, and then, if they have been solicited it is because negative self-appraisals have already been carried out. Empirical evidence though shows that people tend to inhibit direct communication of all types to others, particularly if it is of the negative type or if the recipient is not well known (Blumberg, 1972). In clinical settings, however, where there is an expectancy of information given to patients, it was found that when more information was given and when this was more understandable to the patient, this was associated with a greater wariness of the treatments available (Edwards, Elwyn, Covey, Matthews and Pill, 2001).

Generally though, and as mentioned previously, it is said that individuals are necessarily selective in what they attend to, remember, learn or infer in a given situation (Markus, 1977). This selectivity has been seen to depend on internal cognitive structures that allow the individual to process incoming information. In the literature these structures are called "frames" (Minsky, 1975), "scripts" (Abelson, 1975) and "schemata" (Tesser and Conlee, 1975). Attempts to organise and explain a person's own behaviour have been called "self-schemata" (Markus, 1977). Self-schemata, according to Markus, are constructed from information processed in the past and influence both input and output of information connected to the self. They depict the way the self has been differentiated and articulated in memory and once established, they function as selective mechanisms. Self-schemata determine what information is attended to, how it is structured and how much importance is attached to it. Moreover, and although the empirical evidence offers wide support for the concept of self-schemata (Markus, 1977), the concept does not explain the
persistence of inaccurate beliefs about the self. Lepper, Ross and Lau (1986) argue that, sometimes, the impressions an individual forms about the self are inaccurate or unfounded. Under such circumstances, the individual may be challenged to update those impressions in view of subsequent outcomes and new insights. Failure to assimilate new information would promote erroneous self-assessments and potentially dysfunctional decisions. Empirical evidence for this speculation shows that initial impressions and beliefs are considerably resistant to subsequent logical and empirical challenges (Ross and Leper, 1980). This evidence also shows that individuals' first impressions, in laboratory experiments at least, tend to be lasting and new information that appears to disprove previously formed beliefs is given little weight (Lord, Ross and Lepper, 1979). Further, even thoroughly debriefing participants about deceptive feedback may not suffice to undo the effects of deceptive information (Anderson, Lepper and Ross, 1980).

This last point underlies the importance of the way information, especially information that refers to the self, is interpreted. Shrauger and Schoeneman, (1979) for example, observe that people differ in their interpretation of others' feedback, particularly if the feedback is not explicit. The authors point to the individual's agency in interpreting feedback and to how this feedback is given more importance according to the status of the person that imparts the appraisal. Research from the social cognition field adds to this idea by pointing out that speakers status and memory play a significant role when interpreting information. Holtgraves, Srull and Socall (1989) investigated in three different experiments how speakers' status affected memory of assertiveness. They found that under certain conditions the remarks of a perceived high status speaker were remembered as more assertive than those made by a perceived lower status speaker. These researchers provide evidence for the existence of a relation between how information is communicated (in this case assertiveness) and one interpersonal variable (speaker status). Furthermore, Holtgraves, Srull and Socall explain that their results demonstrate how social knowledge is implicated in the interpretation of communication. By this they mean that they have made explicit the assumption that many aspects of knowledge cannot be understood apart from the context in which the communication occurs (Levinson, 1983). In other words, what
can be taken as a suggestion if spoken by a low status speaker can be constructed as a command if spoken by a higher status speaker.

Thus, it can be seen that how information is interpreted depends, to some extent, on the importance given to the speaker. In addition, more recent research indicates that how relevant the information is made to be is also a factor in the interpretation of information from others (Garcia, Metthe, Paradis and Joanette, 2001). Conversation involves a collaborative process, usually between two people, whose target is to identify and respond to each other's intentions (Grice, 1975). To uncover this target inferential processes must be at work in order to get at the true message and only then can relevant contributions be made (in social constructivist terms, this idea would be referred to as the meaning-making process (Carlsen, 1996)).

According to Bach and Harnish (1979) the conversational partner's goal is to convey an intended meaning to the hearer. Garcia, Metthe, Paradis and Joanette (2001), argue that when communication lacks coherence, as in many cases after neurological impairment, the responsibility of determining relevance lies entirely on the healthy conversational partner. This is also likely to be true when "the partner with a neurological impairment is unable to identify the healthy speaker's intentions due to an incapacity to use contextual information" (p. 18).

Nevertheless, identifying the speaker's intention is only one step. Judgements about the relevance of the content of the conversation must be made in order for a conversation to take place. Garcia, et al (2001) explain that the collection of such information depends on certain cognitive capacities, like attention and memory, which may not be entirely intact in certain populations with brain damage. When this happens, the healthy conversational partner may need to compensate for the speaker with the neurological impairment so that relevance may predominate. However, Sperber and Wilson (1986) propose that a speaker is interested in communicating only what the hearer needs to know to make his or her message relevant. And, according to Sanders (1983), what is relevant depends entirely on the hearer's ability and willingness to infer or invent a reason for the speaker's having made the statement.
In brain injury, what is relevant and how it is explained is important when examining the discourse abilities of the neurologically impaired. Empirical evidence shows that different types of brain injury affect discourse abilities differently. Patients with right hemisphere damage on one hand, are known to have very few problems with the content of communications but significant problems with communicative abilities (Tompkins, 1995). Patients with traumatic brain injury on the other hand, have been found to show irrelevant conversational discourse. Coelho (1995) carried out a study on a traumatic brain injured sample and found that subjects with traumatic brain injury were most impaired at global coherence levels. These subjects were judged difficult conversational partners and were found frequently to rely on their partners to maintain the coherence of the conversations. Coelho, Liles and Duffy (1991) detected that the conversations of subjects with traumatic brain injury had more irrelevant comments in them and that as a consequence, more explicit requests for responses were being made on the listener. Furthermore, Gajar, Schloss, Schloss and Thompson (1984) found that feedback from the listener was crucial in producing positive conversational behaviours.

This feedback is of particular relevance to this thesis not only because of the effect it may have on the conversational behaviour of people with brain injuries but because of the information that it can carry. Arguably, if adults affected by brain injury appear unaware of their difficulties, the kind of information they receive, how it is transmitted and by whom may all enter into the process of gaining awareness of their difficulties.

3.10. SUMMARY AND RESEARCH QUESTIONS
Chapter Two highlighted the neurological, neuropsychological and psychological explanations that are given for the phenomenon of lack of awareness of difficulties following a brain injury. The chapter then hinted at an independence of self-awareness from neurological impairment. In this chapter a social constructionism theory of consciousness based on symbolic interactionism with a "weak" orientation, was outlined for analysing lack of awareness of difficulties. The central question for social constructionism is what is the self or what is the person; that is, how are identities constructed? Therefore, it is necessary to examine the discourses or messages which
are received by the individual in the social context and the messages which may not originate in the social context, like bodily perceptions, but may form part of the contents of awareness. Following Burns and Engdahl, the messages are received by individuals who in turn absorb and interpret them, suggesting a two-stage process for understanding lack of awareness of difficulties. The first stage comprises the messages that are given. The second stage concerns the recipient or the interpretation of these messages.

Brain injury can affect all sorts of individuals in a variety of contexts. The messages given by societies to people with brain injuries include:

- Messages given by medical personnel and rehabilitation staff (which will not be the subject of this thesis as the participants in the research are year/s away from the clinical and rehabilitation settings)
- Messages given by significant others or close to the individual social environment
- Messages given by non-expert health professionals as daily carers of people with brain injuries.

These, then, are some of the messages sent to people with brain injuries. The research presented here asks, "Does social interaction increase awareness of difficulties?" and comprises three studies. Study One is divided into two parts. Part 1 asks if people with brain injuries know about their injuries and subsequent difficulties. Part 2 investigates how significant others explain difficulties to the patients. The research looks at people with brain injuries within a community setting, years after the brain injury has occurred and official rehabilitation efforts have ceased.

Following this first study a Second Study was conducted with the brain injured participants. This study asks how the participants' knowledge of their difficulties is constructed and how this knowledge is used for understanding the implications of their difficulties.

A Third Study was conducted with non-expert health professionals at two day care centres that the brain injured patients participating in this research attend. This study
inquires how difficulties that can be experienced following a brain injury are understood, communicated and dealt with by this staff.

Finally, having discussed the theoretical issues underpinning the present investigation, and having defined the research questions, the following chapter will continue with a discussion of the methodological paradigm underlying the research.
4.1. INTRODUCTION

As discussed in Chapter Three, the double aim of this thesis is: a) to explore the messages people with brain injuries receive with respect of their difficulties in their everyday social interactions and, b) to explore the processes by which they construct their brain injury, subsequent difficulties and implications. In Chapter Two, it was hinted that the level of awareness of difficulties might be independent from neurological impairment. In Chapter Three, it was argued that self-awareness is a product of social interaction and reflection.

This chapter considers the assumptions and implications of some of the methods most commonly used to study the degree of awareness of brain injury and discusses their limitations. It then describes the philosophical framework within which the work in the present thesis has been undertaken. The constructionist ontological position (assumptions about the nature of reality) already outlined in Chapter Three will be explored further here. The constructionism epistemological position (how reality is known) will also be explored. This will demonstrate that the methodology or theory of method, and methods used are congruent within the chosen paradigm. A paradigm according to Patton (1978) is:

"A world view, a general perspective, a way of breaking down the complexity of the real world. As such, paradigms are deeply embedded in the socialisation of adherents and practitioners: paradigms tell them what is important, legitimate and reasonable.
Paradigms are also normative, telling the practitioner what to do without the necessity of long existential or epistemological consideration." (p. 203)

It is important that the ontological and epistemological positions underlying any research are made explicit. It is important since the common assumptions and academically accepted paradigms of times gone by (like the positivist paradigm), arguably, no longer hold in the terrain of the social sciences, if indeed they ever were.

The research design, the definition of the concepts, and the type of evidence sought are all heavily influenced by the epistemological position adopted by the researcher; it is thus consequential that this be made explicit. The second section of this chapter therefore will concentrate on the epistemological position on which this research is based.

The choice of exploring awareness of brain injury by talking to the people most affected by it will be justified and the two analytical procedures employed to examine their accounts will also be explained. The chapter concludes with a consideration of the credibility of the work undertaken.

4.2. SOME METHODS IN AWARENESS OF BRAIN INJURY: LIMITATIONS, ASSUMPTIONS AND IMPLICATIONS OF RESEARCHING LACK OF AWARENESS AFTER BRAIN INJURY

Research into lack of awareness of difficulties following brain injury has, to date, been inconclusive and contradictory. What consensus exists in the literature on this subject refers to: a) lack of conclusive evidence on whether awareness of difficulties is due to organic impairment or psychological impairment and that, b) regardless of the cause, lack of awareness of difficulties usually follows brain injury. The literature also agrees in that awareness of difficulties is important at the time of rehabilitation. Attempts to measure awareness and responses to awareness interventions present more dilemmas than offer answers. This chapter considers some of the methods used in research of awareness of difficulties following a brain injury, their limitations, assumptions and implications while suggesting qualitative methods as better ways to gain an insider's perspective of the phenomena.
4.2.1. In the beginning

It is widely accepted in the literature of awareness of difficulties following brain injury that the aetiology of the phenomenon is largely unknown (Prigatano, 1991). It is also accepted that awareness of difficulties is usually observed following a brain injury (Prigatano, 1999) and that it can be the deciding factor between successful or unsuccessful rehabilitation (Ponsford, 1995). An individual who is not aware of the difficulties caused by a brain injury may be resistant to treatment or reluctant to implement the strategies offered during rehabilitation.

To investigate awareness of difficulties following brain injury researchers have focused on different factors ranging from severity of injury, time since injury to social psychological analysis, neuropsychological analysis, intensive rehabilitation and coping with environmental demands (Crisp, 1992). This focusing on one or a few factors, together with the different methodological designs employed to study them has meant that discrepancies and inconclusive results litter this particular field of study (Crisp, 1992). A closer look at this state of affairs will illustrate the point.

Research on awareness of difficulties following brain injury can be divided into two areas: attempts to assess awareness of difficulties and measurement of responses to awareness interventions. Both areas use patients verbal reports and interpretations of certain aspects of the patients' behaviour, amongst others, as sources from which to infer awareness (Sohlberg, Mateer, Penkman, Glang and Todis, 1998).

4.2.2. How has awareness of difficulties been measured?

According to Deaton (1986) and Fleming, Strong and Ashton (1996b) the literature presents three ways to measure awareness of difficulties following brain injury. These are: differences between patients' self-ratings of their functions and those made by their relatives, differences between self-ratings and those made by rehabilitation staff, and estimates of patients abilities and performance on neuropsychological tests (for a comprehensive review please see Fleming, Strong and Ashton, 1996b).

Differences between patients' self-ratings and a relative/rehabilitation staff are usually found by asking the patient and relative or rehabilitation staff to rate the ease with
which the individual is able to perform certain functional activities. The most widely used measure, the Patient Competency Rating Scale (PCRS) (Prigatano, 1986), for example, asks the patient and relative/rehabilitation staff for ratings on a five point Likert scale on how easy or difficult it is to perform 30 different behavioural tasks. The scale covers the areas of functional ability, interpersonal skills and emotional status and is considered a useful and reliable instrument for self-awareness research. Similarly, the Head Injury Behaviour scale (HIBS) (Godfrey, Partridge and Knight, 1993) asks the patient and a significant other to rate, on a four point Likert scale, how much of a problem it is to perform a particular behaviour and how much distress it causes. On both scales comparisons between the patients' self-ratings and the ratings given by a family member or a member of the staff rehabilitation team are meant to give an indication of the patient's self-awareness.

In the same fashion, it is usual to quantify awareness of difficulties by comparing the patients' self-reports of abilities with performance on neuropsychological tests. Prigatano and Altman (1990) found no relationship between neuropsychological scores and subject's own estimated behavioural limitations and concluded that neuropsychological instruments did not adequately measure lack of awareness. This is not surprising if it is considered that neuropsychological tests are constructed to measure intellectual impairment only.

Other instruments that are used to quantify awareness are questionnaires and structured interviews. Some of these questionnaires gather data from the patient's point of view, like the Change Assessment Questionnaire (CAQ) (Lam, McMahon and Priddy, 1988) or from the perspective of a family member, like the Katz Adjustment Scale (KAS) (Fordyce, Roueche and Prigatano, 1983). Structured interviews have been rarely used and offer an alternative way of collecting quantitative data by given responses which are scored according to a rating scale (Cutting, 1978; Bisiach, Vallar, Perani, Papagno and Berti, 1986).

Although these methods suffer from certain limitations, which will be discussed later in this paper, some researchers have tried to surpass these limitations by developing methods for assessing awareness through more naturalistic enquiries. In a prospective
study, Hart, Giovannetti, Montgomery and Schwartz (1998) developed a method for assessing "on-line" error detection and correction during performance of naturalistic actions. Two groups of 18 participants each, 18 with traumatic brain injury and 18 controls performed two tests of naturalistic action. Subjects were asked to complete everyday activities, like making toast or wrapping a gift, at different levels of complexity. Using a specially developed coding system, each error on the tasks was scored as to whether the participant corrected it and whether the participant had demonstrated awareness of the error. Scores were also compared to participants' responses on a questionnaire in which they had estimated their own performance. According to the authors, the study showed that error detection and correction could be reliably measured during naturalistic enquiry.

4.2.3. How have responses to awareness interventions been studied?
The methods employed to assess changes in awareness of difficulties following awareness interventions are very similar to the ones used for assessing awareness of difficulties. The scant literature on awareness interventions has been reviewed in detail by Sohlberg, Mateer, Penkman, Glang and Todis (1998). The authors have found that awareness interventions are usually studied by either comparing participant's self-reports with those of a relative/rehabilitation staff or through comparing estimated abilities made by the patient with performance on a task/test scores.

Both methods infer the level of awareness of difficulty change by analysing the observed differences between two sources. More recent research though suggests that self-report-performance methods may prove more useful to the clinician treating awareness of difficulties (Schlund, 1999). Self-report-performance draws attention to the subject's verbal report and the behaviour of interest in the rehabilitation setting. For example, Schlund (1999) studied the relation between self-reporting and remembering. Data collected over a number of therapy sessions were used to examine the effects of practice and feedback on reporting recall. The results of this study indicate that self-report-performance methods capture the relations of interest within a rehabilitation setting. In addition, feedback and review all contribute to altering awareness levels.
4.2.4. Limitations of the methods

Fleming et al (1996b) have listed three limitations that the use of quantitative methods impose on the awareness of difficulties research. First, questionnaires and structured interviews, the authors explain, rely mainly on the individual's ability to understand verbal or written questions and to be able to verbalise that understanding. Second, questionnaires and structured interviews only evaluate intellectual awareness. As previous research indicates (Crosson, Barco and Veloza, 1989), people with brain injuries first develop the ability to acknowledge intellectually that certain difficulties exist. Questionnaires and structured interviews give partial information. Thus, there are tests for memory function, attention, language function, and the like. Cognitive functions are not independent of one another in natural everyday life. Rather, in the course of daily social interaction and experience, a range of cognitive functions is called for simultaneously. Thus, there may be considerable differences between the cognitive function as measured by tests and that revealed in everyday life.

Third, the emphasis on verbal accounts only may result in behavioural aspects of awareness going unobserved. Deaton (1986) has indicated that some patients who show little awareness of their difficulties still participate appropriately in treatment.

Further to these three points, some authors have indicated that it is dangerous to rely on others' perceptions when researching awareness of difficulties (Prigatano, 1996; McKinley and Brooks, 1984). The others' perceptions may not be reliable (McKinley and Brooks, 1984) and as Tyerman and Humphrey (1984) have pointed out, what is at stake here is the subjective impairment of the person, not the others' perception of such impairment.

One final limitation is the fact that through the above approaches, one never really comes to understand people with brain injuries in their totality as persons living in the world. What are known are the scores in certain standardised tests of particular functions and the dysfunctions that are thereby revealed. Therefore, what is being investigated is how the brain injury affects a series of neurological functions as opposed to how it affects individuals living in the world.
4.2.5. Assumptions and implications underlying the methods

As has been seen, the methods developed to assess awareness and measure awareness interventions have relied on a variety of sources. These sources range from the use of verbal reports of the patients, to the measure of a behaviour that implies awareness, to the perception of others of a victim's awareness, to the perception of others about behaviour that implies awareness. These investigations of awareness of difficulties following brain injury, in turn, rely on various assumptions. First is the assumption that awareness can be measured. Second is the assumption that patients' perceptions may be distorted and unreliable. Third, the use of self-report and perceptual data as a measurement of awareness assumes that perceptions are amenable to change if there is an underlying improvement in awareness (Sohlberg, Mateer, Penkman, Glang and Todis, 1998). Fourth, the use of behavioural observation as an indicator of a change in awareness assumes that it is possible to identify behaviours that are dependent on intact awareness (Sohlberg, Mateer, Penkman, Glang and Todis, 1998).

These assumptions have serious implications and need a more careful examination: First, measuring awareness directly is difficult and has been done by inferring psychological and behavioural correlates (Sohlberg, Mateer, Penkman, Glang and Todis, 1998). Some of these correlates have been identified and used to develop methods that can be valid and reliable at the time of assessing the nature of awareness of difficulties. The problem is that no method may account for all the correlates that enter awareness. These correlates are, in research, static indicators of awareness that narrow down such research (Sohlberg, Mateer, Penkman, Glang and Todis, 1998) and consider awareness of difficulties as a single entity (Derouesne, Thibault, Lagha-Pierucci, Badouin-Madec, Ancri and Lacomblez, 1999).

Acknowledging this problem some authors have suggested that global measures be used instead (Fleming et al., 1996b). If this was the case, it is argued here, global measures would still be too narrow as they are constructed on these static indicators of the phenomenon which occlude seeing awareness as a process. In other words, they would still seek to see how brain injury affects a series of functions as opposed to how it affects the everyday living of the people with brain injuries.
Furthermore, the objective of developing methodology to assess awareness of difficulties following brain injury is to be able to find instruments that validly and reliably can assess awareness of difficulties across clinical practices. This tendency to want to generalise is an underpinning from the positivist paradigm that characterises most research in psychology (Lincoln and Guba, 1985). The assumption is that what is true for a group of people in one time and in one place needs to be true for other people in another time and another place. This assumption is very risky when studying brain injury for two reasons. First, trying to generalise may make the researcher overlook the clinical recommendations that people with brain injuries should be treated as single cases (Brooks, 1988). Second, it gives brain injury a uniformity that is not characteristic of brain injury. Banja (1999) for example, on talking about medical decisions that rely on assessing patient's degree of ability to communicate, understand reason, and exercise insight, notes that difficulties based in organically mental dysfunction are "spotty, patchy and inconsistent" (p.422) or in Brooks (1988) own words "each patient has to be treated as an individual" (p.42).

Second, to assume in awareness of difficulties research that the views of the patient are distorted and unreliable has epistemological implications. It is a common clinical and research method to assume a division between the knower-researcher/clinician and the known-patient. Many reports indicate that participants provide inconsistent or biased information (Allen and Ruff, 1990) and that the reliability of subjects self report is doubtful as an indicator to the level of awareness (Sohlberg, Mateer, Penkman, Glang and Todis, 1998).

This begs the question, when assessing awareness, how much awareness the researcher believes the patient should have? The assumption here is that cognitively unimpaired and judgementally intact people are aware. Researchers also forget that cognitively unimpaired and judgementally intact people can often be seen to make foolish and uninsightful decisions and choices. Equally, to assume that aware people behave reasonably, if reasonably is understood as choosing non-risk behaviours, is to inject research with value-laden connotations. That is, if the researcher understands aware people to be reasonable (i.e., reasonable people plan for the future, do not
gamble, and control their emotions) the participants will have to adopt such standards or demonstrate that they already have them.

Value-laden research is rendered doubtful, according to Lincoln and Guba (1985) when the values that guide the investigations are not explicitly recognised by the researchers. Lincoln and Guba argue that researchers are not usually conscious of their own predispositions and that these are rarely examined systematically. In fact, the authors claim, accepting the position that research can be value-free brings about "numerous undesirable consequences" (p.173). Amongst these numerous undesirable consequences what Lincoln and Guba call "the veil of objectivity" is perhaps the most relevant to this point. This refers to the belief held by some researchers that methodology guarantees objectivity, that is, it removes all possible contamination from value positions. This belief leads the researcher to overlook other possible perspectives and to run the risk of being fair to different points of view. If there is only one objective perspective, then, no others are worth considering. Lincoln and Guba explain that if knowledge is recognised as interested, then, a new imperative emerges for the researchers guidance. Once aware of the value implications implicit in the research, the researcher is under moral compulsion to take them into account.

Similarly, Murray and Chamberlain (1999) argue that the research situation is constructed in interaction between researcher and researched. The researcher cannot be value-free and facts as well as theory are necessarily value-laden. Furthermore, the participants of research are seen as equally involved in these constructions through the interaction of their expectations and activities with those of the researcher. Murray and Chamberlain propose that any piece of research is constrained to be a construction determined by the possibilities and limitations of the environment, social and historical context. In which case, it is impossible for the researcher to adopt a value-free perspective and for the phenomenon under investigation to be separated from its context. Thus, in awareness of difficulties following brain injury, it is argued here, researchers dismiss too quickly what their participants have to contribute. By taking the view that the reliability of patients self-reports are doubtful indicators of their level of awareness, researchers are failing to see that they, themselves, are fixing a prerequisite level of awareness for their participants.
Third, to assume that perceptions change if awareness improves can imply that awareness causes perception. This implication may be seen as misleading awareness of difficulties research if and when other research into awareness and consciousness is considered. In fact, most literature and research into awareness and consciousness state that it is perception that causes or at least, correlates with, awareness and consciousness, not the other way round. Experiments in the neurophysiological sciences (see Libet, 1996, for a review), for example, show that conscious awareness of an input does not arise until at least 200 milliseconds (ms) after stimuli arrive at the cortical surface. The suggestion that consciousness of input is preceded by a period of preconscious processing is also supported by cognitive research. In information processing terms a stimulus has to be transformed into neural code, analysed and matched to memory traces before it can be identified (Neely, 1977). Complex stimuli, like sentences, also demand syntactic and semantic analysis and interpretation of meaning in verbal and physical context (Velmans, 1999).

Equally, the literature states that many cognitive functions can still happen without either awareness or consciousness. A classical example would be that of "blindsight" produced by striate cortex lesions (Weiskrantz, 1986). In this case, individuals can direct their attention to an input stimulus, describe some of its properties and make correct identification responses. What they cannot do is experience the stimulus to which they are attending.

In addition, and as already discussed in Chapter Three, Tulving in 1985 offered clinical observations made on an amnesia patient and suggested that conscious awareness is a "necessary correlate" (p.5) of episodic memory. Tulving (1985) observed that his patient could learn a variety of new skills but could not remember anything. In the same vein, Glisky and Schacter (1989) did also offer evidence for learning without awareness. This study showed that, information that is not present to consciousness at the time of learning may update long-term memory and influence performance but may not be available for later recognition and recall.

In terms that are more philosophical, the arguments are also in favour of cognitive activity preceding awareness and consciousness. Velmans (1999) indicated that
perception, memory, thinking and judgement could all occur without consciousness. Velmans (1999) argues that consciousness is the result of perceptual processes. If these perceptual processes do not operate, the world as experienced by the individual ceases to exist. Similarly, Giorgi (1995) maintains that humans sometimes learn incidentally but do not know about this learning until they realise that they have done so. This realisation only comes when one becomes aware of consciousness itself or of its contents: ideas, images, memories, feelings and so on.

Fourth and finally, the use of behavioural observation as an indicator of a change in awareness assumes that there are behaviours that are dependent on intact awareness. The implication here being that "if you can't see it from the outside it doesn't exist!" (Velmans, 1996, p. 186). This assumption underlies the strong tendency of researchers to take a more behavioural approach to the study of awareness of difficulties following brain injury. This tendency has been criticised by Sohlberg, Mateer, Penkman, Glang and Todis, (1998). Sohlberg et al. (1998) in a study that examined a variety of awareness indicators in three individuals with brain damage found a disassociation between behavioural and perceptual indices of awareness. The authors argue that a prerequisite level of awareness is not necessary, as currently believed, to utilise adequate compensatory strategies following brain injury. Sohlberg et al suggest that people with brain injuries can be trained to use compensatory strategies even in cases where the patients do not understand why or believe that they need them. In fact, the lack of awareness of difficulties may indeed prevent them from inquiring why they need to use the strategies. The authors conclude that for some patients it may be more productive to tap into implicit learning than into declarative knowledge as to why these strategies are important.

However, the most interesting finding made in this study was the inconsistency of the observers. Sohlberg et al. (1998) made use of caregivers ratings of subject's abilities on a global measure of each participant level of awareness. The observers, who collectively had chosen behaviours that they felt would indicate improved awareness, when those behaviours improved, did not indicate improvement in their global ratings of awareness. The observers did not link awareness with learning but instead they appeared to have linked awareness with open admission of impairments.
In this naturalistic enquiry, the researchers did not take into consideration that when observing a conduct the caregivers or observers appointed to rate the level of awareness of the participants were bringing their own preconceptions to the study. To increase their judged level of awareness they were expecting a causal explanation. Causal explanations, in ordinary life and according to Coulter (1979), play a part in the provision of excuses for conduct not for explaining their own or other people's actions. Thus, the description of behaviour involves appraisals, which are context-bound and open to different interpretations. If these appraisals and interpretations do not match up with those made by the participants the results of the research, yet again, may be misleading.


As has been seen the limitations, assumptions and implications of such assumptions behind the methods employed to date to study awareness of difficulties following brain injury have resulted in many and disparate results. The uniformity and agreement that is often sought under a positivist paradigm (Lincoln and Guba, 1985) has evaded the subject and opened up opportunities for other methods to be used in the field.

Arguably, one of the reasons why research has been so contradictory in awareness of difficulties following brain injury is that researchers have been looking in the wrong place. According to Velmans (2000) when studying conscious awareness examination of the brain from the outside can only reveal its physical causes and correlates. It does not reveal the experiences themselves. Examination of the brain alone cannot lead to the discovery of an inner conscious life within an experienced body in a phenomenal world. Velmans reflects that a person's perspective is the only way to discover the inner phenomenology. As such, qualitative methods are used in this thesis for two reasons. One, to follow the recommendation of well known researchers in the field like Fleming, Strong and Ashton (1996b) and Crisp (1992), and two, as more effective ways of gaining a better understanding of awareness of difficulties following brain injury.
The explanations of awareness of difficulties following brain injury found in the literature are manifestations of the empiricist and positivist paradigms upon which modern science rests (Gergen, 1985). According to the empiricist paradigm, knowledge mirrors the reality of the world. According to the positivist paradigm, knowledge depends on inbuilt mechanisms of processing incoming perceptual information. It has been argued (Gillet, 1994) that both paradigms describe the person as a passive recipient of perceptual information with inbuilt cognitive processing and overlook the role of social interaction in the formation of knowledge. Thus, researchers have no other option but to account for awareness of difficulties by positing a short fall in the cognitive processes.

However, and alternatively, theories of (social) construction of reality and phenomenology offer a very different perspective. For example, from a strong social constructivist perspective (discussed in more detail in Chapter Three), reality is not independent of human action but it is the product of interactions between people in a historical and cultural environment (Burr, 1995). Truth is considered an intersubjective exploit, which entails processes of validation, negotiation and persuasion in specific social and cultural contexts. Further, speakers are not seen as disinterested individuals who are seeking to report objective observations of the world. Speech is seen as action, and interested participants explain behaviour, attribute responsibilities and validate concepts of the self and world through it. Research, then, within this social constructivist paradigm uses conversational and discourse analytic techniques to analyse speech and other texts as forms of social action (Edwards and Potter, 1992).

In addition, phenomenological theories, developing from Husserl's philosophy, can broadly be said to be concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or the event itself (Smith, 1996). Phenomenological theories however, are the inspirational source from which the bases of social interactionism and social constructionism in turn (discussed in Chapter Three), emanate. It will be recalled then, that social interactionism argues that the meanings individuals ascribe to events should be of central concern to the social scientist and that those meanings are only
obtained though a process of interpretation. It also considers that meanings occur (and are made sense of) in, and as result of, social interactions (Smith, 1996).

Psychologists influenced by these theoretical positions use a range of methods for their work and one of them, and the most relevant to the present work would be phenomenological and interpretative phenomenological analysis (IPA henceforth) as the method of investigation. Following on the theoretical precepts of Smith (1996), IPA reflects the dual nature of this approach. The aim of the method, is to explore the participants' view of the world and to adopt, as far as is possible, an "insider's perspective" (Conrad, 1987) of the phenomenon under study. Moreover, while the researcher attempts to get close to the participant's world, it is acknowledged that researchers cannot do this completely or directly. Access is both dependent on, and complicated by, the researcher's own conceptions which are required in order to make sense of that other personal world through a process of interpretative activity.

This emphasis in offering an "insiders' perspective" is most relevant when researching lack of awareness of difficulties following brain injury. These perspectives, which will be called qualitative methodologies, can then be used in this research to legitimise the first person accounts of the patients in the research and clinical assessment. Reporting how things look from the point of view of the patient and therefore, giving the victim responsibility for what has been reported can do this. More pragmatically, the methods can help elicit first person perspectives that can target various points. First, they can investigate the patients' reactions to the brain injury; second, they can ask the victim's reactions to the behaviour of others and third, they can inquire into the behaviour of others in the patients social world (Sabat, 2001). In addition, these techniques can be used to elicit knowledge about the person's difficulties and the implications of these difficulties for the person's everyday life. In other words, if we want to know what people with brain injuries are aware of, there is no better way than to ask them. This point, problematic for some, needs to be defended. In a field with a long tradition of working under the empiricist paradigm, such as awareness of difficulties, first person reports have been consistently rejected as distorted and unreliable. These reports can be legitimised first by accepting them and then can be used as the basis of analysis. For example, Georgaca (2000), in the area of delusions,
Chapter Four - Researching lack of awareness in brain injury: the methodology

argues that instead of dismissing the accounts of patients these can be examined along three lines of enquiry. First, the accounts can be examined for meaningfulness, not because they can express views about the world or of the speaker but because they "employ culturally available discourses" (p. 232). Second, accounts can be seen as claims that are debated and negotiated in speech as non-brain injured individuals do in their everyday speech. Third, accounts can be seen as assertions about the self and the world whose truth or falsity cannot be established by studying speech only.

Furthermore, accepting first person reports is problematic only when qualitative methodologies are viewed from a positivist paradigm perspective. In other words, if they are expected to lead to the same ends that quantitative methodology usually leads to: measurement of the phenomenon at hand and providing certain kinds of evidence for efficacy of interventions. This point, already elaborated in the literature, has led some theorists to argue that the application of traditional concepts to qualitative studies means that this kind of research is never legitimised (Lyons, 1999). Workers that are not familiar with the shift in paradigms when considering qualitative research will regard any materials produced by qualitative researchers as unreliable and not objective or if they are familiar they may not agree with them.

As discussed in the first section of this chapter, assessing such an abstract term as awareness of difficulties has been done through inferences. These inferences are based on the idea that awareness can be studied from a third person perspective and ultimately because of the ontological assumption that there is an ultimate truth "out there". A qualitative paradigm is much better suited to study awareness of difficulties because it does not assume this ontological reality but the existence of multiple realities. These multiple realities are sometimes in conflict and may vary as reconstructions and understandings change (Gergen, 1999). Qualitative research assumes that the knowledge that is derived from such research is constructed by both the researcher and the participants (Lyons, 1999). Thus, what is problematic in the field of awareness of difficulties research when using qualitative methodologies is not how to assess and provide evidence of efficacy of interventions, for example, but how to accommodate the qualitative paradigm along the lines of health disciplines deeply embedded in the biomedical model. This accommodation may be facilitated if all
parties concerned, about what is expected of each paradigm, show an understanding, and more attention is given to a future integration. Accordingly, research questions need to be suited to one or other perspective. Harré (2000) for example, in talking about studies of consciousness, argues this point. Harré suggests that the study of the fields of intentional objects should be left to the domain of discursive psychology, while the study of enabling conditions for the existence of such fields is the province of neuropsychology (i.e. investigating the state of the brain and the nervous system). Thus, researchers working with the concept of awareness of difficulties under a qualitative framework should be concerned with the understandings and knowledge a brain injury victim has of the injury (Lyons, 1999). They should aim at eliciting knowledge, as opposed to making predictions and controlling the research process, while incorporating the social world into the research. This allows the researcher to give a better insight into the individuals perspective that otherwise would go unnoticed under quantitative methodologies (Lyons, 1999).

This thesis adopts a constructionist position in that it sees the "reality" experienced by people with brain injuries as a product of their social, historical and cultural environment (Burr, 1995). It also adheres to an interpretative phenomenological position in that it is concerned with the individual's personal perceptions and the researcher's interpretation of the data. Studies using this position are said to enrich the literature of an area previously only studied quantitatively. Smith (1996) says that while employing different methods, drawing on different theoretical backgrounds and using different terminologies, the shared commitment to mind and cognitions allows for the possibility of quantitative and qualitative researchers usefully having dialogue with each other and quantitative and qualitative studies informing each other.

However, the question of how qualitative research can help the problem of lack of awareness of difficulties following a brain injury needs a more precise answer. From a phenomenological angle, Smith (1996) remarks that phenomenology has always been concerned with the "individually diseased body" (p.264) or in this case, injured body. Thus, while societal accounts may provide valid explanations for the distribution and transmission of illness or proneness to accidents, the individual body still provides an exemplary unit for determining the existence of, and possible boundaries, for the
illness or injury. Further, it is also a phenomenological assumption that people think about their bodies and what they have to say about their bodies in some way relates to those thoughts. For IPA, the body and its perception is an invaluable asset as a subject for research. The phenomenological researcher, while recognising the gap between an object and the individual's perception of it, is interested in elucidating the nature of this gap. Thus, the existence of entities such as bodies and injuries provides a useful background against which to compare different accounts of physical processes (Smith, 1996).

What is then to be gained by employing these methodologies? The answer to this question may be found in the weak and strong forms that these methodologies can adopt (for a general introduction to weak and strong positions see Chapter Three with respect to emotions). In the thesis it is recognised that a strong social constructionism and interpretative phenomenological approach would lead to relativism and the conclusion that no one interpretation has a priority, or a closer claim to the truth than another. A weak constructivist and interpretative phenomenological approach however, adopted here, claims that there are criteria for judging between some competing accounts of a situation, and that rigour, careful attention to the material and repeated questioning by the researcher will lead to conclusions which are not only plausible and theoretically useful but whose veracity can be supported by others. Thus, adopting a social constructivist-phenomenological perspective, this thesis is about how people with brain injuries experience their brain injuries, and subsequent difficulties. That is, what messages are given by their bodies and society to these individuals and how are these messages interpreted. The objective is then to use people with brain injuries' experiences to inform theoretical development, in particular how does social interaction increase awareness of difficulties after a brain injury.

4.4. RESEARCH DESIGN: TALKING TO THE PEOPLE THAT MATTER
So far the methods used to investigate lack of awareness of difficulties have been based on clinical observations, experimental or psychometric testing. Although successful in their different ways as means to research into a difficult phenomenon, their results offer contradictory and inconclusive answers. Equally, the variety of
unacceptable theoretical frameworks suggests the need for a new theoretical framework and the development of new methodology.

More recently, there has been a growing interest in exploring awareness of difficulties from the perspective of those most affected by it, namely the people with brain injury and their caregivers. Reflecting this new interest the present work introduces a qualitative design or naturalistic enquiry into the phenomenon of awareness of brain injury. Qualitative designs are naturalistic to the extent that the researcher does not attempt to manipulate the research process or its participants for research purposes as would be the case in an experiment. In this thesis the investigation comprises three qualitative studies: Study One, exploratory in character, is divided into two parts. Part One examines spontaneous complaints people with brain injuries make about their injuries and subsequent difficulties. Part Two investigates how significant others explain these difficulties to the patients. The study looks at people with brain injuries within a community setting, years after the brain injury has occurred and official rehabilitation efforts have ceased. Study Two was conducted with the brain injured participants. This study asks how the participants' knowledge of their difficulties is constructed. That is, how do they make sense of their brain injuries and the challenges they face following their injuries. Study Three was conducted with non-expert health professionals at two day care centres that people with brain injuries participating in this research attend. This study examines how difficulties that can be experienced following a brain injury are understood, communicated and dealt with by this staff.

Qualitative methods of inquiry were deemed appropriate in this context due to certain inherent characteristics in this form of empirical enquiry that make it suitable for the particular research phenomena. These characteristics (Lincoln and Guba, 1985; Silverman, 2001) are discussed in more detailed below and can be listed as the following: qualitative methods allow for contextual inquiry, they offer an array of qualitative methods for data collection appropriate to human inquiry, analytic induction and purposive sampling. The credibility of the present work is also assessed at the end of the section.
4.4.1. Contextual inquiry

Research carried out under the qualitative paradigm suggests that inquiry must be undertaken in a natural context because phenomena of study, whatever their nature, take their meaning as much from their contexts as they do from themselves. The ontological position exposed in the above section of this chapter specified that reality constructions cannot be separated from the world in which they are experienced. No phenomenon can be understood out of relationship to the time and context that spawned, harboured and supported it (Lincoln and Guba, 1985). Coming back to the present research, the different settings where awareness of brain injury develops were clarified in Chapter Two, i.e. hospital, rehabilitation, re-entering the community. Brain injury is then seen as occurring in various social settings and the ways in which people with brain injuries interpret and make sense of their injuries are understood as real-life events, which can only be examined in those contexts. Such a comprehensive approach is most useful when trying to understand the complexities of those life-events as opposed to more conventional ways of inquiry. For example, experimental research emphasises or insists in not having a natural setting in the name of control or internal validity (Lincoln and Guba, 1985). Experimental inquirers create then contrived contexts that influence behaviour in ways that natural settings do not. Such studies may be successful in showing how participants behave in those contrived settings but almost never show how these participants behave in natural contexts. In natural settings the researcher cannot allow for the complexities of real-life events, therefore if anything may make a difference, then everything must be monitored. Further, the researcher must become so much a part of the context that she cannot longer be considered a disturbing element (Lincoln and Guba, 1985). Thus, the reaction of the researcher in the present work to more conventional ways of investigating awareness of difficulties in brain injury was to take a comprehensive approach to the phenomenon. The research, throughout the investigation, was undertaken in naturalistic settings like day care centres and homes of the participants. The researcher, by becoming a volunteer at the day care centres where the research was going to take place, became at the same time part of the brain injury context. Further, by including in the investigation people that form part of the social environment of people with brain injuries, significant others and care givers (Zencius, & Wesolowski, (1999)), the project emphasised this comprehensive perspective.
4.4.2. Qualitative methods of data collection
Lincoln and Guba (1985) assert that qualitative methods come more easily to hand when the "instrument" used to carry out the research is a human being. That is, the human-as-instrument is inclined towards methods that are extensions of normal human activities: looking, listening, speaking, reading and so on. The researcher will tend to interview, observe, read available documents and so on. The present work used interviews and vignettes to carry out the data collection relevant to the project. The theoretical background of interviewing will be discussed in the first place.

4.4.2.1. Interviews
According to Banister, Burman, Parker, Taylor and Tindall (1994) there are four main reasons for conducting interviews. First is a concern with subjective meanings rather than eliciting responses within a standard format for comparison with other individuals or groups. A concern shared in this thesis given the lack of subjective explanations in awareness of brain injury (Fleming, Strong and Ashton, 1996b). Second, and most relevant to the present work, interviews can permit exploration of issues that may be too complex to investigate through quantitative means. That is, given the quantitative methods tendency to simplify phenomena, they can misrepresent the nature of the questions under investigation. In this thesis, for example, this tendency has been described as problematic in the first section of this chapter. Presenting people with brain injuries with questionnaires and ratings scales is unlikely to provide research with sufficiently sensitive and incisive grasp of brain injured individuals' concerns. This may not be so much because the questionnaire or the scale does not address the correct questions, as because the views of the participants cannot be readily representable within this format. Third, doing interviews forces the interviewer to confront his or her own participation within the research. Conducting interviews demands consideration of reflexivity in the research process extending from the devising of the research question, to identifying and setting up interviews with participants, to the interview itself (i.e. role of the interviewer, how is the interviewer seen by participants). Fourth and finally, interviews are regarded by some writers as "conversations with a purpose". What purpose the conversation is pursuing is a point that leads to power relationships. While quantitative research methods view the people who form the focus of the
research as "subjects", the people who form the focus of the present work were invited to be "participants". This term reflects the researchers' attempts to do research "with" people with brain injuries rather than "on" people with brain injuries.

Gathering data: semi-structured interviews and vignettes

Returning to the second reason stated above, interviews allow for exploration of issues that would otherwise go unnoticed under other methodologies. In this thesis, interviews were carried out with people with brain injuries, significant others and non-expert health professionals. The interviews were carried out in order to explore how people with brain injuries made sense of their injuries and the challenges they have to face following their brain injuries. It was assumed in this context that what the participants had to say during the interviews had some ongoing significance for the participants, and that there was, though not transparent, a relationship between what the participants said and the beliefs that participants were assumed to hold (Smith, 1995). At the same time it was recognised that meanings are negotiated within a social context and therefore, these interviews then draw also from a social interactionist position (Denzin, 1995).

In order to investigate such issues all the interviews conducted in the investigation used a semi-structured format and Study Three included the presentation of two vignettes. Semi-structure interviews, in general, are used by researchers to gain a detailed picture of a participant's beliefs, or perceptions or accounts about a particular topic (Smith, 1995). Vignettes are used to further illuminate and redefine the issues under investigation. The two methods will be explored here but the use of semi-structured interviews over structured and unstructured interviews in the present work will be justified first.

According to Smith (1995) and in general, the use of structured interviews shares much of the rationale of the psychological experiment. When using structured interviews the researcher decides in advance exactly what constitutes the required data and constructs the questions in such a way as to elicit answers corresponding to and contained within predetermined categories which can then be numerically analysed. This format is of limited use when exploring the nature of awareness of
brain injury due to the constraints the structured interview could put on participants and the situation. That is, it would deliberately limit what the participants could talk about, this having been decided in advance by the researcher. This limitation has already been observed and discussed in relation to the methodology employed by awareness of brain injury (see first section of this chapter) and therefore, it will not be expanded here. Suffice to say that the use of structured interviews would have impeded, in the present work, the unravelling of novel aspects of the area (something considered important by the participant but not for the researcher) and the unravelling of complexity in the participants' position.

Unstructured interviewing, on the other hand, rejects the positivist assumption that both the interviewer and the interviewee are treated as objects. Instead, interviewer and interviewee are both involved in the research as participants. In this version of interview, both the type of knowledge gained and the validity of the analysis are based on "deep" understanding. This is because the "humanistic framework" from which this type of interview derives supports "meaningful understanding of the person and wholeness in human inquiry" (Reason and Rowan, p.206, 1981). For this reason, unstructured interviewing rejects prescheduled standardised interviews in favour of open-ended questions. Denzin (1970) offers three reasons for this preference: a) it allows respondents to use their unique ways of defining the world, b) it assumes that no fixed sequence of questions is suitable to all participants, and c) it allows participants to raise important issues not contained in the schedule. However, the use of unstructured interviews was rejected in the present investigation for two reasons. First, the passivity of the researcher could create a constraint on people with brain injuries to talk (as seen in psychotherapy and counselling research (Peräkylä, 1995)). That is, if the researcher maintains a minimal presence, asking few questions, this can create an interpretative problem as to what is relevant to the interview. Second the need to gain some uniformity in the data. That is, it is difficult for researchers to enter an interview situation without some structure in place which, in turn, can lead to some uniformity of answers.

Semi-structured interviews were then considered more flexible than structured interviews and more directive than unstructured interviews. The researchers
employing this format still have a set of questions on an interview schedule but the interview is guided by the schedule instead of dictated by it. The interviewer then has the opportunity to follow up interesting avenues that emerge in the interview and the participant is able to give a fuller picture. In this context, the interviews conducted here were about what each study had set out to explore, but the course and the content of each interview itself depended on each participant.

Constructing the semi-structured interviews schedules

The four interview schedules used in the present work were devised to be exploratory and semi-structured. Exploratory because the researcher was interested in the accounts of the participants in each of the three studies, not in narrow responses to standardised questionnaires. Moreover, for this same reason the interviews had to be semi-structured.

All the interviews followed a series of basic steps. First of all, the opening questions to the interviews were general, destined to gather demographic data and/or establishing an interview context rapport with the participants. Although with the exception of the participants in the second part of Study One the researcher was well known to all the participants. Second, the interviews were a combination of general and specific questions designed to elicit accounts on:

- Study One (Part One): knowledge of brain injury, its subsequent difficulties and implications in brain injured participants.
- Study One (Part Two): ways of communication of difficulties and implications by significant others.
- Study Two: gaining knowledge and interpretation of difficulties, and their implications by people with brain injuries.
- Study Three: understandings and experiences of lack of awareness of difficulties in people with brain injuries and ways of communicating about difficulties by non-expert health professionals.

The questions were not intended as "catch-all" or as interrogations, they were designed to establish a conversation between the participants and the researcher.
Semi-structure interviews allow the researcher to guide and give direction to the interview without constraining the participants to one word answers with little depth or context. This method also allows the researcher to take participants through high degrees of exploration by firmly setting the agenda and limiting the topics for discussion. Further, the method also allows participants to contribute a considerable guidance in the path the interview follows. All interviews were tape-recorded and transcribed verbatim to gain in-depth knowledge, as a first step, from the data.

Vignettes
In conjunction with the semi-structured interview carried out in Study Tree, two vignettes were embedded in the course of these interviews. The use of vignettes as a methodological tool entails crafting a short, descriptive sketch of an incident and then presenting it to the informants to elicit their opinions and reactions to its contents. The vignette is carefully designed to depict a circumstance or represent a germane issue and elicit rich but focused responses from participants. The vignette is essentially a very short story that when carefully constructed and presented simulates real life experiences. After participants read or have been read the story, they are asked to respond to a few directed questions to further involve them in refining the subject under investigation. The creation of meaning and the capturing of attitudes brings the researcher a step closer to understanding behaviour.

As a methodological tool therefore, there are certain inherent characteristics to this form of inquiry that renders it suitable for this particular study. First, while vignettes have certain common features (a brief and familiar hypothetical scenario followed up with questions), they can be modified to be consistent with the research topic of interest. In Study Three, the two vignettes presented were created to depict two different cases of awareness of difficulties in two different scenarios. Second, the story telling character of the vignette is relaxing, pleasant, interesting and may reduce the feeling of being overburden by the interview process (Kayser-Jones and Koening, 1994). Finally, since these stories are hypothetical and generally involve a fictitious other, vignettes and follow-up questions can obtain information beyond the individual's current personal situation. Such depersonalisation is advantageous for the present research topic in two ways. For studies of social phenomena, removing
personal disclosure may ease difficulty or embarrassment. One of the aims of Study
Three was to explore non-expert health care professionals observed experiences of
lack of awareness of difficulties in people with brain injuries. The sensitive nature of
some of these difficulties (as noted in Chapter Three), like disinhibition, makes this
methodology particularly helpful in eliciting participants accounts about these
matters. The second aim of the study, how non-expert health professionals
communicate these difficulties to the patients, adapts to the second way in which
depersonalisation is advantageous. The use of a vignette approach presents a medium
through which to go beyond the discussion of individual life situations and towards
the generation of accounts on a social level. Thus, presenting a vignette to non-expert
health care professionals was a medium through which these participants could
transcend their own particular experiences on to a more socially descriptive level of
accounts.

4.4.3. Inductive data analysis
It is said that qualitative methods are particularly orientated toward exploration,
discovery, and inductive logic (Lincoln and Guba, 1985; Patton, 1987). The present
work can be said to be inductive to the extent that the researcher made attempts to
make sense of the phenomenon under investigation, lack of awareness of difficulties,
without imposing pre-existent expectations in the research setting. Inductive designs
like the one adopted here begin with specific observations and build toward general
patterns. Categories or dimensions of analysis emerge from the data as the research
comes to understand these data patterns.

The method contrasts with the hypothetical-deductive approach of experimental
designs that require the specification of main variables and the statement of specific
research hypotheses before data collection begins. Qualitative analysis is guided not
by hypotheses but questions, issues and a search for patterns or themes.
Extrapolations emerge then when these themes are content analysed or analysed by
conducting an inductive data analysis like IPA.

Content analysis and inductive data analysis bear remarkable similarities but seem to
work at different epistemological levels. For example, and on one hand, content
Chapter Four - Researching lack of awareness in brain injury: the methodology

analysis involves identifying coherent and important examples, themes and patterns in the data and making the information explicit. The researcher looks for quotations or observations that go together, that are examples of the same underlying idea, issue or concept. The contents of the data are thus classified. Organising and simplifying the complexity of data into some meaningful and manageable themes or categories is then the basic purpose of content analysis. On the other hand, inductive analysis means that patterns, themes and categories of analysis come from the data; they emerge out of the data rather than being decided prior to data collection and analysis. The researcher in this case looks for natural variation in the data. That is, the researcher pays attention to processes of the phenomenon under investigation and the interpretation participants in the research give to that phenomenon. Therefore, both methods focus in a search of patterns or themes but while content analysis assumes that these themes are already in the data, inductive analytic methods assume that they emerge from the data. Thus, the methods disagree on the location of knowledge not on the nature of knowledge or the acquisition of knowledge. Therefore, the difference is neither methodological or epistemological but of method.

This difference is important and relevant for two different purposes. First, and in general, to be able to distinguish between method, methodology and epistemology within the qualitative paradigm is an opportunity to develop the idea of a unitary qualitative paradigm (Henwood and Pidgeon, 1994). Second, and most relevant for this thesis, the difference allows the researcher to ask different questions within an entirely qualitative based body of research linked by the same epistemologies and methodologies.

In this thesis, the questions guiding Study One referred to how often the participants talked about their brain injuries, difficulties and implications thus rendering the data appropriate to the classificatory nature of content analysis. Study Two and Study Three however, asked different questions. The focus of these two studies was on how participants make sense of this phenomenon. In other words, the interest lay in the phenomenology of the experience, not in classifying it. This change of questioning, from "what do they know" (content) to "how do they know" (process) integrates the two different analytical procedures or methods in the thesis. The change represents a
change of method to allow the researcher to ask different questions, not a change of epistemological position.

4.4.4. Purposive sampling

Sampling in qualitative methods is said to be quite different from the sampling carried out in more conventional, statistical methods (Patton, 1987). All sampling in qualitative methods is done with some purpose in mind. In statistical methods the purpose always is to define a sample that is in some sense representative of a population from which it is desired to generalise. In qualitative methods a purposive sample is selected with the aim of obtaining "information-rich" cases for study in depth. Information-rich cases are those which the researcher can learn a great deal about issues of central importance to the subject under investigation. In the present work, people with brain injuries, significant others and non-expert health professionals were selected as sources of information-rich cases. This selection however served various purposes.

Throughout the investigation, the strategy for purposeful sampling aimed at capturing and describing the main themes cutting across a great deal of participant variation. For small samples like the ones presented in the present studies, a great deal of heterogeneity can be a problem because individual participants are so different from each other. This weakness however, was turned to be advantageous by utilising maximum variation sampling in the investigation. That is, any common patterns that emerged from heterogeneity or variation were of particular interest and captured the core experiences as shared aspects in the research. The point of the research was then not to focus on the similarities that could be developed into generalisations, but to detail the many specifics that give this context its unique flavour (Lincoln and Guba, 1985).

A second purpose was to generate information upon which the emergent design could be based. Emergent design means that in this project there was no a priori specification of the sample. The researcher recruited and selected participants into the project in order to obtain information and compare information (Study One), fill in information (Study Two) and extend information (Study Three). The original sample
was chosen for three reasons. First, the heterogeneity of the group fitted with the well
known principle in brain injury literature that no two brain injuries are the same.
Therefore, the sample was, in part, theoretically "guided". Second, easy access or
convenience to the group since the researcher worked for the organisation where the
participants were recruited. Third, to act as a base for successive samples. Such
successive samples were obtained by personal nomination (in Study One participants
were asked to nominate significant others) or were based on theoretical information
(literature points to professional care givers as the second most important social
interaction of people with brain injuries (Zencius & Wesolowski, 1999) and therefore,
were used for Study Three).

4.5. THE CREDIBILITY OF THE RESEARCH
The use of qualitative research methods in brain injury affects the criteria by which
research in this area is assessed. Traditionally, research in brain injury has employed
quantitative methods which offer a well defined set of criteria which in turn, is applied
to all research findings to evaluate the goodness of a particular study and its results.
These criteria emanate from the positivist assumption that there is a truth out there
that is defined as having some form of correspondence with reality. This assumption
then allows questions about whether the research carried out under the positivist
paradigm yields an accurate account of this reality (Smith, 1990). For example,
questions about the reliability of the measurement process, questions about the
adequacy of the measurement and its results (otherwise known as validity) can be
asked. Further, and assuming that there is a reality out there that can be depicted,
then research findings should be generalisable across different contexts.

In contrast, concepts such as reliability, validity and generalisability are often seen as
irrelevant in the evaluation of qualitative research (Lyons, 1999) as they are based on
assumptions central to the positivist perspective. As stated previously, qualitative
research concerns itself with meaning and because meaning in human experience is
not considered to be universal, generalisation from qualitative research findings is not
relevant (Zyzansky, McWhinney, Blake, Crabtree and Miller, 1992). Further, some
qualitative research workers reject the standard of issues of reliability and validity in
favour of:
"An intensive personal involvement, an abandonment of scientific control, an improvisational style to meet situations not of the researcher's making" (Agar, 1986, p.12)

However, not all workers in the field share Agar's postulate because it is very difficult for any reader to take on trust any research findings made on such claims. Instead, within the qualitative research community, researchers look to aspects of the work such as credibility, dependability, trustworthiness, transferability and authenticity (Denzin and Lincoln, 1994). These evaluation criteria do not decontextualise the data, on the contrary, qualitative research is firmly situated in a historical context (it takes into account the social, political, cultural, economic and gender antecedents of the situation). Further, the extent to which the findings stimulate action and change existing socio-political and cultural structures may also be examined (Guba and Lincoln, 1994). For research findings to be dependable then, it is expected that different investigators using similar procedures will perceive similar meanings. This will be discussed further below.

According to Guba and Lincoln (1994), researchers working within the constructivist paradigm have two sets of criteria. One circumvents the trustworthiness of the work and the other is authenticity. From this perspective, the present work on awareness of difficulties following brain injury emphasises participants' understandings of brain injury and their interpretations of the brain injury experience. The starting assumption is that there are multiple realities so no one true description will exist. Further, it is explicitly acknowledged that the researcher and the participants co-produce any findings that are derived within the present context of the research process, and the results provide a new and, hopefully, useful construction of the brain injury experience. This construction can then be evaluated for its trustworthiness, in terms of its credibility (to other researchers and people with brain injuries), whether it is dependable (would a similar construction be produced in similar contexts?), transferable (would a similar construction be produced in different contexts?) and also whether it is confirmable (do similar people with brain injuries have similar constructions?).
In general though, no one set of evaluation criteria exists to evaluate all qualitative research. In many qualitative methods the concepts of credibility, dependability and confirmability are applied and are examined with the use of triangulation, reflexivity and independent audits (Banister, Burman, Parker, Taylor and Tindall, 1994). Triangulation involves approaching the data from different perspectives to gain a richer and more illuminating interpretation. According to Banister et al. (1994) there are three levels of triangulation such as data, investigator and method triangulation. Data triangulation involves collecting accounts from different participants involved in the chosen setting, from different stages in the setting and if appropriate from different sites of the setting. In the present work this point was addressed by not only collecting data from people with brain injuries, significant others and care givers participants but by collecting data from different sites of the setting (two day care centres). Investigator triangulation refers to the use of more than one researcher, preferably from other disciplines or perspectives, to talk through, comment and challenge the work at various stages of the research. The present work addressed this point by inviting other researchers to act as coders during the analytical stages of the data. Finally, method triangulation refers to the use of different methods to collect information. Since all methods have limitations, a danger of using only one method is that the findings may merely be an artefact of the method (this point was not addressed by the present research).

These three levels of triangulation highlight the notion that there are various ways of "knowing", all of which can contribute to building a body of knowledge. However, the value of triangulation for evaluating research has been put in question amongst qualitative researchers, with some arguing that it rings too many "positivist criteria bells" (Lyons, 1999). Instead, these researchers suggest another set of methods for validating studies based on entirely qualitative data. Silverman (2001) for example, concedes that the use of inductive data analysis (discussed above) does not lead to the assumption, shared by many researchers, that the work is only exploratory or descriptive. Although inductive analysis demands no a priori hypotheses, the use of the method allows for generating and testing hypothesis "grounded" in the data. Fielding (1988) describes it like this:
"One case is studied to see whether the hypothesis relates to it. If not, the hypothesis is reformulated or the phenomenon redefined to exclude the case. While a small number of cases support practical certainty, negative cases disprove the explanation, which is then reformulated. Examination of cases, redefinition of the phenomenon and reformulation of hypothesis is repeated until a universal relationship is shown." (p. 7-8)

Thus, inductive data analysis boils down to two techniques. The use of comparison and the search of deviant or negative cases. Glasser and Straus (1967) suggest that the qualitative researcher should always attempt to find another case through which to test out provisional hypothesis. What this means is that the method involves inspecting and comparing all the data fragments that arise in a single case while at the same time seeking out and addressing deviant cases. In this context however, the term deviant case assumes a different meaning from that encountered in quantitative methodology. In statistical procedures, for example, the researcher turns to deviant cases when the existing variables will not produce sufficiently high statistical correlations or when good correlations are found but there are reasons to believe that these are "spurious". By contrast, the qualitative researcher should not be satisfied by explanations, which appear to explain all the variance in the data. In this context, deviant cases are identified on the basis of concepts deriving from a particular framework. Thus pieces of data are never intrinsically deviant but rather become so in relation to the approach used. In other words, in qualitative research every piece of data has to be used until it can be accounted for. Therefore, the approach to qualitative data is comprehensive in a way that quantitative methodologies are not always. This is another strength of the approach and addresses complaints that findings are:

"Based on a subjectively selected, and probably biased, sample of cases that happen to fit the analytic argument." (ten Have, 1998, p. 8)

Such comprehensive data treatment can be aided by the use of appropriate tabulations, where the categories counted are derived from theoretically defined concepts. Silverman (2001) points out that simple counting techniques offer a means
to survey the whole corpus of data ordinarily lost in intensive, qualitative research. Instead of taking the word for it, the reader has a chance to gain a sense of the flavour of the data as a whole.

For the purpose of this thesis, the standards of the qualitative research community were aimed to be met the following way. The research was situated in context and the procedure followed throughout the body of work was standardised and clarified. Accordingly, each step of the research was described in terms of specific rules and procedures. For this purpose, a detailed presentation is included in each of the three studies of the data collection, coding and analysis of participants' accounts. This renders the analytical process transparent and accountable.
CHAPTER FIVE

STUDY ONE - WHAT PEOPLE WITH BRAIN INJURIES TELL
AND WHAT THEY ARE TOLD ABOUT THEIR DIFFICULTIES

5.1. INTRODUCTION
This chapter presents the first study of the thesis. The study examines:

- The extent to which people with brain injuries participating in the study talked about their difficulties.
- The way difficulties are communicated by significant others to people with brain injuries.

The research addresses the possibility that, in some cases, awareness of difficulties following a brain injury may be increased during social interaction. As discussed in Chapter Three, the explanations about difficulties, and explanations of the implications for everyday living of these difficulties, given by others may play a role in the awareness process. The changes in awareness of difficulties may be a consequence of the recognition by the victims of the influence of evaluations and attitudes of others on the self. This influence depends on who those others are and on an open communication. On the part of significant others who care for brain injury patients, lack of knowledge about brain injury, its resulting difficulties and its implications may impinge upon this communication.

As already seen in Chapter Two, advances in medical technology have meant that a greater number of victims of brain injury survive for longer than they would have done a few years back. These individuals experience the acute stages of their injuries in hospitals, they undertake official rehabilitation following the acute stage and finally,
they reintegrate into the community. This reintegration into the community often means going back to families that are more often than not naive as to brain injury and its possible consequences, which can be of a physical, cognitive and/or emotional nature.

In addition, it has been pointed out that physical difficulties are usually the first difficulties that a brain injured person becomes aware of (Fleming and Strong, 1999), usually during hospitalisation. Cognitive effects include a range of difficulties that often take some time to make themselves felt. These can include problems with language and communication skills, intellectual difficulties, memory and learning difficulties, attentional difficulties and difficulties in executive function (McKinlay & Watkiss, 1999). Emotional effects, which have been studied under the term of psychosocial changes, emerge in the weeks and months after the injury (McKinlay, et al, 1981). The most frequently reported are irritability and impatience, slowness and tiredness, bad temper, verbosity, lack of inhibition and change of character (McKinlay & Watkiss, 1999). The frequency with which these problems arise varies according to injury severity and the problems themselves can vary over time (McKinlay, et al, 1981) plus they may be exacerbated by problematic social interactions.

Recognition of physical, cognitive and emotional difficulties tends to emerge during rehabilitation and come into focus once the brain injured person reintegrates in the community. Prigatano (1995) notes that at this stage the patients want to return to work or school or to pre-injury activities. In the cases where they do return to previous activities, Prigatano observes, more often than not, they do not succeed in their attempt. This failure, sometimes, illustrates the difficulties to the patients and to those around them. Reactions to this discovery, not surprisingly, are manifest in an increase in emotional and behavioural difficulties during the first year post-injury.

Neurological explanations for this increase could have been suggested but appear unlikely due to the nature of brain injury. Brain injury is not a degenerative disorder and recovery or some recovery of function is possible (cognitive functions in particular). Instead, explanations turn to the role of the family in pointing out these difficulties as time goes by and stopping making allowances for the patient, or to the
secondary nature of these problems, i.e. the patient exhibits these problems as secondary reaction to limitations (McKinlay and Brooks, 1984). Empirical evidence seems to verify the existence of these increases in emotional difficulties and emphasises the role of awareness of these difficulties, as well as awareness of physical and cognitive difficulties, as the necessary ingredient for adjustment to brain injury (Ponsford, 1995). This has led some researchers to point to the role of denial on the part of the relatives (Romano, 1974) as a coping mechanism and as part of a process in coming to terms with a brain injured relative. However, this may have alternative explanations, like the role of social interaction in adjustment to brain injury.

As has been seen, the problems encountered by the brain injured person and their family, years after the injury, are due to the cognitive and emotional sequelae, as opposed to the physical sequelae of the brain injury (Blyth, 1981). Lack of awareness of some cognitive difficulties and lack of awareness of some emotional problems continue to be a cause of concern. Furthermore, some researchers have observed that denial may have been adopted as a negative defence mechanism by some patients (Prigatano, 1999). However, and as already stated in Chapter Two, the adoption of denial as defence mechanism does not explain why not all people with brain injuries react to the injury in the same way. An alternative explanation can be offered which does not assume that the brain injured person is responding to the difficulties caused by the injury in this way. This explanation refers to the discursive environments and the ways in which these may affect the understanding of difficulties and their implications by the brain injured person.

Furthermore, and as discussed in Chapter Three, if the development of self-awareness depends partly on the views of others, the way these views are transmitted, received, interpreted and acted upon maybe crucial for the development of awareness of difficulties following a brain injury. The development of this awareness may be influenced by the accurate perception of how others see us which, in turn, depends on open communication. However, according to Shrauger and Schoeneman (1979), incongruences between self-appraisals and others' appraisals are often due to strong cultural sanctions against making direct appraisals, especially if these are of a negative nature and, by the same token, the way information is interpreted carries the same
importance as to how it is transmitted. Shrauger and Schoeneman, (1979) observe that people differ in their interpretation of others' feedback, particularly if the feedback is not explicit. The authors point to the individual's agency in interpreting feedback and to how this feedback is given more importance according to the status of the person that imparts the appraisal. Research from the social cognition field adds to this idea by pointing out that the speaker's status and memory play a significant role when interpreting information. Holtgraves, Srull and Socall (1989) investigated in three different experiments how the speaker's status affected memory of assertiveness. They found that under certain conditions the remarks of a perceived high status speaker were remembered as more assertive than those made by a perceived lower status speaker. These researchers provide evidence for the existence of a relation between how information is communicated (in this case assertiveness) and one interpersonal variable (speaker status). Furthermore, Holtgraves, Srull and Socall explain that their results demonstrate how social knowledge is implicated in the interpretation of communication. By this they mean that they have made explicit the assumption that many aspects of knowledge cannot be understood apart from the context in which the communication occurs (Levinson, 1983). In other words, what can be taken as a suggestion if spoken by a low status speaker can be constructed as a command if spoken by a higher status speaker.

The research presented is the first step towards answering the thesis research question "Does social interaction increase awareness of deficits?" The present study then, divided into two parts, asks:

- **In Part One:** Do people with brain injuries know about their difficulties? Do they know about the implications of having these difficulties? Do they think about them? and, How does having a brain injury affect the self?
- **In Part Two:** Do significant others think their brain injured friends and relatives know their difficulties and implications? How do significant others explain these difficulties to the patients?

In part one, 30 people with brain injuries attending two different day care centres were interviewed. All the individuals had sustained a brain injury for about a year or
Chapter Five - Study One - What people with brain injuries tell and what they are told about their difficulties

longer previous to the study. The aim in this part of the study was to focus on the participants' talk about their difficulties and the implications of these difficulties. The study explores to what extent self-knowledge of difficulties is spontaneously salient to the person. This is important since according to McGuire, McGuire, Child and Fujioka (1978) when people are confronted by a complex stimulus, they selectively attend to and encode distinctive aspects of the stimulus. This selectiveness, argue the authors, affects the self-concept both directly and indirectly: directly, by our noticing our own distinctive features; indirectly, by others perceiving and responding to us in terms of our peculiarities and our adopting others' views of ourselves. Therefore, brain injury and possible difficulties that can be experienced following a brain injury were not addressed directly during the interviews unless the participants referred to the brain injury or their difficulties.

In part two, 22 significant others, nominated by the brain injured individuals participating in the first part of the study, were interviewed. The aim of this second part of the study was to examine the extent to which the discourses to which people with brain injuries are exposed in their everyday lives can contribute to the development of awareness of difficulties following a brain injury. It was noted in Chapter Three that significant others sift the world to the person. It is these communications which make up the discourse in which people with brain injuries develop their self-knowledge.

Part One of the chapter describes the techniques utilised to analyse the data from interviews with people with brain injuries and the results of this analysis. Part Two contains the techniques utilised to analyse data from interviews with significant others and the results of this analysis. The analyses carried out on the interviews sought to explore, illustrate and specify the elements involved in constructing brain injury. The interviews with the brain injured participants sought to capture the spontaneous complaints of their difficulties and the implications of these difficulties. The interviews with significant others sought to inquire into the knowledge of significant others about physical, cognitive and emotional difficulties observed in their brain injured relatives or friends. These were then matched to the brain injured participants.
accounts of their difficulties. The study also explored how these difficulties were explained or not to the victims of brain injury.

5.2. PART ONE: TALKING TO PEOPLE WITH BRAIN INJURIES

5.2.1. Method

5.2.1.1. Participants
Thirty people with brain injuries, 8 females and 22 males (age range 19 to 62), attending two day care centres in the South of England were invited to participate in the study. Individuals were admitted to the centres if they had suffered a traumatic brain injury (car accident, work accident, etc.) or had an acquired brain injury (stroke, brain haemorrhage, etc.). In some instances, the centres also admitted individuals with degenerative diseases (MS, Alzheimer’s, etc.). All participants had been suffering from brain injury for one year or longer prior to the study. Demographic characteristics of the sample and injury details are presented in Table 1. All data were self-reported and matched against the day care centres' files, GP records (where available) and relatives' information.

5.2.1.2. Ethical considerations
For the purposes of this part of the study permission was sought and obtained from the University of Surrey Advisory Committee on Ethics. In this study, sensitive data were collected from participants who had sustained a brain injury. The interview procedure was explained carefully to the participants. Participants were assured that their participation was voluntary and that they could end the interview session at any time. None of the participants ended the sessions early and only one appeared unduly distressed. In this case the interview was terminated and re-scheduled at the participant's request. Follow-up contact did not suggest that participants had been adversely affected by the procedures.
Table 1. Means and Standard Deviation for demographic data and injury details

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>41.96</td>
<td>13.99</td>
</tr>
<tr>
<td>Education (in years)</td>
<td>11.92</td>
<td>3.38</td>
</tr>
<tr>
<td>Time since injury (in years)</td>
<td>9.36</td>
<td>5.71</td>
</tr>
<tr>
<td>Duration of coma (n=21) (in days)</td>
<td>61.83</td>
<td>78.95</td>
</tr>
<tr>
<td>Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cause</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Road accident</td>
<td>15</td>
</tr>
<tr>
<td>Brain aneurysm</td>
<td>1</td>
</tr>
<tr>
<td>Tumour</td>
<td>2</td>
</tr>
<tr>
<td>Brain haemorrhage</td>
<td>2</td>
</tr>
<tr>
<td>Lack of oxygen to the brain</td>
<td>2</td>
</tr>
<tr>
<td>Stroke</td>
<td>5</td>
</tr>
<tr>
<td>MS</td>
<td>1</td>
</tr>
<tr>
<td>Work accident</td>
<td>2</td>
</tr>
</tbody>
</table>
5.2.1.3. Procedure
Participants were interviewed at the day care centres they attended and interviews lasted between twenty minutes and half an hour. At the beginning of the sessions, participants were asked to sign forms of consent as to their agreement to participate in the research. Participants were also given information sheets as to the general terms of the research and contact telephone numbers to provide further information or advice on any matter related to the investigation. It was recognised also that the researcher could be perceived as a person with some authority or influence in the context of the interview. To this effect every effort was made to explain that this was not the case. The research was explained to the participants as being part of a course that the researcher was doing as part of a university degree. It was explained that the research was confidential and that they could end the interview at any time if they so desired.

5.2.1.4. Interviews
The interviews consisted of a semi-structured interview schedule designed to elicit different aspects of participants' descriptions of themselves and their daily lives. The questions were designed to focus on the participants' self-knowledge and to enquire about the effect of this knowledge on the individual. The schedule (see Appendix 1) covered six categories of interest: (a) daily activities of the participants (i.e. what activities do you do here?); (b) health issues and ways of keeping healthy (i.e. do you consider yourself healthy?); (c) employment status and goals for the future (i.e. have you always had the same job?); (d) social life and relationships (i.e. do you feel people respect you?); (e) general worries (i.e. how do you feel you cope with life at the moment?); and (f) perceived changes in the lives of the participants (i.e. do you think your life has change for you?).

5.2.1.5. Doing content analysis
The transcriptions from the all the interviews were analysed using content analysis (Miles and Huberman, 1994). This approach, discussed in Chapter Four, in most cases involves searching for and identifying the key themes present in the data rather than having a set of pre-conceived hypotheses and using the data to confirm or disprove those hypotheses. The process of content analysis involves progressive
"sorts" of the data, firstly sorting the data into categories, and then re-examining the data thus categorised for commonalities or themes that can be identified.

Part One of the present study underwent four stages of analysis. First, the content of the interviews was sorted by the researcher into the major categories on the interview schedule. Second, the researcher reviewed the transcripts and found that data for some key issues was spread across a number of the initial six categories, so developed three domains (Talking about difficulties, Reflecting on difficulties and Maintaining the self) to use as the framework for analysis of the data. A revised set of nine categories was then devised (see table 2). Third, the transcripts were re-analysed using this more detailed framework with each paragraph being coded and ascribed to one of the six categories. Code-re-code reliability by the researcher found a Kappa coefficient of 0.90 (0.70 is the recommended rate by Miles and Huberman (1994)) on six randomly selected transcripts. An inter-rater reliability rate of 0.92 was achieved between the researcher and a colleague independently coding four randomly selected transcripts, which is above the 0.90 level recommended by Miles and Huberman (1994). Fourth and finally, once the transcripts had been coded, the data in each category were examined for explanations or themes that were recurrent and therefore, significant. This was done by going through each code selecting the themes brought out by the coded text and checking its support across all the interviews in order to note down the theme of the quotation. In this manner, a record was kept of themes that were popular and themes that were less common. The organising principle in the selection of themes was simply that of counting frequencies, which did not quantify the analysis but provided a criterion for selection. That is, a theme selected by one participant could have been supported by another participant, while another theme may have been supported by five other participants. As it was, most themes were included in the study not only to capture the commonality of accounts but also to reflect maximum variation of accounts. For example, maximum variation involves looking for outlier cases to see whether main patterns still hold. The critical case is the instance that exemplifies the main findings. Thus, searching for confirming and disconfirming themes serves to increase confidence in conclusions (Miles and Huberman, 1994).
### Table 2. Domains, categories and coding guides.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Category</th>
<th>Coding guide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking about</td>
<td>Talking about</td>
<td>Reasons given for attending the centre, talk of activities carried out in and outside the centre,</td>
</tr>
<tr>
<td>difficulties</td>
<td>brain injury</td>
<td>talk of activities carried out alone or in the company of others, abilities or current functioning, secondary changes (i.e. now unemployed).</td>
</tr>
<tr>
<td>Talking about</td>
<td>Talking about physical</td>
<td>Reasons given for attending the centre, talk of activities carried out in and outside the centre,</td>
</tr>
<tr>
<td>physical</td>
<td>difficulties</td>
<td>talk of activities carried out alone or in the company of others, abilities or current functioning, secondary changes (i.e. now unemployed).</td>
</tr>
<tr>
<td>Talking about</td>
<td>Talking about cognitive</td>
<td>Reasons given for attending the centre, talk of activities carried out in and outside the centre,</td>
</tr>
<tr>
<td>cognitive</td>
<td>difficulties</td>
<td>talk of activities carried out alone or in the company of others, abilities or current functioning, secondary changes (i.e. now unemployed).</td>
</tr>
<tr>
<td>Talking about</td>
<td>Talking about emotional</td>
<td>Reasons given for attending the centre, talk of activities carried out in and outside the centre,</td>
</tr>
<tr>
<td>emotional difficulties</td>
<td>difficulties</td>
<td>talk of activities carried out alone or in the company of others, abilities or current functioning, secondary changes (i.e. now unemployed), problems with friends and family.</td>
</tr>
<tr>
<td>Talking about</td>
<td>Talking about implications</td>
<td>Talking about health issues in the present and in the past, ways of describing good health.</td>
</tr>
<tr>
<td>implications of</td>
<td>of physical difficulties</td>
<td></td>
</tr>
<tr>
<td>Talking about</td>
<td>Implications of cognitive</td>
<td>Future goals (i.e. desire for a job), present abilities/need for help and future hopes.</td>
</tr>
<tr>
<td>Implications of</td>
<td>difficulties</td>
<td></td>
</tr>
<tr>
<td>Talking about</td>
<td>Implications of emotional</td>
<td>Talking about social behaviour, problems with family/people outside family.</td>
</tr>
<tr>
<td>emotional difficulties</td>
<td>difficulties</td>
<td></td>
</tr>
<tr>
<td>Reflecting on</td>
<td>Thinking about</td>
<td>Thinking about their own health, thinking about activities and abilities, thinking about the self.</td>
</tr>
<tr>
<td>difficulties</td>
<td>difficulties</td>
<td></td>
</tr>
<tr>
<td>Maintaining the self</td>
<td>Continuity of the self</td>
<td>Reports of change in the lives of the participants, experiences of changes in the attitudes from others, pre-injury/post injury circumstances.</td>
</tr>
</tbody>
</table>
Chapter Five - Study One - What people with brain injuries tell and what they are told about their difficulties

5.2.2. Results

Findings of key themes are reported here from nine categories. A number of verbatim quotes are reported to illustrate the kinds of statements underpinning the identified themes. Some quotes may not be grammatically correct, but all have been reproduced verbatim.

Do participants know about their brain injuries and subsequent difficulties?

Summary tables are presented here as to the frequencies of accounts of brain injuries, physical difficulties, cognitive problems and emotional problems found in the responses of participants to questions about reasons for attending the day care centre, living arrangements, activities carried out in the centre and outside of it, perceived personal abilities, employment history and social life. These categories are not mutually exclusive.

Table 3. Participants accounts of brain injury, physical, cognitive and emotional difficulties. (n=30)

<table>
<thead>
<tr>
<th>ACCOUNTS</th>
<th>FREQUENCIES</th>
<th>FREQUENCIES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Talking about their brain injury</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>Mention of physical difficulties</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>Mention of cognitive difficulties</td>
<td>14</td>
<td>16</td>
</tr>
<tr>
<td>Mention of emotional problems</td>
<td>11</td>
<td>19</td>
</tr>
</tbody>
</table>

It can be seen that the majority of participants (20 out of 30) talked about their brain injuries. These were mentioned in eleven cases as reasons for attending the day care centre where the investigation was carried out:

"I come here because I crashed a car and had a bad head injury and this has helped to rehabilitate me and go back to a normal life."

to explain the loss of ability to perform certain functions (7 participants),

"I just do, I put my pants the wrong way, I do silly things like that but I couldn't tell you why, and again is all part of having had these strokes."
to explain doing something by three participants:

"At the moment I do exactly as my Doctor tells me. Which is, well, I have a list of things that I am not supposed to eat. It seems a long list to me, but it's mainly because it includes all the things I used to like. Like cheese and eggs, butter, anything with serious fat content I am not allowed to have I am on a very low fat diet, which is understandable. Well, let's put it this way, since my Doctor has told me very clearly that I shouldn't eat various things, I probably lost two and a half stone, which is fair enough. It overall makes me feel better, but to a large extent it has help to eliminate the fears of having another stroke, because I had two so a third one would be really, really, serious."

and to explain a change in the participant's life by five participants:

"I had a brain aneurysm haemorrhage, but it did me good in some ways, it stop me drinking and I never had so much money in my life."

Of the ten participants who did not mention having had a brain injury, one did not know where he was but explained that he attended the centre to socialise and get better from heart problems:

"I: Why do you come to...?
R: I come here to get better, the things I do!
I: Any other reasons?
R: To get some work and get better, because I want to drive.
I: How long have you been coming here?
R: About a year or so.
I: What made you decide to come here?
R: Well, so that I can talk to my friends, so that I can have somebody to talk to, because when I first came here I couldn't talk and then I started to talk. I was in hospital and then I went home and it happened again.
I: What happened?
R: My heart, in the first date they gave me fifteen things, tablets. For the heart, liver and I had to have an operation and they put three things in here, I looked like an Indian. It was my heart."
Two participants admitted in response to inquiries as to where they were and why, that they did know where they were but did not know the reasons why they attended the place. One of these participants did not mention any kind of brain injury, physical, cognitive or emotional problems throughout the interview. He answered all the questions in a jovial and matter of fact manner. The other participant explained that he had no idea of what was happening to him:

"I have no idea, I don't feel upset or discontent in any way but apart from just having eaten something, I have no idea of what I am doing here or anything. I got to be honest and say that I don't know. My memory is that I live at X and live with my wife T and I got two children but I haven't seen any of them for years, as far as I know. I got no idea or understanding of anything."

The other seven participants did not mention having a brain injury but referred to having had accidents. Five participants said that they attended the centre because they had had car accidents. For the other two participants who also mentioned having had accidents, one explained that his work accident was the cause of his present inactivity:

"Nothing, I try to do some things but I can't. I broke my back at work; I broke my back twice, the second time I was just sitting having a coffee. I felt pain but everybody thought I was moaning about the first injury and then they did an x-ray and found that I had broken my back in a different place."

and a second one mentioned being run over by a car in response to a question about life change:

"I: When did it change?
R: After my accident.
I: Would you like to talk about it?
R: I can't remember it but I know that it was all my fault. I got drunk and walked down the middle of the road and a car hit me."

Twenty participants referred to having physical problems but not always as a direct consequence of having had a brain injury. Four people did refer to their physical problems because of their brain injury:
"I am fine in myself. The bleed that caused my stroke, followed by the stroke, I completely lost my right side of the brain and of course, it is the right side of the brain which controls the left side of the body, physically, and the left arm and the left leg are totally paralysed, but over the years I got my left leg working again, my arm is completely useless, the left side of my mouth is paralysed as well, that is why I dribble and I don't know I am doing it."

"I nearly went to ballet school, and then I nearly went to gymnastic school but now I can't do either because of my head injury has affected my balance, for walking, so I can't be athletic or dance."

while a further sixteen participants talked about their physical problems in two different ways. Participants either regarded their physical problems in their own right and separate from the brain injury (12 participants):

"I have trouble with wetting the bed but it goes in phases, two or three days and then nothing for weeks, so it is difficult but is not bad enough to warrant a catheter or anything."

or caused by reasons different to the brain injury, like medical skill (one participant):

"When I was in hospital I had a lot of lumbar punctures. I can't tell you how many but a lot, and I often wonder if they did damage to my spinal cord, as some people were better at doing lumbar punctures than others, naturally. But there was one particular day when she kept pushing this needle in and out of my back, and I know that it sounds silly, but I could feel my spinal cord. I could feel it hitting it and pushing it to one side, and that happened several times, and I did not take much notice but in hindsight, I wonder if it did any damage to my nerves because it has all got to do with the nervous system."

or as a consequence of having had an accident (three participants):

"After the accident I thought I had lost all me, all my fitness, I lost it all. If they asked me to walk, it would take me a couple of hours to walk up the road. After the accident, I was dragging my foot and I was conscious of it and thinking that everybody was looking at it. That got me but now I am fit, I can run, I do exercise."
The ten participants who did not mention physical problems did not have any apparent physical difficulty except for two. One was in a wheelchair and another could not walk unaided.

Cognitive problems were found to be related to the brain injury by the participants in three cases:

"Because of the head injury, I forget names, so at home I got a little electronic diary and I record things, all my days and dates, so I check every morning to see what I have got to do."

while in nine cases cognitive problems were talked about as single problems, unrelated to the brain injury:

"The only big problem I think I have got, as my father said to me today is, short-term memory is not something I am clever with. I don't know what happened, my father phones me up and says some thing and I have forgotten it by the following day. So as to whether I can change that, I would like to say, maybe, I don't know."

generalised and de-personalised as a single problem in one case:

"Well, as I said, I do get some conversation. I also like talking to the volunteers to have some sensible conversation because with the best will in the world it is not the best conversation when you are talking to the members because, well, as you know, we all got memory problems and its just that some are worse than others. Unfortunately some people just can't handle themselves, I know this, they do repeat the same conversation."

or as consequences of having had an accident by one participant:

"The problem is, after the accident, I lost a lot of memory and some of that memory I never got back. So, I am still hoping that one day, may be, I will get it all back, but I don't know."

Out of the sixteen participants who did not mention any cognitive deficit, only one reasoned that his problems were merely physical, not cognitive:
"X and I agree that this place is not addressing my needs, my needs are physical, not cognitive. I came here originally for rehabilitation, to socialise"

The other fifteen participants did not refer to any cognitive problems.

Accounts of emotional problems (11 participants) show that five participants related their emotional problems directly to having had a brain injury. One participant recounted problems with respecting people, being impatient, inconsiderate and his "unhealthy interest" in other people's personal lives:

"One of the most incidental, ridiculous things like people's star signs and when they got married, what job have they got and things like that which I never worried about before or what their surname is, personal questions as well. I think my social graces aren't absolutely right. Like I upset a friend of mine, John the other month, well several months ago..........."

A second participant talked about using foul language and being angry and frustrated as a consequence to the accident while two other participants explained about "losing control of emotions" without knowing why:

"So you can sit in there watching nothing in particular, it can be a news item for example, on television and you can sit in there quite upset. No particular reason, an item that you quite happily would have dismissed before the stroke, but now, for whatever reason, it just has an impact, which is sometimes difficult to cope."

One of these two participants also admitted to what can be seen as a contradiction:

"It is also difficult to control the emotions, keeping temper wise, I have been quite amazed that that has not been the problem for me."

Further accounts by a fifth participant showed that losing the sense of humour was considered problematic.

Six participants reflected on problems with depression not as a direct consequence of having a brain injury but because of the implications of having a brain injury:
"I know I have been worse, but I have been far better as well, so I don't think I cope very well at all. I get very, very low, very down, depressed about it, but I think its because it has been such a long time away, that I have been spending practically all my life in a hospital and away from my family, it's just awful."

"Since the accident I got more depressed. When I came out of prison I was trying to rebuild my life and now I am a cripple, I can do nothing, I can't walk long and my brain gets tired, I can't think or concentrate."

Nineteen participants did not mention emotional problems.

Do participants know the implications of having a brain injury at a physical level?

Summary Table 4 is presented here as to the frequencies of responses to questions addressing past and present health states of the participants and their ways of keeping in good health.

Table 4. Frequency of responses to questions about health. (n=30)

<table>
<thead>
<tr>
<th>Talking about health</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants talking about their health excluding the brain injury</td>
<td>22</td>
<td>8</td>
</tr>
<tr>
<td>Number of participants talking about their health including the brain injury</td>
<td>4</td>
<td>26</td>
</tr>
<tr>
<td>Number of participants considering themselves healthy when excluding brain injury and unhealthy when including brain injury</td>
<td>4</td>
<td>26</td>
</tr>
</tbody>
</table>

Twenty two participants talked about their health as something completely separate from their brain injuries:

"I: Do you consider yourself healthy?

R: Except for my broken knees, I am overweight and I am trying to do something about it. One knee has a splint on, the other, I got to go and see a doctor in
September, because is gone as well. And they will operate in both knees because they are both bad, but I am walking and this is good.

I: Would you say that you have always been healthy?
R: No, I had always had asthma and I have broken my left cheekbone, fallen from bicycles when I was younger, but I mend."

Four participants talked about the brain injury as a disruption to their health:

"I: Would you say that you have always been healthy?
R: I guess up until my injury I was healthy."

"Now, that is one thing that annoys me, am I allowed to say this? The only thing that annoys me about X is that, while most of the people here have had head injuries as a result of an accident, I got, well, is not exactly a head injury, I got a disability as a result of having a stroke and unfortunately most of the staff don't realise or don't appear to realise, that my brain does actually work quite well most of the time. OK, there are little bits where it needs a kick and a push and a bit of help, but most of the time, I accept that some of my ideas may be a bit different to most people, most of the time my brain is still working, even if the rest is crapped out, and that annoys me sometimes. My stroke is disability arising from an illness; I mean the illness itself. No doctor has given me clear guidelines on diet. Obviously, she told me about washing and exercising but as long as I stick to the diet, I know that things should be fine, so as far as I am concerned the stroke is the past. There may be another one sitting round the corner somewhere but I don't want to know about that, thank you."

and four participants made the distinction between the brain injury disrupting their health and health as separate from the brain injury:

"I: Do you consider yourself healthy?
R: Healthy in the sense that I have very few coughs or colds or flu, perhaps once a year, once every two years, in that way I am healthy, but I haven't had a convulsion since last Christmas."
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Do participants know about the implications of having a brain injury at a cognitive level?

Summary Table 5 presents the frequencies of responses to questions about activities, abilities, job issues, desire to drive, and long terms plans and short term plans for the future.

Table 5. Number of participants responses to questions about employment, plans for the future, daily activities and known abilities. (n=30)

<table>
<thead>
<tr>
<th>Responses to:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid employment</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>*Desire to drive</td>
<td>4</td>
<td>26</td>
</tr>
<tr>
<td>Plans for the future</td>
<td>8</td>
<td>22</td>
</tr>
<tr>
<td>Involvement in activities in and outside the centre</td>
<td>18</td>
<td>12</td>
</tr>
<tr>
<td>Knowledge of own abilities and limitations</td>
<td>14</td>
<td>7</td>
</tr>
</tbody>
</table>

*Participants were not asked about desire to drive after the brain injury but this desire was mentioned spontaneously and included in this table. Desire to drive has been considered in the past literature as an indication of lack of awareness of difficulties.

Although not one of the participants was in full time employment at the time of the study, three participants held voluntary jobs. Eighteen participants expressed a desire for a job and four participants specified that they would like to go back to the job they had in the past, before the brain injury:

"Well, I worked in cancer research, worked with drugs which were convulsive drugs and making up specialised electrodes in London University. I would like to go up and visit the University and talk to my professor, see if anything could be arranged, but I have my doubts that I could ever work again. Well, it was a specialised job. I think I could do that work again."

Twelve participants saw the jobs they used to hold as their main ability:

"I: What do you think you are good at?

R: Building surveying I guess, identifying buildings, I did do a part-time degree... the
fifth year I had this..........., what I am good at? Building surveying, yeah, I enjoy it immensely, doing specifications, writing all those out, contractors............. "

while six participants considered the brain injury as no obstacle to going back to work:

"I am just starting to look for employment. People won't let me get back to work, sounds daft but this is how it is. They say that I got to ask people if they will let me get back to my job but they have problems getting insurance for me. I would like to get back to what I was doing but my social worker is very reluctant."

Twelve participants did not express a desire for a job. Three participants were retired, two did not give a reason for not wanting a job, three did not consider themselves fit enough and thought of themselves as disabled, another participant thought that he was unemployable but did not give a reason as to why he saw himself as such. Another participant did not know what he could do, another one confessed to having no idea if he was looking for a job or not and another one professed to have a job as the saviour of the world.

Although participants were not asked if they wanted to drive a car four participants expressed a desire to drive. The participants thought that driving would be a step towards the sort of life they used to lead before the brain injury. One participant focused on his physical difficulties and presented strategies to overcome those in order to be able to drive:

"I used to drive a car and I would like to drive again. You see, we have an automatic car and I think I could drive it quite easily because I don't have to use the left foot, so I will apply to the DVLC."

When talking about the future, eight participants mentioned having a plan for the future. These plans were short-term and included taking holidays, moving house, going too see a football match and acquiring computer software:

"Well, in theory we are supposed to be moving. My eldest son has said that the house is far too big for us, which it is, but John does not want to move and I got some great friends that live not very far from us, so it would be nice if we could
move closer to them, but we'll wait and see, it just depends what my husband wants to do.”

Six people remarked that they did not have specific plans for the future but emphasised the importance of being active, to keep going. Fourteen participants said that they did not have plans for the future but some had aims towards improving (two cases):

“I aim to improve all the time, everything I do is hard at the moment, the crash was in 91, which is nearly ten years ago now, then I was told I would be a vegetable all my life and now I live on my own and I do everything.”

hopes of starting a new life (2 participants):

“I have to start a new life, because of my divorce and that, you know, start a new life.”

hopes of recovering lost memory (one case):

“I lost a lot of memory and some of that memory I never got back, so, I am still hoping that one day, may be, I will get it all back, but I don't know.”

and determination to get back to pre-injury self (one participant):

“I am determined to rebuild myself back to what I was.”

In addition, when asked about the organisation of their days and plans for the next day, twenty five participants described routine activities, four gave dismissive answers and only one participant did not know how his days were organised or what he would be doing the next day.

Participants talked in their majority (18 participants) about their activities and how these were designed to counteract boredom:

“I get very bored in my flat, but now that the fishing season has started I can go fishing and cycle rides, it's a day out really, it breaks up the monotony of the week, it makes the week go pass very quickly, I look forward to coming here and I am glad to get back to my flat.”
two commented on doing nothing or very little:

"Eating, smoking, sleep, I just go to sleep, nothing."

and seven viewed activity as a means to rehabilitation:

"I find it very beneficial and I do think that all the sessions that I do here are very useful and also the contact with the other people in similar situations is very useful, so it is very good."

Two participants thought that their daily activities were better kept to a minimum to reduce the possibility of making their situations worse:

"Not too much, well that is not totally true, I basically I do what is necessary. I really do mean necessary, in the course of day to day living, if it needs to be done I'll do it. If it is something that I can maybe do today or maybe tomorrow, the chances are, I'll probably leave it till tomorrow, to be honest I used to be scared stiff about having another stroke, because I had two, well, you know how rumours go around and the one about strokes is that if you have a third one you are left very, very seriously disabled or you may not come back and that did concern me quite a lot for about, oh eighteen months, and now I got to the stage that I think, what the hell! It's quite true, this is what I have come to."

Fourteen participants admitted to knowing that they had some limitations at the time of looking for a job or when carrying out certain activities. One participant mentioned not being allowed to cook:

"No, not really, I can read, do basic things, I am not allowed to cook because I might burn myself which infuriates me."

another participant talked about being limited because of the loss of control of a part/s or the body:

"I find it too difficult to, I always used to be good with my hands you see, engineering and modelling but I find it so complicated to do simple tasks now, because I can't control my left hand properly, so I can't really do anything."

and another participant referred his limitations to a memory problem:
“If I put my mind to it I can do whatever I want, it is only because of my memory, that is the only problem.”

Some participants who expressed not knowing what they could do referred to not knowing why they could not do something (seven participants):

“at one stage I couldn't come to terms with things that we were doing, and I don't do now, I just couldn't cope with them but I can not tell you why.”

Nine participants doubted their abilities:

I: Are you seeking employment at the moment?
R: No, I do not know what I can do actually, I'll probably get back to what I was doing before actually but I don't know, its debatable.

I: What do you think you are good at?
R: Building surveying I guess, identifying buildings, I did do a part degree.. the fifth year I had this........., what I am good at? Building surveying, yeah, I enjoy it immensely, doing specifications, writing all those out, contractors.......... 

I: Could you improve?
R: I don't know about that, I doubt it very much actually.

and one could not remember his activities and abilities:

“Your questions carry some implications that I have been here before and carried activities here but as far as I am aware that is outside my memory or knowledge or anything.
I got to say that I got no idea, I got to say that I got no understanding of what has happened to me or what effect is had on my mind, so I got no idea about what I am good at or defective at.”

Do participants know the implications of having a brain injury at an emotional level?

A summary of the responses to questions about social life and relationships is presented in Table 6.
Table 6. Participants' responses to questions about their social life and relationships. (n=30)

<table>
<thead>
<tr>
<th>ACCOUNTS</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants who admitted knowing when they</td>
<td>19</td>
<td>11</td>
</tr>
<tr>
<td>had upset the other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participants who had experienced break up of</td>
<td>6</td>
<td>24</td>
</tr>
<tr>
<td>relationships</td>
<td></td>
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</tr>
</tbody>
</table>

As it can be seen nineteen participants admitted to knowing that they had upset others. One participant commented that she upset others because they thought that she was not trying hard enough in her day to day rehabilitation process. Fifteen people did not give any reason as to why they had upset other people or how they knew that they had upset others; upsetting people in these cases was seen as something inevitable, part of life:

"I am sure I do, again, not intentionally, certainly not, because as far as I am concerned I got no reason. I don't like upsetting people, so I know how it feels to be upset so I would not intentionally upset somebody, but I guess if they intentionally upset me I might hit back and do the same, but I hope I don't, that I don't have to."

One participant explained that, in the past, he only knew that he had upset another by the absence of other people who could have caused the upset:

"In them days I was not very well and my wife used to cry, and I knew that it was me that was causing it, because I was the only one in the house. But I don't know how I was doing it, I needed help because I can't see X crying. I would never let my wife cry but somewhere along the line, it was happening. And I was the only one there."

Only two participants explained that since their brain injury they seemed to upset more people:

"I seem to upset a lot of my friends since I came out of hospital by asking them personal questions."
From the eleven participants who replied that they did not know if they had upset anyone, only one commented on his problems as the cause of not knowing if he had upset others:

"I think that by my nature, I don't think I do. I also feel, as I never seen any evidence of it, that there are aspects of me that are upsetting and I am surprised that I haven't seen more evidence of people's disquiet about it."

It is worth noting also that twenty five participants admitted to getting on with most people and only one person admitted to getting on with some people only sometimes.

In respect to questions about relationships, six people talked about the break up of relationships. In five cases the break up referred to a marriage and was seen as a direct consequence of the participant's having had a brain injury or accident:

"When I got to the rehabilitation home, I got a court injunction. I was not allowed to see my children or my wife. I didn't know that she was going to divorce me."

Only one participant referred to a break up of a friendly relationship due to a lack of social graces, impulsivity and not "thinking properly":

"I think my social graces aren't absolutely right. Like I upset a friend of mine, John the other month, well several months ago. I was cleaning up my flat and I had these comics, like Superman and Batman and I thought "Oh lets get rid of those". They were old magazines and I thought, "Oh John will probable will like these". Anyway so I gave them to him and he gave them to his son, and last month I thought "I want them back" and I phoned him and I said I want them back and he said "well, fine, have them back". So I went round and he was upset and said "it is not me, is my son, you know, when you say you give somebody something you mustn't ask for it back", "but you said I could have them back", and he said that he did not want to see me ever again after that. So I wrote a very corny letter about how long we have known each other and so on and I think he accepted my apologies. I was being impulsive, I don't think about things properly, I do it in the spirit of the moment."

Two other people who were divorced had done so before the brain injury. The eight divorced people in the sample indicated themselves as the most important people in
their lives (in three cases), their children (three cases), themselves, and their children in two cases. When talking about the people they disliked three participants indicated their ex-partners, two participants pointed at politicians and three other people commented on not disliking anybody at all.

Of the twenty two participants who did not mention problems with relationships, one suspected that she might have a problem with her marriage due to her memory problems:

"I: Why don't they let you stay longer at home?
R: I don't know if it is the hospital or my husband that does not want me to stay. I don't know who is the decision maker, and you know, I want to be able to ask why I haven't been home for a while. I suspect it could be a bit of both, but probably it is because my husband is not asking if I can come home. He is not putting the wheels in motion, you know, because normally, until a relative asks if the patient can come home it does not happen, so I guess it is because he is not asking.
I: And why do you think that is?
R: I just don't think he wants me home to be honest. I am a nuisance. I just basically, I don't know. I mess his routine, he has moved house and my husband's new house is not my home, it won't be for a long time. If I go there I am not going to feel comfortable there, I don't know where anything is. Every time I have been home I just search everywhere for things and I can't find anything. None of my belongings is visible, they must be packed away in the loft and each time I mentioned it my husband gets stroppy. Basically, it is not my home because I have not lived there and there is nothing around to indicate that, you know, that I could possibly live there in the future, it is very stressful.
I: Have you talked about this to him?
R: Yes, but I just get negative vibes. I am not sure he really wants me to go back, it is the case that he feels that I will be a nuisance and I can understand that in a way. He will have to think about me all the time and won't be able to leave my side. He thinks that I can't cope on my own and I can't be trusted to do things on my own, you know, that I will have an accident and do something stupid, he does not trust me any more.
I: What are you doing that is making him think like that?
R: I think it's all excuses, he does not want me back. At the end of the day, I don't think he wants me back. I do have memory problems but I hope that I am improving and I have learned strategies to cope with it. I write things in my diary or post-it notes, anything, you know."

and another participant explained that he had decided to stay indoors as a way to keep out of trouble socially:
"that is why I don't go out, that is why I feel so very, very bad. When I do go out, for the first ten minutes, I feel fine but after I feel that they are looking at me and I get angry."

Of those participants that were married (8 participants), one could not remember if he had a wife and the others designated wives or husbands as the most important people in their lives. In these cases, participants' dislikes turned towards people that were not seen as immediate part of their lives, like politicians, "queer" people in general or nobody at all.

Single participants (11 cases) designated parents or close relatives as the most important people in their lives and only one expressed an explicit desire to meet members of the opposite sex:
"I: Given the chance, what would you like to do?
R: Go out with lots and lots of men."

When talking about people they disliked three participants mentioned not being able to think of anybody they disliked. One mentioned a politician, one a particular friend, one the person that caused the accident, one a step-father, one said that he disliked everybody, one the people who "does not let you do it yourself" and another participant admitted to not liking himself.
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Do participants reflect about their health, the things they do and themselves?

A summary of responses to questions addressing thinking about health, thinking about activities and abilities, and thinking about the self is given in Table 7.

Table 7. Frequencies of responses to questions on reflectivity on health, activities and self. (n=30)

<table>
<thead>
<tr>
<th>Reflexivity on</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>Activities and abilities</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>Self</td>
<td>13</td>
<td>17</td>
</tr>
</tbody>
</table>

Most participants admitted to thinking about their health (20 participants). These, as above, reflected the understanding that the brain injury was considered apart or different from their state of health. Participants talked in terms of thinking about diets, exercise or drinking and smoking:

"Yes, I do think about my health, specially smoking. I get pains occasionally in my chest, like last night, I always take a few heavy drags before I go to sleep. In fact, that is the reason why I feel fitter now, I don't seem to smoke as much now."

One of the ten participants who commented on not thinking about health or being worried about it specified:

"I don't think I think about anything, but as far as I know I have not spoken to any one about my health for donkey's years."

When talking about thinking about their activities and their abilities most participants said that thinking made them realise what they could not do or the abilities they had lost with depressing consequences:

"Yes, it gets frustrating sometimes, specially when it is something that you used to do well. That is what I find most frustrating, such as DIY and stuff like that, I can still do things but it is twice the effort. Keeping control of whatever I am working on or whatever, everything is awkward and takes twice as long as it used to and twice the
effort, otherwise I do the best I can. I have no option, I can dwell on it but one just makes oneself worse."

Two participants emphasised the need to think prior to carrying out activities:
"Yeah, I obviously have to think about them, I have to gear my mind to do something so that I can do it as best as I can."

Participants who admitted to not thinking about what they were doing or the abilities they had did not give any particular reasons for not doing so. In some cases they expressed a desire to not think and just go ahead and do what ever it was that they wanted to do:
"I: Do you think about what you do and what you can do?
R: No, not really, I don't think about it, I just do it."

When it came to talking about the self, thirteen participants mentioned thinking and worrying about the self. Two respondents remarked on how thinking about the self brought home the realisation of the situation they were in:
"it brings it home, how useless you are, and that is the worse part really, that is usually when you are on your own, for example, when I am with people, I don't get the time to think about it, so it does not matter, when I am on my own I get frustrated because I can't do something, it is a bit sad then."

Seventeen participants said that they did not think about themselves without giving reasons for not doing so. One participant admitted that he used to think about himself in the past but not at present and a second participant was surprised that he did not think or worry about himself:
"Having sat and talked for this time, I am very, very surprised to find that I have not worried about myself. Just on what I do know, I feel I ought to be very worried or at least, concerned about what has happened to me or what is happening to me to follow things through."
Continuity of the self

A summary of the responses to questions addressing possible changes in the lives of the participants, perceived changes in the attitudes of others and temporal comparisons is given in Table 8.

Table 8. Frequencies of responses to questions about changes in the lives of the participants. (n=30)

<table>
<thead>
<tr>
<th>ACCOUNTS</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain injury seen as point of change</td>
<td>27</td>
<td>3</td>
</tr>
<tr>
<td>Life better before the brain injury</td>
<td>24</td>
<td>6</td>
</tr>
<tr>
<td>Life better after the brain injury</td>
<td>6</td>
<td>24</td>
</tr>
</tbody>
</table>

As can be seen, the majority of participants (27 participants) considered the brain injury as a point of change in their lives. Three people did not mention their brain injuries as a turning point when questioned about change in their lives. One participant did not know about any changes in his life, another one thought that the turning point was the day he was born and a third saw change as a constant in people’s lives:

“I: Do you think your life has changed for you?
R: I think it has slightly, but I think everybody could say that, you know, due to circumstances or whatever.
I: When did it change?
R: When we left Somerset and came back up to London, I was not aware that my life had changed, the change was very slow.”

Out of these twenty seven people, twenty four felt that their brain injury represented a change in their lives and that these were better before the injury. One participant expressed a preference for the way he used to be before the brain injury and admitted that a return to the person he was had been his main objective just after his injury:

“Is not better now being disabled. I much prefer to be like I was which was my original objective after the stroke. Back to how I was but I am only half a brain now.”
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*Things are going to improve very, very slowly. The neurologist already said that my walking was not going to be that good."

another participant mentioned life was better in the past because there was no physical problems to be aware of:

"In the past. I didn't have a leg to be aware of, so definitively better in the past."

Six participants felt that the brain injury was a turning point in their lives for the better. Three felt that their lives had been changed since they had suffered brain injuries and they were much better people because of it:

"**R**: Yeah, since the crash I feel that I am now a much nicer person. I don't swear at all at anybody, I like to be nice to people, I like to be helpful and that, and the people that annoy me I ignore.

**I**: When did it change?

**R**: When I had the crash.

**R**: Would you like to talk about it? Before the crash, I used to go to pubs with friends and caused trouble and stuff but since the crash, I like to be nice to people and so on."

**I**: Is life for you better now or in the past?

**R**: In the past, I had more friends but now, I enjoy it a great deal. I am more responsible now, so I am enjoying it better now, each week I manage to do something that I couldn't do before, it is nice to see all the improvement"

One other participant felt that his life had been changed for the better because he could not remember what his life was like before the injury:

"It is a bit more tolerable now, but the thing is, I can't remember before my accident, it is a blank, I didn't even know my own parents, after the coma."

For three participants the change in their lives was understood because of the injury in as much as this had affected their mobility:
"When I had the accident because I became so immobile. I can get from A to B and walk around, short distances, but I can't go shopping on my own without transport or help to carry it, I can cook and clean and things like that all right."

and a loss of independence (4 participants):

"As soon as I was disabled for want of a better word, that is the worse part really, I am either pushed in the chair or I am driven from A to B, I lost my independence, I hate that."

For eleven people this change had meant a perceived loss of respect and rejection from others:

"I: Do you feel people respect you?
R: No, I just don't seem to see any respect shown by other people towards me. They probably do it and I just don't notice it, I just don't see it, then I probably didn't notice it before the accident, is probably just one of those things, I just can't see it, is not there.
I: Do people upset you?
R: Yes but not on purpose, I am just sensitive and sometimes people say things not intentionally to upset me but they say things that I take to heart and I take the wrong way and therefore that upsets me."

"I: Do you feel people respect you?
R: No, you know, I never feel that people respect me, they just take me for granted, like my ex, you know, she was always taking me for granted, she expected me to do things that I couldn't do. At X is different, because everyone is the same here, but outside yeah, because of my head injuries, you know, they take the mickey.
I: Do people upset you?
R: Well, you know, they call me names, you know, I got to live with it."

Nine participants who did not perceive loss of respect felt that people respected them as before the injury and four people mentioned not knowing if others had lost respect
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for them or not. One participant confessed to not caring about the respect from others and another one reasoned that he was respected depending on the values of the other:

"Some, it depends on people's perceptions of me, some people only respect people with big jobs, big money and big houses."

Furthermore, five participants thought that they were perceived by others as disabled people and pitied:

"I think people go around saying, "oh, she is disabled, bless her", you know what I mean, in quite a patronising tone, whatever."

while eleven people said that they did not know how others thought of them and nine thought that they were perceived as nice ordinary people. One participant thought that how he was seen depended on the various perceptions of the other.

5.2.3. Part One - Summary and discussion

The main findings of this part of the study can be seen at a glance in Table 9 (n=30).

Table 9. Summary of main findings for Part One of Study One.

<table>
<thead>
<tr>
<th>Accounts</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking about brain injury</td>
<td>20</td>
</tr>
<tr>
<td>Mention physical difficulties</td>
<td>20</td>
</tr>
<tr>
<td>Mention cognitive difficulties</td>
<td>14</td>
</tr>
<tr>
<td>Mention emotional disabilities</td>
<td>11</td>
</tr>
<tr>
<td>Reflectivity about health</td>
<td>20</td>
</tr>
<tr>
<td>Reflectivity about activities and abilities</td>
<td>20</td>
</tr>
<tr>
<td>Reflectivity about self</td>
<td>13</td>
</tr>
<tr>
<td>Brain injury as point of change</td>
<td>27</td>
</tr>
</tbody>
</table>

In summary, Part One of the study found that:

- Most participants referred to their brain injuries and physical difficulties in the first place, some mentioned memory problems and a few made references to a variety
of emotional difficulties. Participants who did not refer to their difficulties thought they were suffering from a different ailment (like heart condition), they did not know of or could not remember any afflictions or referred to having had car accidents.

- Physical, cognitive and emotional difficulties were mentioned in most cases as difficulties on their own right, not as direct consequence of having had a brain injury.
- Memory problems and concentration problems were the only cognitive difficulties discussed by the participants.
- Some participants had observed some emotional difficulties (like mood swings) in themselves and from the time of the brain injury but did not know why they were experiencing such difficulties. Other participants felt their emotional difficulties (i.e. depression) were secondary to having had a brain injury.
- Participants, overall, considered themselves healthy. Their brain injuries were viewed as separate from their state of health. Only a handful considered their difficulties as a disruption to their health and four made both distinctions.
- Most participants, although all of them were unemployed at the time of the study, expressed a desire to find a job. Some acknowledged limitations but those who did not did not know why they could not get back to performing certain activities or seek a job. This group expressed doubts as to knowing what they could do and some were fearful that doing something would worsen their condition.
- Most participants did not refer to any emotional difficulties and thought that their emotional responses were their natural behaviour, part of life. Those who acknowledged emotional difficulties did so after observing reactions of others towards their behaviour.
- Thinking about their difficulties helped most participants realise their limitations and put their situations in perspective. Those who did not admit to reflecting about their difficulties felt that thinking was an activity best avoided in favour of just doing. One participant felt that he did not have any memories to reflect on.
- The brain injury was considered by the majority of participants as a point of change in their lives and most thought that their lives had been better pre-injury. Surprisingly, a few participants felt that their lives were better after the injury.
In general, the findings of Part One of this study point to the brain injury and physical difficulties experienced after the injury as the most salient characteristics in the participants' accounts or narratives. This finding, which if interpreted as individuals focussing only on their brain injuries and physical difficulties is in accordance with past work in the field (Nockelby and Deaton, 1986; Prigatano and Fordyce, 1986a), is not surprising under a constructionist view of the self. That is, what happens to the body is likely to be fundamental to a person's narrative. However, under this view (discussed in Chapter Three) it is also acknowledged that a wholesome account of the self is likely to allow constitutive roles both for the body and for non-bodily difficulties in the narratives of selves. Non-bodily or cognitive and emotional difficulties were found to be of low salience in the narratives of the participants in this part of the study. Participants whose narratives did not include these difficulties thought that they were suffering from something different from a brain injury, they did not know if they had any difficulties, could not remember them or did not mention brain injury and referred to car accidents and accidents instead. All of which, in turn, points to the role of confusion, communication, memory and self-presentation in brain injury. Furthermore, when the accounts of the participants incorporated expressions of their difficulties these were mentioned as individual, single problems not as sequelae of the brain injury. This finding can be interpreted in two ways. It may indicate compartmentalisation of difficulties by the participants in an effort to deal with their difficulties in a separate and pragmatic way, or a genuine lack of knowledge of brain injury and its consequences. The accounts of the participants offered no clear evidence for one or the other explanation.

The finding that memory loss and concentration problems were the only cognitive difficulties mentioned by the participants is also not surprising. It supports most studies into long term rehabilitation of people with brain injuries that account acknowledgement of these two concrete cognitive difficulties as the most common cognitive difficulties self-reported by people with brain injuries (Fleming and Strong, 1999). More abstract cognitive difficulties like perceptual and information-processing difficulties seemed to remain unacknowledged. This finding that can point to a difference in the degree of abstraction of these "invisible" difficulties could be interpreted in three different ways. First, people with brain injuries participating in this
study may not be affected by these more abstract difficulties. Evidence for this explanation was not sought during this study as diagnosis purposes are beyond the aims of this thesis. Second, if participants were affected by more abstract cognitive difficulties, they may not have had the self-knowledge to interpret them as cognitive difficulties and as consequences of their brain injuries. Evidence for the knowledge, or the lack of, that people with brain injuries have about difficulties that can follow their traumas will be sought in Study Two of this thesis. Third, people in the social environment of the brain injured may not have informed participants about these difficulties. This interpretation will be explored further in Part Two of this study and in Study Three.

Similarly, the finding that a few participants had observed some emotional difficulties in themselves also corresponds with the literature. However, and in general, participants were able to distinguish between primary emotional difficulties and secondary emotional difficulties, with most participants accepting that they were affected by the latter. What is interesting though was that participants who had observed primary emotional difficulties in themselves did so in reaction to behavioural reactions from others or through being told that their behaviour was upsetting. This finding would then point towards the importance of the other emphasised in the symbolic interactionist tenet which is postulated in this thesis. However, and bearing in mind that these difficulties were the least mentioned and the most troublesome reported in the literature, it is possible to assume that emotional difficulties could have been more widely spread amongst the participants in the study.

Furthermore, and in reference to participants talking about their difficulties it is worth mentioning that two participants did not make references either to brain injury or any kind of difficulty. One of these participants said that he did not know what was happening to him and the other declared that he could not remember anything. While the first participant's account indicates possible confusion, the second participant's account emphasises the role of memory in self-knowledge. The finding may be the first indication that individuals with brain injuries construct their post-injury identities in terms of what they can remember or know. This distinction, which will be explored further in Study Two, is important because it allows people with brain injuries to
learn about their difficulties during social interaction without really remembering them. This has practical implications for rehabilitation which will also be discussed at a later stage.

Participants in general, showed poor understanding of the implications of their difficulties. Although a few participants mentioned explicitly that they did not know the extent of their difficulties, most participants considered themselves healthy and saw their difficulties as no obstacle to returning to work or pre-injury activities. For example, in most cases when participants talked about their health, brain injury was not included in their accounts. This finding could be interpreted in three ways. First, participants genuinely did not understand their difficulties and therefore could not foresee their implications (this interpretation will be explored further in Study Two of this thesis). Second, brain injury was not part of the participants' social representations of health. The concept of social representations, as used by Moscovici (1984), points towards the social nature of beliefs. That is, people do not merely have an individual stance or attitude towards something, they also partake of general beliefs and shared theories about the nature of the world. In this case, if the general concept of health does not include specifically not having had a brain injury, it may be that brain injury is not included into any possible concepts of health an individual may held. Third, participants were giving accounts of health excluding brain injury in order to present themselves as healthy individuals. This last interpretation is explained better by Radley and Billig (1996). According to these authors when people are asked about their states of health, their accounts construct states of health as part of their ongoing identity. This means that the accounts that are given of health, and illness, or in this case brain injury, are more than a disclosing of a supposed internal attitude. In offering views, Radley and Billig suggest, people are also making claims about themselves as worthy individuals, as more or less "fit" participants of the social world. In consequence, any shortfall in health has important implications for other areas of one's life (i.e. work, relationships) in terms of which people feel that they are evaluated. Accounts of health are therefore, more than descriptions of one's physical conditions and more than views about what people in society should do to avoid illness or injury. They also articulate a person's situation in the world and indeed, articulate that world, in which the individual will be held accountable to others.
Therefore, and in the interview context, the accounts of health given by most participants in this study could have been efforts to show "normality". Indeed, participants' expressed desires to return to work or pre-injury activities would support this interpretation.

Another finding of this part of the study was the tendency to reflectivity expressed by most participants. When participants talked about thinking about health their thoughts reflected the understanding that brain injury was regarded as different from their state of health. Instead, their thoughts about health indicated the "normality" in which participants regarded their state of health by focussing on diets, exercise and healthy life styles (i.e. drinking, smoking). Thinking about what participants could do and were able to do were the main areas participants felt "brought home" the realisation that they could not quite do certain pre-injury activities, like their previous jobs, or that they had lost certain pre-injury abilities, like being able to do DIY. This realisation however, did not seem to lead participants to attribute their lost skills to particular difficulties. In addition, a minority only of participants admitted to focussing their thoughts on themselves. Thinking about the self gave participants a global perspective of their situations as opposed to perspectives of their difficulties. Interestingly enough, participants who did not admit to thinking about themselves were still conscious of declining to think about themselves. Only one participant remarked that he could not remember his thoughts, which would point yet again to the role memory plays in self-knowledge and awareness.

Finally, and to another finding, even when participants in the study talked about their difficulties and the implications of these difficulties in a way that indicated that they constructed themselves positively, these constructions were negative in their temporal comparisons. For most participants it was found that the brain injury had not only provided the participants with a point of change in their lives but this change was seen in an unfavourable light. Surprisingly, for six participants the brain injury had represented a turn for the better.
5.3. PART TWO: SIGNIFICANT OTHERS TALKING TO PEOPLE WITH BRAIN INJURIES

5.3.1. Method

5.3.1.1. Participants

All the participants in Part One of the chapter \((N=30)\) were asked permission to approach a significant other, either a relative or close friend known to them before their brain injury. During this first study, participants were asked whom they considered the most important and close person to them in their lives. Twenty nine people with brain injuries appointed relatives as their significant other, one designated a friend. Of these twenty nine, sixteen lived with and cared for the brain injured person. Twenty-two significant others agreed to take part in the study. The criterion for participation was that the brain injured participant had appointed them as significant other. These included 4 fathers, 3 husbands, 6 wives, 1 sister, 1 son, 5 mothers, 1 friend and 1 brother. The participants were aged between 17-73 years.

5.3.1.2. Procedure

Participants were interviewed in their homes, places of work or in the day care centre that the brain injured person attended. Interviews lasted between thirty minutes and an hour. The interview consisted of a semi-structured interview and the answers were recorded, transcribed and analysed using content analysis. The interview schedule, which was developed from the literature (see Appendix Two), targeted two areas: knowledge of difficulties and implications in people with brain injuries by the significant other, and interaction between the significant other and the brain injured person when faced with these difficulties and their implications.

*Observed difficulties and their implications*

In order to investigate the observed knowledge of difficulties and implications of these difficulties in people with brain injuries by significant others a series of general questions addressed:

- Changes in the activities of the brain injured person (i.e. whether the brain injured person used to be viewed as active pre-morbidly, whether the brain injured person was considered as active after the injury).
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- Changes in the abilities of the brain injured person (i.e. whether the brain injured person was considered as able in daily activities as before the injury).
- Knowledge of future plans of the brain injured person (Did the significant other know about future planned activities of the brain injured person? Possible return to work?).
- Changes in the social life of the brain injured person (i.e. whether the brain injured person keeps in touch with friends and vice-versa, how much did the person socialise before/after the injury?).
- Character changes (Did the significant other notice any character changes in the brain injured person?).
- Motivational changes in the brain injured individual (i.e. whether the brain injured person was considered a motivated person in the past, what was the motivation then, and was the person motivated in their daily activities after the injury).
- Understanding of difficulties in the brain injured person from time of injury to present time (i.e. whether the significant other thought that the brain injured person understood about the injury just after it had happened/in the present).
- Understanding of implications for the brain injured person from time of injury to present time (direct question).
- Perception of changes in reflective processes in the brain injured person (i.e. was the person inclined to be thoughtful pre-morbidly and post-injury).

Observed complaints made by significant others in this part of the study were compared with the spontaneous complaints made by the victims of brain injury in the Part One of the study. Each reported problem was characterised as either physical, cognitive or emotional.

**Explanation of difficulties and implications**

In order to investigate the discourses that the significant others used to explain difficulties and the implications of these difficulties, a series of questions addressed how significant others explained the following:

- Physical difficulties (how do you talk/explain about physical loss/complaints?).
- Cognitive difficulties (how do you talk/explain about memory/information processing, etc, complaints?).
Emotional difficulties (how do you talk/explain about mood swings/verbosity/depression/lack of inhibition, etc.)

5.3.2. Results

A summary of the responses to general questions addressing observed knowledge of brain injury, difficulties and implications of these difficulties in the brain injured by significant others is given in Table 10.

Table 10. Frequencies of responses to questions regarding knowledge of brain injury, difficulties and implications of these difficulties in people with brain injuries made by significant others. (N=22)

<table>
<thead>
<tr>
<th>Questions about:</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in activities</td>
<td>21</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Changes in abilities</td>
<td>17</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Changes in social life</td>
<td>15</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Character changes</td>
<td>18</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Motivation changes</td>
<td>11</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Understanding of difficulties</td>
<td>15</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Understanding of implications</td>
<td>10</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Reflectivity</td>
<td>16</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

It can be seen that the majority of significant others had observed changes in the activities, abilities, social life, character and motivation of the brain injured person. The majority of significant others also thought that the brain injured persons understood their difficulties and the implications of these difficulties.

Twenty one significant others thought that the brain injured person had undergone a change in the level of activities carried out after the injury compared with the activities carried out before the injury due to the trauma:
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"Yes she was, always on the move. She was always a girl that got up to all sorts of stuff, she was a competitive sailor, now she still sails but it is restricted mainly because of her sight. She cannot see very well, she gets tired very quickly and easily. I think the knowledge is still there, you know. The mechanics of sailing are still there but she is just limited by sight and tiredness, I think."

Only one person thought that the brain injured individual was as active in his daily activities as before the injury:

"No, he worked very hard but I don't think he was an active person."

Similarly, the majority of significant others had observed a change in the abilities of the brain injured person due to the consequences of the brain injury:

"Sport, football, cricket, he was good at school, reading spelling, he had an analytical mind, especially for historical matters. His problems now stem from his memory deficit. He is still very astute, he could still come up with an answer and see through something, just like that. But, you ask him to consider say a piece of history and then to ask him to comment; that is difficult for him. So it is the memory that is the problem. I don't think his sharpness has been affected by that, which I think is quite unusual in brain injury. I heard that people lose that ability to perceive things clearly. F is not like that at all, is just his memory which does not allow him to get the whole picture and does not allow him to make a proper judgement of it."

Significant others who did not perceive any ability changes in the brain injured person reasoned that the brain injured person was as able as before the injury:

"I: What do you think ___ used to be good at?
R: Figures, spelling, predicting the Man United results.
I: What do you think ___ is good at now?
R: He is still good at spelling, he watches a lot of quiz programs, he knows about 60-70% of the answers, figures is still reasonable, word searches he loves.
I: In your opinion, is there room for improvement?"
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R: No, I think he has reached a level, which is not much less that what it was before the accident."

Two participants who did not know of any changes in the abilities of the brain injured person did not know because, in one case the brain injured person had sustained the injury at a young age so there was no established ability to compare with:
"He was ten years old so it is difficult to say anything in particular. He was sporty and a normal child growing up."

and a second participant did not feel that she knew the brain injured person well enough before the injury:
"His job, figure work, he used to be good at his job, the rest of the time he sat on a chair. I wish you were not recording this but I think that he was quite lazy and still is, before and after. I am on the go all the time, he sits down and that is a lot of his trouble. If I go back, I only got to know him because he bought a house about twenty yards from here, and it wasn't ready but he got his job and needed somewhere to stay. I got a bed and breakfast and he stayed with me for three months. I didn't get to know him well then because he was very quiet."

With respect to social life, fifteen significant others had observed changes in the social life of the brain injured person as a consequence of having had a brain injury:
"I don't think that his friends see him as the man/boy that he used to be. They don't come around as much, they don't talk to him in quite the same way, some of them treat him like a charity case, which is depressing. I think that he is very aware of that, although he tries to deny it, but I think that he is aware."

Five significant others who had observed no change in the social life of the brain injured person explained that the brain injured person did not have much of a social life before the injury:
"Not really, he spent a lot of time on his own and now he still does. He goes down the pub, smokes too much, drinks too much, the same as before. He always wanted to get married and have kids but know I think that he knows that because of the brain injury his chances of that happening are reduced."
One participant explained that the brain injured person had managed to maintain the same social life as before the injury because of the ability she had of "putting up a front":

"most people don't realise she has had a stroke. She is very good at hiding it naturally, but I think that there is an element of purpose as well. She knows that she can give herself away, she gets tired, and then she will try to explain what her problem is but not in brain terms but in high blood pressure terms. She will talk about her father and having inherited high blood pressure from her father, in a way she is minimising her problems."

One participant did not know of any social life change in the brain injured person due to the young age at which the injury had been sustained. This significant other did not feel that he had any basis to compare with.

Eighteen participants in this study found that the brain injured person had undergone a character change due to the brain injury:

I: Do you think ____ has changed since the injury?
R: Yes.
I: How has ____ changed?
R: She is a different person. I mean, she is really OTT about, you know, she will ask anybody anything than comes in her mind. She talks, I mean the one good thing, in a sense, is that somehow she is confident now. She does not feel any embarrassment and she will talk to people. Before she would not talk to anybody, not to start a conversation herself, but now she is extremely friendly. Children and old people love her, she will talk to anybody in a wheelchair, she will wave at them, she is good with people. The social skills seem to have improved but sometimes it is too much and we know more people now because of her than ever before. Because she is good with people, she knows that she lacks inhibition and thinks it is good.

Significant others who had not observed any character change saw the brain injured individuals as they were before the injury:
"He has lost confidence, but it is not a character change. He has lost his confidence because he is aware of his own disability. He does not speak as easily as he used to do. He finds it difficult, when he meets new people he just freezes, and he often complains "I don't know how to make new friends". With people here he is fine, with the family he is great."

One participant did not know of any character change in the brain injured person due to the young age at which the injury had been sustained.

Eleven participants felt that the brain injured patient had lost motivation after the trauma:

"His only motivation is the taxi that comes to take him to Y two days a week, his visits here, Saturday morning visits. When he moved, it was awful. He knew that he was moving on a Saturday and we gave him some cardboard boxes three days before for his books. I went to do some of it a day before the move and his plate was on the floor, next to his chair. In the morning of the day of the move, his plate was still on the floor next to his chair, the washing up was sitting in the sink, when he knew that he was moving. And he sat there with the TV on and us doing the moving. When he got to his new home, he sat in front of the TV and left us to do all the work again. He didn't do a thing, he didn't prepare a thing."

Ten significant others explained that they had not observed any change in motivation in the brain injured person after the trauma:

"Daily living, he was very disciplined before and he has not lost that. He asks me what we are doing during the day and so on."

One participant didn't know of any changes in motivation because she was not in regular contact with the brain injured individual.

Fifteen significant others had observed that the brain injured individuals had understanding of the difficulties that afflicted them:
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"She does, she gets very depressed and she has had this relapse and her legs had got worse and she said to me, not long ago, "before long a shall be in a wheelchair". You know, so she does realise and gets very depressed about it."

Significant others who felt the brain injured person did not understand their difficulties (four participants) reasoned that the aims the brain injured individual had set for themselves were unrealistic:

"I think he thinks that he is going to go back to work, then he wants to drive and then he gets fixed ideas in his mind about what he is going to do. His GP said to him that he could not go back to work and he could not drive either so he thinks of other things he can do"

Participants who did not know if the brain injured person understood their difficulties explained that memory problems made understanding difficult:

"I don't know, he knows it, he knows that there is a lot of his life missing because of it."

Ten significant others thought that the brain injured person understood the implications of the difficulties encountered as a consequence of the brain injury:

"He knows that he will not do what he wanted to do before the injury. I mean the very fact that he comes to Y, and he accepts that, shows that he does know. Because he never would have come to a place like this. Obviously, any young person does not want to be seen dead in an institution. He is getting rather fed up with coming here, he would like to have a job. But this is a difficult subject because he is on benefit and any job that he did would have to be very secure and well paid as, as soon he had a job, he would lose the benefit and it is difficult to get it back. Head injuries are not very well understood by social services. But he is capable, if it is supported, he needs someone to tell him what to do. He does show a certain amount of initiative now but it is still leaning on me.

Seven significant others thought that the brain injured individual did not understand the implications of their difficulties. One participant explained that the invisibility of
the difficulties made it difficult for the brain injured person to understand the implications:

"Not really because it is not physical. He can't see it so he can't understand it. He seeks pity and sympathy from others. He says that he has no confidence. He was in a five year relationship and his girlfriend could not take it anymore. In the end he attacked her, knifed her because she wanted to leave. And that is what he does if he cannot have his way. He has to have his way. He seems a bit better now because he attends the day care centre and has a new job but his bad temper will not allow him to keep his job."

Another participant explained that the brain injured person did not understand the implications of the injury because no one had talked to her about it:

"No, I don't think she knows how awful it can be. I would not like to put that in her mind. However, I hope that it will not happen to the degree that it can happen, why make somebody more frightened? You know, you should enjoy each day at the level it is, I am sure, because it can get worse, obviously."

Three participants who did not know if the brain injured person had an understanding of the implications of difficulties explained that the complexity of the person made it difficult to judge the understanding of the implications of difficulties:

"I don't know, not knowing how his brain works or not, how does anybody know? he is very cunning, he is very good at disguising things, other people don't know, he went to this centre and his eyes were poorly then, they gave him a test to do in which he had to read the instructions, he couldn't do the test, but he couldn't do it because he couldn't read the instructions and made up that he could, at that time he didn't have his glasses, he couldn't read the instructions and then the people there said that he could not follow instructions, they did not notice that his eyes had got worse, he could not read, so you see, sometimes people are very stupid. It is very hard to know how much he knows, how much he disguises, how much he plays."

Two participants said that they did not want to talk about the subject so as not to discourage the brain injured person:
"I am never sure that he is fully aware of his problems and I don't want to dwell too much either because I want to keep his hopes up that things are going to get better. I keep quiet for his sake."

Sixteen significant others had observed changes in reflective processes in the brain injured person. Most of these changes meant that the brain injured person had become more self-centred since the brain injury:

"She is thinking all the time on the things she can do or would like to do and on how to do them. I think she thinks a lot about what she is going to do, before she does it, and of course, she goes ahead, and when it comes the time to do it she has forgotten half of it. She remembers everything she has to do until she comes to doing it, then she forgets about it."

However, two significant others did not think that the brain injured person had become more self-centred but obsessive:

"He worries now, he gets what I call obsessions in his head and he will get something in his brain and he will not get it out."

Four participants who explained not knowing if the brain injured person had become more self-centred pointed to the fact that memory problems made it difficult to judge:

"Is hard to say, because he is always in this feeling of "just come round". I think that is partly why he does not expect to do too much,"

In general, observed brain injury, physical, cognitive and emotional complaints are summarised in Table 11.
Table 11. Percentages of complaints made by significant others (Part Two, N=22) and people with brain injuries (Part One, N=30).

<table>
<thead>
<tr>
<th>Complaints</th>
<th>Significant other</th>
<th>People with brain injuries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mention of brain injury</td>
<td>77.2%</td>
<td>66.7%</td>
</tr>
<tr>
<td>Mention of physical</td>
<td>77.2%</td>
<td>66.7%</td>
</tr>
<tr>
<td>difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mention of cognitive</td>
<td>81.9%</td>
<td>46%</td>
</tr>
<tr>
<td>difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mention of emotional</td>
<td>81.9%</td>
<td>36.7%</td>
</tr>
<tr>
<td>difficulties</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In general terms, it can be seen that significant others made more complaints about cognitive and emotional difficulties, brain injury and physical difficulties, in that order, than people with brain injuries made in the previous study.

It is also useful to compare complaints about brain injury, physical, cognitive and emotional difficulties made by significant others with the spontaneous complaints made by the brain injured participants of the Part One of the study on an individual basis (Table 12).

Table 12. Number of brain injured participants who mentioned brain injury in Part One compared with their significant others who mentioned brain injury in Part Two.

<table>
<thead>
<tr>
<th>Mention of brain injury in Part One</th>
<th>Mention of brain injury in Part Two</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
</tbody>
</table>

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Of the twenty people with brain injuries who mentioned having had a brain injury in Part One of the study, three significant others declined to participate. Of the remaining seventeen, thirteen mentioned brain injury in the present study.

Twenty brain injured participants made physical complaints in Part One of the study. Of these twenty, four designated significant others refused to take part in this study and twelve talked about physical difficulties. Four significant others did not mention any kind of physical difficulty (Table 13).

Table 13. Number of brain injured participants who mentioned physical difficulties in Part One compared with their significant others.

<table>
<thead>
<tr>
<th>Mention of physical difficulties in Part One</th>
<th>Mention of physical difficulties in Part Two</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
<td>12</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
</tbody>
</table>

Fourteen participants in Part One of the study mentioned cognitive difficulties. Eight designated significant others in this part of the study talked about cognitive complaints, two did not mention cognitive complaints and four declined to participate in the study (Table 14).
Table 14. Number of brain injured participants who mentioned cognitive difficulties in Part One compared with their significant others.

<table>
<thead>
<tr>
<th>Mention of cognitive difficulties in Part One</th>
<th>Mention of cognitive difficulties in Part Two</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
</tr>
</tbody>
</table>

Eleven brain injured participants of Part One of the study made emotional complaints. In this part of the study, five designated significant others made emotional complaints, one did not mention any kind of emotional complaint, four declined to participate and one died before the interview.

Table 15. Number of brain injured participants who mentioned emotional difficulties in Part One of the study compared with their significant others.

<table>
<thead>
<tr>
<th>Mention of emotional difficulties in Part One</th>
<th>Mention of emotional difficulties in Part Two</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
</tr>
</tbody>
</table>

In summary, significant others made more spontaneous complaints about brain injury, physical, cognitive and emotional difficulties in the people with brain injuries than those made in Part One of the study.
Chapter Five - Study One - What people with brain injuries tell and what they are told about their difficulties

How do significant others explain difficulties to people with brain injuries?

A summary of the responses to questions asking how significant others addressed physical, cognitive and emotional difficulties is given in Table 16.

Table 16. Number of significant others who explained physical, cognitive and emotional difficulties. (N=22)

<table>
<thead>
<tr>
<th>Difficulties</th>
<th>Explanations in terms of brain injury</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Cognitive</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Emotional</td>
<td>4</td>
<td>14</td>
</tr>
</tbody>
</table>

As can be seen only a minority of significant others tried to explain physical, cognitive and emotional difficulties in terms of the brain injury.

Four significant others explained to the brain injured individual about physical difficulties in terms of the brain injury:

"She keeps saying about the driving test, that she will take the disabled person one. Whether it is a longing rather than a feel that she can do it, I am not sure, because she has lots of ambitions in her own way, overconfident. I am not sure that she realises that she can't do things. Lately she has come up saying that she wants to do this or that and I think its mad and I had to say to her that she has to realise that she has a brain injury, a slight one, but a brain injury, and she has taken this on board and now when she does something stupid she apologises and says, well, I am sorry, but I have a brain injury. Whereas before, she never admitted that she had a brain injury, the fact that she went to a day centre for brain injured people was incidental for her. When it got too much I said, well, it is because you have a brain injury that you are going there and you have to realise your limitations."
Sixteen significant others did not explain physical difficulties in terms of the brain injury. Five thought that it was better to give the brain injured person things to do instead of talking:

"I just tell him to get off his backside. Sometimes I tell him that something needs doing and he looks at me and says "I can't do it yet". I want the bathroom decorated and things like that. After his stroke I wanted my bedroom decorated so to make him do something I emptied the room and started. I made him do it but he is a perfectionist. It is not how he likes it done, because I went on painting above him and below him and he came behind me to do it all. But because he is a perfectionist if he cannot do it properly he won't try. He gets into his head that he cannot do it and he does not bother to do it. My daughter's hair drier broke down and she said "Oh Dad will fix it" he used to fix things like that so I gave it to him and said "This needs fixing go and do it". Because it took him two days, it was not good, or so he thought. But he fixed it."

Four assumed that the brain injured person knew about physical difficulties because they were obvious and somebody else had explained them to them:

"The first thing he remembers, he thought that he was in hospital because he had had an asthma attack. That is what he thought he was in hospital for. Then when we spoke to him afterwards we realised that somebody in the hospital had told him that he had had an accident and that he was going to be disabled for the rest of his life. And he seemed to accept it, you know, he does not remember much. He remembers quite a lot about his childhood and everything but there seems to be a blank about eighteen months before his accident and about a year after his accident. So he is missing two and a half years of his life. I think that a psychologist at the hospital explained everything to him. We never had to talk about it, we thought that it was obvious."

Five significant others thought that it was better not to talk about physical difficulties so as not to make the brain injured person focus on them and that it was better to listen and encourage the brain injured person:

"We don't talk about it very much because I feel that if we talk about it he focuses on it too much, I don't know whether that is right or wrong".
"He manages most things and he does it without complaining. He is not very amenable to having advice given. I suppose his difficulties are not that great that I had to say "Why don't you do it this way or that way?". He picks up the kettle with his right hand, and sometimes with his left hand and does a peculiar movement to compensate for his right hand and I say "why don't you use that hand?" and he says because it is easier with this one, so I try to encourage him to use that hand."

One significant other was afraid of the consequences of talking about the physical difficulties:

"He asks me the reasons of his failures but he does not always like the answers that I give him and he gets very nasty and angry. If I am frank he gets nasty and thinks that we don't want to help him so we have to be careful and tell him that we are supporting him but if he does not see immediate results he gives up. He is hard. We guide him and when he does not want to do something, he does not do it."

Another significant other thought that it was better not to talk about physical difficulties but to treat those with a bit of humour.

Three significant others talked about cognitive complaints in terms of brain injury with the brain injured person when these inquired into their cognitive difficulties:

"Well, I keep going over things really. We have got a white board in the sitting room and another one by the bed, with a list of things, its got about five questions that he asks over and over again with their answers. I have printed those on paper so that I can put it in the car and other places so that he can go over them, but basically I just tell him what happened, briefly. If he goes into "where was I?" and that sort of thing, I do tell him. We spend most sort of time having the same conversation."

However, thirteen significant others did not explain cognitive difficulties to the brain injured person in terms of brain injury. One mother and one son felt that the brain injured person did not wanted to talk about their cognitive difficulties:

"Well, I say to him "Hey, this shows that your memory is improving" and he will often say "can we not talk about this please?". He does not like me talking about it. I think he is thinking about it so much himself that he does not want to have anyone to
confirm it, and yet I am not confirming it, I am trying to look ahead. It's possible that he is thinking that if no one talks about it, it does not exist, I am not sure."

One wife did not talk about cognitive difficulties because she was afraid the brain injured person would focus on these too much:

_We don't talk about it very much because I feel that if we talk about it he would focus on it too much._

Five significant others felt that there was no need to explain cognitive difficulties but giving things to do to the brain injured person minimised these difficulties:

_"She does not really ask. We just say, you know, try and concentrate, read that again, would you stop talking. She will do it for a few minutes and then she is bored, we try to tell her to do things instead of explaining, we try hard most of the time and then we give up."_

Three significant others assumed that the brain injured person knew their cognitive difficulties because someone else had told them about them:

_"I don't explain, the medical personnel, the doctors, have explained what is going on, she has by and large accepted that, I left it to the professionals."_

A wife and a father felt that it was better to listen and only talk about positive things in the life of the brain injured person:

_"By talking about all the positive things that are in his life. There is no point in talking about negatives."_

Four significant others explained to the brain injured individual that the emotional difficulties experienced were a consequence of the brain injury:

_"I just say that he has been very ill and I go through the business of explaining what happened and tell him how lucky we are to have him. I tell him that he is getting better. I try to be optimistic about this getting better, but realistic when he asks about getting his memory back, I say, well, it will get better than what it is now, it won't get back to what it was."_
However, fourteen significant others did not explain emotional difficulties in terms of the brain injury. Two mothers preferred to tell their brain injured sons what to do instead of reasoning:

"I say 'Come on snap out of it'" 

Four significant others thought that it was better not to mention the subject so as to help self-acceptance:

"No, I feel is best to let him get on with his life as he is now, not to keep thinking back and try and tell him what he was like. I think that that is unfair to A. because he has got to accept life as it is now, not what it was like sort of twelve years ago."

Three thought that it was better to listen and not say anything:

"I don't, I just listen. If I know he wants to argue I leave and I go up to my room. In the past, a strategy that he has used is to go out for a walk."

Three significant others did not mention the subject because they assumed the brain injured person knew about the emotional difficulties:

"I think she knows because when she gets into a mood I tell her to go away and come back when she is different and that really winds her up. She calls me everything and then the following day is all calm. Sometimes I go out and come home, you know, and go out to get the newspapers and she is OK but when I come back she is in a mood, something has happened."

One husband who did not mention explaining about emotional difficulties explained that employing a different strategy, like using humour to refer to difficulties, was a better way to deal with problems:

"There are changes, she has put on weight, significantly, and she does not like it and we have a quiet chuckle about that. Medication has a bearing on it. She is remarkably cheerful which you have to appreciate, but that is due to the fact that she is taking an anti-depressant. This anti-depressant is being reduced, slowly, whereas it was a tablet a day, now is a tablet every other day."
and one wife found that trying to explain emotional difficulties in the past had not been successful but a change of subject was a better strategy:

"It is very difficult. I used to put his arm round and try to make it better, talking to him but now I just change the subject and I find that is easier. Get his mind thinking of something else."

5.3.3. Part Two - Summary and Discussion

- Significant others reported having observed cognitive and behavioural changes, alongside character changes, changes in social life and loss of motivation in the brain injured individuals they supported.

- Most significant others thought that their brain injured friends or relatives understood the nature of their difficulties and their implications. A minority of significant others, however, reported unawareness of difficulties and lack of understanding of the implications of these difficulties based on the unrealistic expectations observed in the brain injured, their lack of memory, the invisibility of the difficulties and lack of communication.

- Overall, significant others made more complaints about cognitive and emotional difficulties in the brain injured individuals they supported than those brain injured individuals made about these two areas of difficulty.

- Only a minority of significant others had tried to explain the difficulties and implications to the brain injured. Overall, significant others actively avoided approaching these subjects.

In general, and in contrast with the results of Part One, the results of Part Two of the study were very much in accordance with past literature on the outcome of brain injury (Prigatano, 1999). Significant others reported cognitive and behavioural changes, alongside character changes, changes in social life and loss of motivation in brain injured individuals. A minority of significant others reported unawareness of difficulties and lack of understanding of the implications of the difficulties that follow a brain injury in their brain injured relatives or friends. Most significant others, instead, expressed the view that their brain injured relatives or friends seemed to show an understanding of their brain injury related difficulties and of the implications that these difficulties posed for their everyday lives. An observed tendency to become
more reflective or self-centred was also expressed. However, when comparisons were carried out across both studies it was found that significant others reported more complaints about brain injury, physical difficulties and cognitive and emotional difficulties, in that order, than the brain injured people they supported did. This is also consistent with previous work in the field (Santos, Castro-Caldas and Sousa, 1998).

Thus, and although the correspondence found between the accounts in Part One and Two of the study provides some evidence for the importance of communication in awareness of difficulties following a brain injury, the disparity of accounts does not. This disparity of complaints could support on one hand the hypothesis of denial of difficulties by people with brain injuries. On the other hand however, it could point to a lack of communication between significant other and patient about these particular difficulties due to a variety of reasons. These reasons could be enumerated as follows: 1) information is not given by significant others so as not to discourage the rehabilitation attempts of people with brain injuries; 2) memory problems in people with brain injuries, in some cases, means that patients forget information when given; and 3) significant others lack of information about cognitive and emotional difficulties that can follow a brain injury. In addition, "invisible" difficulties like cognitive and emotional difficulties, due precisely to their invisibility could be judged by some significant others as difficult to understand and therefore, they avoid talking about them.

Further, and although reasons one and two were found in Part Two of the study, no significant other complained about lack of information about difficulties that could follow a brain injury or lack of understanding of such difficulties. On the contrary, the accounts of some significant others implied knowledge and implied understanding of cognitive and emotional difficulties, and believed them too difficult for people with brain injuries to understand.

However, the findings that are more relevant to this study are those related to explanations of difficulties and implications given by significant others to people with brain injuries. Overall, significant others did not try to explain brain injury related difficulties and implications to the patients in their everyday interactions. This was
observed across all physical, cognitive and emotional reported difficulties. Significant others who reported physical difficulties experienced by the patient gave a number of reasons as to why they did not explain these difficulties. Significant others thought that: when it came to physical difficulties it was better to keep the person occupied and active instead of talking; that talking about physical difficulties would just bring the difficulties into focus for the patient; that not talking about difficulties would be interpreted as a sign of encouragement and support by the patient. In addition, some assumed that the patients knew about these difficulties because they were too obvious and others were afraid of the negative reactions explanations would have in the patient. Significant others who did not explain about cognitive difficulties and implications explained that: it was better to explain only if asked; some assumed that the brain injured person did not want to talk about difficulties; that talk would make the patient think about these difficulties; that it was better to talk about positive things only and others assumed that the brain injured person knew about cognitive difficulties because someone else had told them about them. Emotional difficulties were not explained either because significant others thought that it was better to keep the brain injured person occupied instead of talking; silence was seen as a help to self-acceptance and that listening was considered better than talking. Significant others felt that explanations would upset the brain injured person, diminishing the problem was better than talking about it and some assumed that the brain injured person already knew about the emotional difficulties experienced. Lack of communication seems to be due, then, to two reasons: the visibility of physical difficulties and the active avoidance of the subject or subjects.

Visibility of physical difficulties is analogous to the adage "A picture is worth a thousand words". The finding that significant others avoid explaining physical difficulties because these are obvious comes as no surprise. The phenomena of people with a brain injury knowing about and focusing on physical difficulties has been assumed clinically and in the literature to arise from the obvious. That is, physical difficulties are hard to deny, being visible and demonstrably present (when they exist), and that such difficulties are arguably more acceptable to the patient. In addition, the neuropsychological literature offers plenty of evidence in support of the idea that
awareness of physical difficulties is the first awareness that develops in the patient following the trauma of brain injury (Fleming and Strong, 1999; Prigatano, 1999).

However, social psychological research into active avoidance of communication has shown that when adverse events occur in life, family and friends rally to restore a person's self-esteem by focusing on the positive qualities of the person or situation (Taylor and Brown, 1988, 1994). The link between physical difficulties (including changes to the body) following brain injury and self-esteem has been empirically demonstrated by Keppel and Crowe (2000). In a study with stroke patients, the authors indicated that self-reported body image was associated with significant reductions in all measures of self-esteem. Significant others in this study, using perhaps what could be called "common psychology" chose to avoid talking to people with brain injuries about physical difficulties. This silence, in some cases, was supposed to be interpreted by the brain injured person as a sign of encouragement and support. The implication being that normative social interaction, or in this case the lack of it, would encourage if not positive self-evaluations, at least realistic ones.

Similarly, studies on communicating negative information (Tesser and Rosen, 1975; Todd and Shearn, 1997; Finlay and Lyons, 1999) indicate some reasons for avoiding this sort of communication. These are that the role relationship between the people communicating counts at the time of transmitting negative information, that the content of the communication can be considered unimportant, that communicating negative information is unnecessary, that the information may upset the recipient of the news and that communicating negative information may not be practical for the everyday dealing with difficulties. Four of these reasons correspond to the reasons given in this study. Significant others thought that communicating positive information was more important than negative. In some cases, significant others tried to diminish the importance of the communication. In other cases, significant others thought that the brain injured person would get upset if difficulties and implications were talked about and in addition, some significant others felt that it was another person's responsibility to tell the brain injured individual about these matters. Furthermore, Tesser and Rosen (1975) also explained that denial on the part of the recipient, that the communicator would be evaluated negatively and that it would
cause the communicator to experience negative feelings, could count as reasons for actively avoiding communicating negative information. Of these further reasons, only one of them applies to this study. That is, significant others assumed that people with brain injuries would not want to talk about brain injury difficulties and their implications.

Nevertheless, this study found additional explanations for actively avoiding giving negative information. First, some significant others reasoned that giving explanations would only make the brain injured person focus on his or her difficulties. This reason can be interpreted as trying to keep the person away from the self and it offers support for Duval and Wicklund's (1972) theory of objective self awareness. Duval and Wicklund (1972) argued that contact with the ideas of others would serve as a stimulus that would cause objective self awareness (objective because the self is considered an object for these authors) as far as these ideas are different to the ones held by the self. Second, some significant others thought that keeping the brain injured person active was preferable to giving explanations. This reason, keeping the brain injured person active, offers support for the idea of "imposition". Imposition is a form of behaviour outlined by Kitwood in 1998 in what the author called "malignant social psychology". This malignant social psychology is described as an assault on the person's feelings of self worth, leading to the person being depersonalised. Imposition is then conceptualised in this context as the forcing of the person to do something without allowing choice on the person's part. Imposition, Kitwood explains is not intentional but rather, an innocent consequence of the often daunting and exhausting task of caregivers. The quotes below are examples of how significant others practise imposition:

"I tell him to go and walk around so his legs will get some exercise."

"I just tell him to get off his backside. Sometimes I tell him that something needs doing and he looks at me and says "I can't do it yet". I want the bathroom decorated and things like that. After his stroke I wanted my bedroom decorated, so to make him do something I emptied the room and started. I made him do it but he is a perfectionist. It is not how he likes it done, because I went on painting above him..."
and below him and he came behind me to do it all. But because he is a perfectionist if he cannot do it properly he won't try. He gets into his head that he cannot do it and he does not bother to do it. My daughter's hair dryer broke down and she said "Oh Dad will fix it" he used to fix things like that so I gave it to him and said "This needs fixing go and do it". Because it took him two days, it was not good, or so he thought. But he fixed it.

"My approach is entirely different, it is more "for God sake K, get on and do it". I am quite nasty to him some times, because he comes to see me once a week, but the next week he'll come and thank me. It makes me so mad, I mean, there was a time when we got him to cook himself a meal once a week. Since he has been ill he has had meals on wheels but they don't come anymore. So we said, OK, why don't you cook something for yourself and he will say: "Oh, I don't know if I can" and I said, "you can if you plan it". For several weeks he did it but one day he came and said that he had not cooked and that the social worker had said that if he didn't feel like it he shouldn't do it. It made me so mad. I used to walk him on Saturdays but that has stopped also."

Third, another reason given by significant others for not explaining difficulties and implications is that it is better to wait for requests for information. This reason supports Goffman's (1955) idea that negative evaluations are only given when directly solicited, and then, if they are solicited it is because negative self-evaluations have already been carried out. In other words, the brain injured person would have needed to have carried out some sort of self-evaluation before approaching the significant other for information. By implication, if self-evaluatory mechanisms are not in working order or used or only positive self-evaluations are made, the brain injured person will not request further information and an impasse may be reached with the significant other which would prolong ignorance of difficulties and the implications of these difficulties.

Finally, the assumption that significant others had about others having already given explanations about difficulties to the brain injured victims needs a closer look. More concretely, significant others assumed that hospital and rehabilitation staff had already
dealt with explanations. This result adds to the finding (Tesser and Rosen, 1975) that the role relationship between the two relevant people is inappropriate. That is, significant others felt that it was not up to them to provide this sort of information. However, this "buck passing" can be better understood if the level of complexity that explaining about brain injury would require is taken into consideration. Although not one participant in this study complained about lack of information on brain injury research into this area shows that this is a common problem. Swift and Wilson (2001) investigating the lack of knowledge and misconceptions concerning brain injury among the general public found that the public not only held inaccurate and inadequate knowledge about brain injury but inaccurate beliefs about recovery time and extent of recovery, lack of awareness of the problems it can cause, misconceptions about the capabilities of the brain injured person and misidentification of the brain injured person as mentally ill or learning disabled.

The findings in this study add to a body of research that shows that people tend to inhibit direct communication of all types to others (Blumberg, 1972). The findings do not, however, explain the salience of knowledge of some difficulties that follow a brain injury and their implications; which were demonstrated by the brain injured individuals in the first part of the study. A variety of factors may have contributed then to the latter findings. For example, the fact that all the participants in this study were appointed by the people with brain injuries as significant others may correspond to what Swann (1987) calls self-verification. This concept suggests that people select others for interaction if these others are perceived as supporting one's views of the self.

In addition, and from a social constructivist perspective, the self is dependent on the concepts available in a culture to construe a person (Harré, 1987b). Within a culture, there is a variety of perspectives on social actors and phenomena. That is, within the "culture" of brain injury there is a variety of perspectives ranging from the medical profession talking about brain injury, to families affected by brain injury, to rehabilitation staff, to the general public, to the views expressed by carers at day care centres. These perspectives would help construe the knowledge of people with brain injuries. If, out of all these perspectives, people with brain injuries are in regular
contact with one or two (the social network of people with brain injuries is usually reduced to family and rehabilitation staff, (Zencius and Wesolowski, 1999)), these may serve not to construe but to maintain the level of knowledge acquired while in contact with medical staff and during more professional settings (i.e. during hospitalization). Empirical research points to the fact that people tend to remember what speakers with perceived high status say more than what speakers with perceived low status say (Holtgraves, Srull, and Socall, 1989). The salience of the difficulties experienced by the brain injured person found in the first part of the study needs to be seen, then, as the product of social interaction with perceived higher status significant others (memory permitting) and maintained by significant others, of varying degree of perceived level of status, by actively avoiding contravening these ideas. This would explain the finding in this study (and previous others (Santos, Castro-Caldas and Sousa, 1998)) of significant others observing more cognitive and emotional difficulties than their brain injured relatives or friends. If people with brain injuries have been instructed on difficulties by health professionals, usually following a biomedical model which focuses only on the body and because the physical difficulties are most salient in the early stages after the trauma, then the more invisible psychological difficulties that can follow a brain injury would remain obscured and therefore, less well acknowledged by the patient. Further research into the ways health professionals communicate with people with brain injuries will be conducted in Study Three of this thesis. The study will attempt to establish the role these professionals play in awareness of difficulties following a brain injury. In the meantime, Study Two will address directly how people with brain injuries come to know about their difficulties.
6.1. INTRODUCTION

Part One of the first study of this thesis examined the salience of the brain injury and the difficulties that follow the brain injury in the narratives of people with brain injuries. It was seen in the study that most participants referred equally to their brain injuries and to their physical difficulties. Cognitive difficulties and emotional difficulties were referred to in second and third place respectively. The results also indicated that although some participants understood the limitations imposed by their difficulties most participants did not. In Part Two of the same study, most significant others showed reluctance to give information to people with brain injuries. This was in view of the physicality of some of the difficulties and in favour of protecting the person they supported and as a caring practice.

The low salience of cognitive and emotional difficulties found in the accounts of people with brain injuries was explained in terms of lack of communication that was received from significant others in Study One. Thus, and as illustrated in the review of the literature, if the major source of self-knowledge is the coming into contact with the ideas of others and people with brain injuries vary in the extent to which they receive, attend to, understand, interpret or remember the information provided by others, then it is clear that some will not have this source of input into their self-knowledge. This is a possible explanation for the low salience of cognitive and emotional difficulties.
However, the low salience of cognitive and emotional difficulties together with the indication that some participants did not seem to understand the limitations imposed by these difficulties would support another interpretation. These results could be evidence of denial. That is, participants were aware of these difficulties and the implications of these difficulties and these then had been evaluated negatively for the self. Hence, during the interviews, people with brain injuries avoided describing their difficulties and only used these descriptions when talking about the reaction of others and the situations they were in. This interpretation is difficult to contradict because, by definition, it refers to mechanisms that are hidden. Therefore, it could be applied to any situation whereby participants had not shown any concern for their difficulties or traumatic events occurring in their lives. In addition, the interpretation of denial would require the assumption that people with brain injuries were consistent with this strategy since it would have to be assumed that people with brain injuries both recognise the importance of their difficulties and their implications and avoid acknowledgement of them, across the physical, cognitive and emotional contexts.

This consistency nevertheless was lacking throughout the interviews with these participants. More evidence is then necessary to support the explanation that the low salience of cognitive and emotional difficulties in the narratives of people with brain injuries is due to other reasons rather than motivated denial. Therefore, a second study was carried out to clarify how people with brain injuries gained knowledge of their difficulties, and to find out how they constructed these experiences. This study explored how information relating to the brain injury and subsequent difficulties was given and when and whether this information was remembered or known by people with brain injuries. This distinction is an important one to make since memory has been found to be an essential component in awareness (Chapter Three). To propose this distinction however, requires explaining the relationship between knowledge and remembering. It was described in the review of the literature (Chapter Three) that individual representations of the self are articulated and differentiated in memory. It was seen then that cognitive science has classified these representations in memory into two types of knowledge: semantic personal knowledge and episodic personal knowledge (Tulving, 1989). Semantic personal knowledge refers to information that has been abstracted from memories of the self in specific events (Tulving, 1989).
Semantic personal knowledge of traits may include the facts that a person is generous, active, unable or lazy. Episodic personal knowledge refers to memories of specific events involving the self (Tulving, 1989). Episodic personal knowledge of traits includes those instances in which behaviour was generous, active, unable or lazy.

It was also seen that empirical evidence has examined the relationship between these two kinds of trait knowledge about the self. Research has consistently supported the view that in the field of trait knowledge, semantic personal memory and episodic personal memory are functionally independent. In other words, functionality of semantic personal memory does not require the functionality of episodic personal memory (Kihlstrom and Klein, 1994). Klein, Loftus and Plog (1992) for example, utilised the concept of transfer-appropriate processing in a study of recognition memory traits to show that different processes are involved in accessing the two types of memory. Klein, Loftus and Burton (1989) applied the principle of encoding variability in a study of recall for traits and found that the type of information made available by accessing semantic personal memory was different from that made available by accessing episodic personal memory.

Thus, the remember-knowing distinction is of particular relevance to this study. The distinction may help underline that an individual may have knowledge of difficulties following a brain injury without having the memories from which to infer that knowledge. As already illustrated, in a study carried out by Levine, Black, Cabeza, Sinden, Mcintosh, Toth, Tulving and Stuss (1998) the authors found that remembering episodes from one's personal past is not possible in the absence of awareness of one's self. Using the remembering-knowing paradigm on a brain injured participant, the authors found that the participant's behaviour was driven by generic information about how he should behave, rather than by the goals and intentions that could arise from his own identity. Furthermore, Cermak and O'Connor (1983) reported the case of another patient with amnesia who spontaneously provided what initially appeared to be descriptions of memories but which, on further investigation, turned out to be well-established narratives that the patient was in the habit of relating during social conversations. Thus, knowing about difficulties may indicate that some
people with brain injuries may have learned to "narrate" their difficulties without really understanding them.

This study was carried out in order to clarify the extent to which people with brain injuries participating in the research knew about their difficulties and the implications of these when asked explicitly. This is important when it comes to understanding the relationship between self-knowledge and others. Study One investigated the references made to their difficulties in descriptions of the self and the social environment without participants being prompted to describe their difficulties. Whilst providing evidence of the salience of their difficulties, it did not actually investigate whether participants would refer to their problems when asked about them. In terms of denial, this is important to know. If this is the case it will provide additional evidence for the interpretation that difficulties are not salient for other reasons than motivated denial, since the extent brain injured participants talk about their difficulties will be related to the relationship between representations of the self, communication and memory-knowledge.

6.2. METHOD

6.2.1. Participants
All the participants of the first part of study one (N=30) were invited to take part in this study a year after the first interviews. Of the original participants, two had died and four had moved away. Twenty four people with brain injuries, 7 females and 17 males (age range 19 to 62), attending two day care centres agreed to participate in this study.

6.2.2. Ethical considerations
The research ethics committee of the University of Surrey reviewed the proposal for the study. In this study, data were collected from participants who had sustained a brain injury. The interview procedure was explained carefully to the participants. Participants were assured that their participation was voluntary and that they could end the interview session at any time. Follow-up contact did not suggest that participants had been adversely affected by the procedures.
6.2.3. Procedure

Participants were interviewed at the day care centres and interviews lasted between twenty minutes and half an hour. At the beginning of the interview, participants were asked to sign forms of consent as to their agreement to the participation in the research. The interview consisted of a semi-structured interview and the answers were recorded and transcribed verbatim.

Each interview inquired about the precise difficulties mentioned by the participants in the first interview, i.e. if the participants had mention, memory problems or mood swings, the researcher focused the questions on these specific difficulties in this interview.

The interview schedule (see Appendix 3) was designed to cover a defined spread of topics:

- **Emergence of knowledge** - In order to elicit information to establish a time progression from injury to realisation of difficulties, questions addressed knowledge of physical, cognitive and emotional difficulties during hospitalisation, rehabilitation and reintegration into the community (i.e. whether the patients knew what was happening to them physically/cognitively/emotionally while in hospital/rehabilitation/home). To elicit information as to how this realisation came about, questions addressed pre-morbid knowledge of brain injury and brain injury difficulties which may have helped recognition of difficulties (did the participants know brain injury victims prior to their own brain injury?). Questions also addressed the way in which the patients realised their difficulties (i.e. was it through own observation, were they told about them), which situations made their difficulties more obvious, their reaction to this knowledge and their actual situation (i.e. did they think that they knew about all their difficulties at the time of questioning?).

- **Role of the other in emergence of knowledge** - In order to inquire about the role of the other in increasing awareness of difficulties and implications of these difficulties, questions addressed who gave information to the participants about physical, cognitive and emotional difficulties, who explained to the victim the possible implications of having had a brain injury and what he/she could do to help these
difficulties. Participants were also asked with whom they discussed their difficulties on a daily basis (i.e. with whom do you talk about the difficulties you have in your daily life?).

- **Remember/knowing paradigm** - The remember/ knowing distinction was introduced in the interview by explaining to each participant such distinction. The researcher asked each participant to remember an important event in his/her life and invited him/her to describe it. Similarly, the researcher asked the participants a general knowledge question (i.e. what is the capital of France?) and invited a response. Once the distinction was clear to the participants the researcher inquired about their particular problems in relation to remembering or knowing (i.e. whether the participant could remember or knew about difficulties following the brain injury and whether this distinction had always been the same since the time of the injury). In addition, the participants were asked to explained how the brain injury had occurred or been diagnosed and were asked if they could remember or knew about the event.

### 6.2.4. Analysis

Data from the interviews were analysed following the steps of the interpretative phenomenological analysis (IPA) method prescribed by Smith, Jarman and Osborn (1999; also Smith, Flowers and Osborn, 1997) and with the help of the qualitative research computer program NVIVO. Transcripts were analysed for recurrent themes. Themes emerged within individual interviews and across different interviews. The process of identifying themes involves several steps. Each transcript was read a number of times. Consequently, the analysis of each transcript began with initial thoughts, possible codes and anything of particular interest being highlighted. These were then coded with a key word or phrase that captured, broadly, the essence of the content. These represented emergent themes. The process was repeated for each of the transcripts. Following this, repetitions of these recurrent themes between the transcripts were taken to represent shared understandings. Each theme was then selected for more intensive analysis. This involved going back to the transcripts for further examination. First, all the transcripts were examined to identify all the extracts pertaining to each theme and make sure that text previously not selected was included. The next stages of analysis were all directed to determine what exactly
constituted the shared aspects of the participants' experience in relation to each theme. This involved looking at the extracts for each theme and re-coding them. Once this coding scheme had been created, each extract was then re-labelled. The next stage was to group the extracts according to these new coding categories. These categories were then used to explore patterns and relationships within and between the conceptual groups, thinking how different themes come together to help understand the participants' experiences.

6.2.5. Results

Although the participants in this study varied in background, characteristics of brain injury and present life situations, they articulated several common themes in their accounts of their past and present experiences. Three main themes were found to be relevant for understanding participants' sense of self: finding the bits of the puzzle, filling the holes in memory and redefining the self.

Finding the bits of the puzzle

The expression "finding the bits of the puzzle" is used here as a metaphor to help describe the virtual detective work that participants had to undertake in order to put a picture together. This picture is one of a traumatic event, the brain injury, and the challenges that participants had to face because of having had a brain injury.

The progressive character of knowing about the difficulties one can experience following a brain injury was a theme common to all the participants. Participants, when asked about their recovery process most mentioned becoming aware about some of their difficulties. Joel said when talking about his time in rehabilitation, "I was beginning to realise then that I had something wrong with my memory". To refer to this realisation of difficulties participants often used terms associated with discovery. Tony, for example, used the phrase, "I have discovered that I have these problems, I have discovered them because of the amount of trouble they are causing me". Thus knowing about one's difficulties following a brain injury was for participants in this study like trying to fit "discovered" bits of a puzzle together.
The progression was experienced in different stages. The stages can be easily compartmentalised as the knowledge acquired in hospital, during rehabilitation and knowledge acquired during their return home to the present day. During their time in hospital, the majority of participants explained that they did not know what was happening to them. A few awoke after coma or operations to observe physical difficulties, some suspected that there was something wrong with their memory and a few found themselves being more aggressive than they thought usual for them. When participants talked about this time spent in hospital, they described themselves as being trusting. For example, Miriam accepted treatment without quite understanding why she needed it:

One day at the hospital I asked for a pillow and they said no, that I had to lay flat. Then B came and saw me and told me that I was dead in all my left side. Then the physio came up and gave me exercises. So I thought, "well, I must be dead in one side if I am doing these exercises" so I did them.

Miriam accepted the treatment because she assumed that the experts would help her "to get better".

This trust seemed to decline as participants explained their experiences during rehabilitation. At this stage, most participants explained that they knew about their physical difficulties, some about their cognitive difficulties and some about their emotional difficulties. Trusting was still a characteristic of participants that did not know about their difficulties at this point:

I did not know what was happening, therapist kept trying to move my legs and so on but I did not know why.

But it declined for participants that had some knowledge of what was happening to them:

Yes, because I always asked people why I was doing what I was doing.

On their return home, trusting had changed into an effort to get things back to pre-injury days or to try to become independent. A typical example was found in Tom's account:
after working with my Dad, we decided that I would go and work on my own. My Dad was not making enough money to keep us both. I looked in the paper and found a job in the garden centre. I applied there and I got the job then left and found the job I got now.

Thus, getting things back to normal or attaining independence was the goal to which participants aspired. The equivalent of having completed the puzzle.

Searching for bits. In the early stages of the brain injury, most participants did not know what was happening to them. They found themselves with no memory of what had happened to them and/or where they were and why. At this stage, all the participants relied heavily on the information received from others. A member of their family told some participants about what had happened to them:

No, when I came round after three months I asked my wife what was I doing in the hospital. She told me that I had been involved in a car accident and that I was going to be moved to another hospital.

Medical staff told others:

It was described to me by my consultant as pouring acid on the foam. You can imagine what that does, it dissolves it away, the foam.

Both, medical and family members told two participants. A minority was not told they had had a brain injury at all. Tom stated, "I was not told that I had a brain injury at all".

In these early stages, learning about physical difficulties that were likely to follow their brain injuries meant relying on the information received by others. Some participants recalled learning about their physical difficulties from their families:

I guess that it happened when I realised that I spoke with a slur and I was limping.

In fact, it was my family who told me I was doing both.

Others received the information from their doctors:
After a few months, the reality hit me and talking to the doctors, they told me that there was no cure, that I was going to be a vegetable.

In some cases, the information was received from both families and medical team. Information about cognitive difficulties, on the other hand, was received at later stages, usually during rehabilitation, and was imparted in a few cases by a member of the medical team, a family member or staff at the rehabilitation centres. However, this information was not always communicated directly to the patient. Amy said:

someone told me not to drive anymore so I knew I had some sort of cognitive problem.

In other occasions, the medical team had communicated the information to the family and thus the family was left in charge of passing on this information:

The doctor told my husband and my husband told me.

Some participants received no information about the cognitive difficulties that could follow a brain injury. In a few cases, the information was generalised, leaving the patients to draw their own conclusions:

No one really but a speech therapist that was trying to get me to talk properly mentioned that I would probably forget things because people that had accidents often had memory problems. She did not say memory problems were a consequence of brain injury, she said people who had been involved in accidents.

This lack of information was more obvious when participants were asked about their emotional difficulties. Most participants did not know that emotional difficulties could be experienced after a brain injury. Members of their families told a few participants who experienced emotional difficulties about those on their return home:

At home I was really nasty to my mum but I did not know until my mum died and my sister told me that mum was terrified of me.

These explanations, in general, may have sounded reasonable to the participants but they were more readily accepted when they came from medical staff.
Because he was a specialist and I thought "I got to do what they say because they know what is all this about". He was a neurologist so he must have all the qualification and gone to college and everything. So I had to believe him.

Information received from the family was attended to but cultural perceptions and fear of hidden motivations influenced the degree to which it was accepted. For example, Doug when talking about his wife said, "I can't always do as she says because in a marriage it is the man that is in charge", while John explained: being my wife, I find that I can't readily accept what she says because she is my wife and she has something to work for and something to work towards. A medical person has a different approach. They are not working for the same reason, for the same purpose. The medical people are experts. She is working to the same end but from another angle not necessarily with the same understanding and all the rest of it.

Searching for more bits. Incomplete information meant for the participants that they continued to look for more detailed information. Some participants found that their familiarity with brain injury helped them to recognise the difficulties observed in somebody else in their own cases. These participants were familiar with brain injury because their pre-injury jobs involved dealing with people with brain injuries or because a member of their family had suffered a brain injury or because they had academically studied the physiology of the brain: I was surprised but because I had studied neurophysiology at length, I understood what had happened.

The obviousness of the visible injuries was another clue that help participants gained knowledge of their difficulties: To me the broken bones was all there was anyway. The broken bones were an obvious side, but I couldn't see anything else.

When the obviousness of the physical difficulties was not enough, external objects served as point of references for acquiring knowledge of their difficulties:
I discovered that my leg was shorter because of the shoes I had to wear. They were shoes with heels and I didn't like them but for a long time I didn't think that my leg was shorter. Now I wear boots. I want to be like everybody else.

These external objects aided the acquisition of knowledge for the less visible difficulties too:

The last year that I can remember in any way at all is 1997 and in my diary, it says that the year now is 2001. I am puzzled by this. I feel my memory up till 1997 is the same as everybody else's.

However, activity was the biggest clue to acquisition of knowledge pointed at by most participants. For some participants undertaking an activity was an attempt to going back to normal life:

When I went back to work, I noticed that I couldn't concentrate on anything for long. Certain aspects like memory and concentration were suffering. At home, it was the same; I could not pick up where I left. I was forgetting things.

For other participants, activity was a situation they found themselves in, out of their control:

I was discharged home and the hospital knew that I lived alone and had no one to care for me. They still sent me home, so I supposed it was as soon as I got home. Then I saw that I was not much good at doing anything.

Social situations offered also an opportunity for realisation of difficulties. Tony said:

In social situations, when I am about to go out to meet people, as I say the social situations. I find myself asking questions from people that I should not ask and I know that I should not ask them. I am impulsive, I don't think before I open my mouth. I got a bad curiosity and want to know private things from people. I don't know why I do it. I know is wrong but I am still doing it. I want to know how much people earn, their sexual habits, their horoscope. Some people get very, very annoyed with me when I start asking the questions, especially if they don't know that I have a brain injury.
Thus, putting the picture of their brain injuries and the challenges they had to face, together involved bits of information given by medical and family members. When this information was found wanting participants found other bits of information in their everyday lives. The time spent in hospital, and in some cases the duration of the coma, provided the frame to this puzzle. Participants used this information to evaluate the gravity of their conditions:

*During three months, I was out for the count. For three months, I did not know what had hit me, was that bad.*

**Filling the holes of life.**

The "holes of life" was an expression that one of the participants used to refer to the blanks in her memory. Memory loss or difficulties with memory is one of the most common consequences of brain injury (McCarthy and Hodges, 1995). Although this memory loss usually affects short-term memory or/and long term memory, the term here was used by the participants in an autobiographical sense and to describe difficulties with short-term memory.

All the participants in this study obtained some knowledge about their injuries and difficulties. Information received in the early stages of brain injury however, was used to fill the memory loss created by the brain injury. This information could not be contrasted with the happenings in memory to verify the information because for most participants the memory was not there:

*I don't remember what happen to me, but my mum told that I had had an accident. I was in the back sit of a car and the driver went round the corner too fast. I was clobbered; big time, smashed up totally. This is what I have been told anyway.*

However, these participants were able to give coherent accounts of what had happened to them. Thus, the stories and hearsay that was given to them by families and medical staff had filled the hole left in memory by the injury. They had found some missing bits of the incomplete puzzle.

Similarly, when information about the difficulties that were likely to be experienced after the brain injury was given to the participants, blanks in knowledge seemed to be
filled. Barry said, "I was in no condition to remember or understand what was being said to me. It was like if they were telling me a fairy story, I would not have been able to dissociate the story from the truth". However, this filling in the blanks with information led the participants to know what was happening to them but to no real understanding of what was being explained to them:

I had to stay in hospital for tests. Yes, but I did not understand what they were saying, it had no meaning for me. The doctor told me what was wrong with me but I did not understand what it meant. I did not know why I was walking weirdly. I had no idea.

Acquiring knowledge in this way made participants believe that they knew about some of their difficulties in the early stages of the injury. Blanks of knowledge were filled with names of conditions that did not exist in their everyday language. Peter explained, "those problems I can't understand, they don't exist in my vocabulary". While for others it meant that they could recall their difficulties with no memory of them:

I know I have a memory problem but I can't remember it.

The process of learning about their difficulties was one that was considered by most participants as incomplete. These participants did not feel that they had managed to put all the bits of the puzzle together. Some participants felt at the time of the interview that they knew about of their difficulties and could put a name to them. Most participants however felt that the blanks were not filled and were a major obstacle in the continuity of their self while making them feel insecure in their everyday actions. Colin said, "the whole picture is not there, only parts of it stay".

Redefining the self

Although most participants learned the names of their conditions and had filled some holes in memory during the recovery process, many, at the time of interview, felt that this knowledge was not enough for understanding their present self. Most participants knew that their present situations could be explained by their brain injuries, by causal relations with the brain injury. Some participants made use of this knowledge in different ways. A few did not refer to or refused to use such knowledge.
Attributing behaviour to the brain injury. Some participants in this study explained some behaviour as a result of their brain injury. These explanations were usually given when relating incidents about a behaviour that was not intended. Then, the causal relationship appeared as a disruption between intention and action by creating an outside agent that participants felt they could not control. This agent was talked about as something they could not understand.

For instance, Tony mentioned various times that his brain injury accounted for difficulties in his life. He stated that the unnatural curiosity he experienced hindered his reintegration into society:

*I have discovered that I have these problems, I have discovered them because of the amount of trouble they are causing me with my friends. I seem to upset everybody and anybody.*

He thought that these difficulties were beyond his control. To overcome them he relied on outside help. He said, "some people get very, very annoyed with me when I start asking the questions, especially if they don't know that I have a brain injury. My friends have to explain to people that I have a brain injury so they will understand".

Here, Tony explains his inadequacy with his brain injury but the assistance of his "friends" relieves him from blame for annoying people.

Similarly, other participants believed that their brain injuries were the main cause of their difficulties in life. However, this belief led them to recognise that something they could not understand was controlling their behaviour. Sarah said, "I do ask intimate questions to people but I do not know why I do it, it is like my brain is ahead of me".

This, in turn, made it hard for these participants to assert themselves:

*I know I am uninhibited too because my mum tells me. I have no choice but to accept what my mum tells me. Why no choice? I can't argue with my mum.*

From the preceding example it can be seen that when people with a brain injury believed that their behaviour may be caused by their brain injury, they cannot be totally confident in their control over their own behaviour. Other people are perceived then as having better judgement than they have.
Not attributing behaviour to the brain injury. Not all the participants in this study explained their behaviour as a result of their brain injuries. Some participants explained their behaviour in terms of specific difficulties as opposed to general brain injury. These explanations were given to describe loss of skill or management of memory loss. The example below illustrates the point:

_I had cognitive problems but I was not thinking that they were so because of the stroke. I didn't know that they were the consequence of the stroke._

What do you do about them now?

_I live with them, for my memory, I use a diary and I try to be very organised. I follow a set routine and I try to stick to it._

A few of these participants, and as seen in the example above, pointed out that the causal relationship between their specific difficulties and the brain injury had been unknown to them for some time. The causal relationship had then been either discovered, "when I got the booklets I was telling you about before I was able to make the connection" or explained to them by staff at the day centre they attended. Two participants described not being able to remember their difficulties.

Some participants thought that the brain injury could not be used as an excuse for the difficulties they experienced. Adrian, for example, said when talking about being told of his physical difficulties, 'Whatever I wanted to do, I would do. There isn't such a word in the English dictionary as "I can't"'. Adrian seemed to have regarded the causal explanation as a feeble excuse to avoid the difficulties he had to face.

Other participants thought that ignorance was more to blame for not accepting the causal relationship as a more self-evident fact. Tom explained,

_Nobody, ever, actually sat me down and talked to me at all about brain damage._

_What happens is, and this is my impression anyway, they try to get you to act normal or what is supposed to be normal. Without explaining, when you come out from the hospital and just make your way back to what is supposed to be normal without telling you: "You are doing this and this is why you are doing this". They tell you to stop doing things but do not tell you why. They are not saying why you are doing it, they just say "Stop it" and not giving a reason._
Tom implies here that leaving people with brain injuries in ignorance is a tool that society uses to control people afflicted by these injuries. However, while this may be true it discounts the possibility that something, the outside agent mentioned above, maybe responsible for his behaviour. Thus, when participants chose not to explain their difficulties in terms of the brain injury, the cause of mistakes and inadequacies was attributed: a) to personal characteristics and/or b) specific difficulties which, although were not perceived to be connected to the brain injury to begin with, had come to be understood as a consequence of their brain injuries. In two cases however, memory impairments did not allow participants to remember this information and/or understanding.

Furthermore, causal relationships showed how participants made sense of their self in the present. Participants' narratives, in some cases, suggested ways on how the self was protected during earlier stages of the recovery process. Gaining knowledge of difficulties meant the realisation that certain abilities had been lost. This loss was perceived as a threat for the self in all cases. The perspective towards this differed among different individuals.

**Accepting but avoiding.** Some participants explained how on gaining knowledge of their difficulties they had avoided situations that would remind them of these difficulties. This avoidance was not associated with denial of their difficulties but with accepting the loss of abilities that made them look bad or feel bad, in other words, self-presentation. For example, Andrew said, "one person asked me to write things down but my writing was so messy that I didn't bother. It made me feel worse". This perspective often led the participants to seek privacy and not ask for assistance. Andrew said, "I try to sort my problems on my own". Andrew resorted to comparisons with a pre-injury self that used to believe that he was responsible for his life and actions:

*If I have a problem trying to do it on my own then I think back and realise that I used to do a lot of things on my own. It bugs me a bit.*

**Buying Time.** Other participants mentioned realising their memory problems and not communicating them in the hope that the self would be restored to its former glory.
Participants were hoping the problem would cure before any further damage to the self could be done (like, admitting it in public). For instance:

*I admitted to myself that I had a memory problem but not to anybody else. I didn't want to tell anybody because of pride. I was hoping that my brain would get itself better so that my memory problem would go away and there wouldn't be a problem any more. Of course, the new brain would not carry on as before.*

Participants who bought time for their selves accepted their difficulties and eventually sought assistance:

*I have to think to myself if I know about something about my deficits first so that I can remember them. I am not shy about asking people what is the matter with me and the neurologist told me everything.*

*Accepting and improving.* Most participants found that gaining knowledge of their difficulties, although damaging for the self, was the requirement needed for self-improvement. Paul said, "Well, I try to do what I have been told to do by the rehab staff and so on. I want to improve myself, I know perhaps I never will but I want to do as much as I can".

Thus, when participants accepted their difficulties they sought and accepted assistance to overcome their functional challenges. However, accepting difficulties was not always enough, personal characteristics influenced the meaning of this acceptance.

**6.3 DISCUSSION**

The participants' accounts in this study show that gaining knowledge of the challenges to be faced after a brain injury entails what amounts to detective work. For these participants acquiring knowledge was a process that required passive acceptance of information from others sometimes, actively seeking information from others at other times and interpreting clues from their everyday lives. Putting together these bits of information and clues was equated to putting together bits of a puzzle. How these bits were then put together was then the key to redefining the self.
Chapter Six - Study Two - The emergence of knowledge after brain injury: finding the missing pieces of the puzzle

The process to which some participants referred to as a process of "discovery" was described as a product of individual, social and physical environment. For the participants in this study the process started during the patient's stay in hospital. At this stage, the discovery of having had a brain injury seems to have come in some cases from medical staff and/or family. In other cases the information given to the patient by family, wittingly or unwittingly, did not refer to brain injury but to other causes, like having had a car crash. This explanation, which not only leaves the patient in ignorance as to the actual consequences of having had a car crash in terms of brain injury, gives the first indication to the patient that the injuries suffered are merely of a physical nature. Either way, at this stage participants described themselves as passive receptors of an information that in some cases they could hardly understand. The next stage in the process of discovery takes place during rehabilitation for the people who had undergone this phase or on their return home. During rehabilitation participants found that their knowledge of some difficulties, mainly physical, was clear to them but were beginning to inquire of rehabilitation staff about more invisible difficulties. Cognitive difficulties, and in a few cases emotional difficulties, were explained by rehabilitation staff in general terms and often left the patient to draw their own conclusions. On the patients return home armed with some information and after or while attempting to return to previous to brain injury activities, these patients begin to discover further difficulties which had not been previously envisaged or explained. These new difficulties, ranging from problems with reintegration into the family to coping with work to doing DIY, made the participants actively engage in seeking answers to questions probably better explained by the professionals that they had left behind. Instead, the questions were asked of relatives and significant others that were not entirely perceived by the brain injured as the appropriate people to answer them. Cultural prescriptions and fear of hidden motivations in the people surrounding the brain injured were the reasons behind these perceptions. In this way, the bits of the puzzle that some people with brain injuries actively come to seek are not entirely put together years after they have suffered their brain injuries.

Furthermore, this puzzle was described by the participants in this study, as incomplete at the time of the interview. Memory loss was regarded as another obstacle to
constructing the complete picture of the puzzle. When the holes experienced by memory loss were filled with explanations in the early stages of recovery, these were found to be lacking in understanding by a majority of participants. At the time of the interview however, and as seen in Part One of Study One, some names and some explanations of their conditions had been incorporated into their accounts. Nevertheless, most participants felt unsure that they really knew all about their conditions, which in terms of denial would mean that these participants could hardly deny what they did not know.

However, the expressed knowing without remembering, which according to Tulving (1985) can be interpreted as lack of awareness, indicates here that some people with brain injuries learned to express their difficulties and insecurities about those difficulties during social interaction. Indeed, if the brain injury experience occurs in a social context (hospital, family, day care centre), thoughts and forms of understanding may be appropriated from conversations and internalised in individuals' memories and emergent understandings. Tulving's (1985) model of memory suggests that there are different varieties of memory that make possible the utilisation of acquired and retained knowledge. But they differ in the kind of knowledge they handle, and in the ways in which different kinds of knowledge are used.

Tulving differentiates between three kinds of memory: procedural, semantic and episodic. Procedural memory is concerned with how things are done, semantic memory has to do with symbolically representable knowledge and episodic memory mediates the remembering of personally experienced events. The relationship between them is one of "class-inclusion hierarchy" (Tulvin, 1985, p.2) in which "procedural memory entails semantic memory as a specialised subcategory, and in which semantic memory, in turn, entails episodic memory as a specialised subcategory" (Tulvin, 1985, p.2-3). According to this model, it is impossible for an organism to posses one without the other, although, Tulving explains, they can exist independently of each other.

Empirical evidence for the independence of function between semantic memory (which reflects knowing) and episodic memory (which reflects remembering) provides
support for Tulving's experiential approach (Gardiner and Conway, 1999). Studies with Alzheimer's disease (Dalla Barba, 1997) and autistic participants (Bowler, Gardiner and Grice, 1998) not only have shown a disassociation between remembering and knowing but an association between decreased remembering and, in some cases, an increased knowing.

For the purposes of this study, some of the knowing responses encountered here seem to be in line with long term learning studies of just knowing (Conway, Gardiner, Perfect, Anderson, and Cohen, 1997). Conway et al. (1997) described a very large scale naturalistic study of changes in awareness during the acquisition of knowledge by psychology undergraduates. In their study, students answered questions featuring information that they should have acquired in a series of lectures. For each question the students were required to indicate whether they knew the answer, they could remember the answer, the answer was familiar or if they were just guessing. The results demonstrated that there is a remarkable remember-know shift in the awareness that accompanies the acquisition of knowledge. Similarly, the comments made in this study by a minority of participants point to a similar shift in the remember/knowing distinction:

"I know about them, I don't have the feel for my problems, I remember not being able to walk but now I know that I have problems with my legs."

Conway et al. (1997) explains this shifts as a reflection on the schematisation of conceptual knowledge in semantic memory. Initially gaining access to newly acquired knowledge depends largely on episodic memory, but with repeat encounters knowledge becomes more abstract, more schematised, and gaining access to it no longer involves remembering specific learning episodes. The role of episodic memory is to facilitate conceptual learning. Superior episodic memory results in a greater ability to remember. Poor episodic memory makes this more difficult but not impossible. Tulvin, Hayman and Macdonald, (1991), demonstrated that conceptual learning was possible with amnesia patients. Thus, the accounts of the majority of participants in this study that expressed just knowing about their brain injuries and their difficulties seem congruent with learning without awareness clinical theories. That is, if the participants' injuries account for impairment to episodic memory, thus
not being able to remember the event and the experience of difficulties, semantic memory would still allow the individual to learn about the event and subsequent difficulties. Repetition of narratives in contextual social interactions would facilitate this learning and encoding in semantic memory.

Nevertheless, learning about one's own difficulties or filling in the holes in memory and acting according to this information are two different things. Understanding the implications of the participants discovered difficulties entailed a redefinition of the self. Redefining the self was described by these participants as a combination of behaviours that participants could not control, physical difficulties, loss of skills and what was remembered or not.

On the one hand, participants described behaviours in terms of their brain injuries. However, this attribution was only used to explain some behaviours that were not intended and judged by others as unacceptable. Participants created then an outside agent, something participants could not understand and could not control. On the other hand, when the narratives of participants did not explain behaviour as a result of their brain injury, behaviours were then explained in terms of specific difficulties or personal characteristics. In these instances, difficulties which had come to be seen by participants as consequences of the brain injury or difficulties not attributed to the brain injury were used to describe loss of skills that participants were striving to manage. In a few cases however, memory impairments did not allow participants to remember this information and/or understanding. Furthermore, these difficulties referred mainly to cognitive difficulties or physical difficulties while behaviour explained in terms of the brain injury described emotional/behavioural difficulties.

Thus, the finding that specific difficulties were not always connected to the brain injury helps explain why in Part One of Study One some participants talked about their difficulties as independent of their brain injuries. Participants may have known about the causal relationship existing between difficulty-brain injury at the time of the first interviews. However, participants may have been used to refer to their difficulties, for practical purposes, as independent of their brain injuries. Time until the "discovery" of the connection could mean that participants had incorporated in
their narrative references to their specific difficulties without having to refer to the brain injury. The difference here is then dialectical not attributional. Moreover, and although this finding may be considered evidence towards learning about difficulties without awareness of those difficulties, it leaves other questions unanswered. For example, it does not explain why some behaviours were explained in terms of brain injury and therefore, out of the control of participants, and not others. Arguably, the way these difficulties are addressed by professionals in the social environment of people with brain injuries may influence these perceptions. This possibility will be explored further in Study Three.

Moreover, despite the frustrations of dealing with this combination of uncontrolled behaviour, loss of skill, memory loss and in some cases, physical difficulties, most participants indicated that they strove to maintain a positive attitude towards their difficulties. Overall, most participants maintained a realistic attitude about the future (i.e. attending the centre, using strategies for their memory loss, undertaking physiotherapy). Some researchers have identified the role that positive thinking plays in helping patients cope with their brain injuries (Herbert and Powell, 1989; Malia, Torode and Powell, 1993).

While adapting to a new normal, participants struggled with desires/wants and physiological requirements by accepting their difficulties. In brain injury, and whilst the trauma is not a degenerative disorder, recovery or some recovery of function is possible. Participants dealt with their difficulties by implementing strategies, dissipating own false beliefs about their difficulties (i.e. my memory loss is going to cure) and reframing these difficulties within as normal a life context as possible. This tendency to engage in a normalising process was continually balanced against the negative experiences consequent upon the brain injury. Or in other words, the completion of the puzzle.

Implications for rehabilitation

The implications of both accounts concerning the acquisition of knowledge and redefining the self, for rehabilitation practice will be discussed below.
Chapter Six - Study Two - The emergence of knowledge after brain injury: finding the missing pieces of the puzzle

Constructing the puzzle during rehabilitation. Although the literature on brain injury often reports loss of sense of self as a consequence of brain injury, there was very little in the accounts of the participants in this study that could be described as loss of self. On the contrary, efforts to contribute to a continuity of the self and self presentation were observed. However, the continuity of the self was obstructed by memory loss. This memory loss represented blanks in autobiographical memory and difficulties with short-term memory or the inability to learn and retain new information.

Rehabilitation professionals need to consider this loss. More specifically, loss of certain memory function does not automatically mean loss of self. Therefore, professionals should open up their scope of interventions for memory changes accompanying brain injury. This could be achieved in three different ways. First, professionals could avoid thinking of memory dysfunction as yet another disorder of brain injury. Instead, they could centre on its practical aspect for treatment. According to Meltzer (1983) and in agreement with the participant’s accounts in this study, problems with short-term memory cause uncertainty in the self. Rehabilitation professionals may not be able to solve these problems but they can help fill in the "holes". Rehabilitation professionals can provide detailed information, repetitive information and help prioritise the importance of remembering certain things over others.

Second, rehabilitation professionals need to consider enlisting the help of families in the use of these strategies. Rehabilitation professionals and family members, together and separately, could play a role in putting together the person's puzzle.

Third, reconstructing memories may not be the sole aim of rehabilitation but supporting clients in creating new memories may be another aim during rehabilitation. Many people with a brain injury may feel anxiety relating to memory loss during the early stages of recovery. This anxiety may interfere with the rehabilitation process itself. Alleviating this anxiety may help with the recovery process.
Redefining the self after the brain injury. Accepting the challenges that a brain injury brings may be a first step towards using causal relationships between difficulties and the brain injury. Using these causal relationships is useful for the self-understanding of the brain injured person and it protects their self-esteem. However, by explaining their mistakes and inadequacies in this way the brain injured person is positioning him/herself as helpless. The brain injury dominates the self and therefore, the brain injured person sheds responsibility for the consequences of the brain injury.

According to Shotter (1984), and in more general terms, accounts that explain deviant behaviour (i.e. dishinbition) are important in social interactions if the accounts are to be acceptable as strategies for protecting self-esteem. If the accounts are accepted, Shotter argues, the person causing the deviant behaviour is then accepted in society. Nevertheless, and according to Sabat (2001), what these people are also doing is positioning themselves within the dynamics of social interaction. In other words, by explaining their mistakes and inadequacies as causal relationships with the brain injury, they are situating themselves in roles that make their actions intelligible and relatively determinate as social acts. Such roles can lead to not only explanations of behaviour consistent with the persons positioning, but also to the development of expectations about and the interpretation of the person's subsequent behaviour.

For instance, and for rehabilitation purposes, if professionals position the brain injured as being dysfunctional, it is more likely that in future situations in which a variety of explanations of behaviour are possible, professionals will opt for the explanation based on the initial positioning. However, if the positioning is initially carried out by the person him/herself, professionals may consider helping the individual to use this positioning to his or her advantage. This could be done by teaching people with brain injuries to use causal relationships when engaging in social situations. For example, if a client needs over the telephone services, the client can be taught to communicate difficulties with, say, information processing, and ask the receiver to speak at a slow pace. Similarly, if the explanations of behaviour of people with brain injuries put too much emphasis on the individual, rehabilitation professionals may help these individuals to re-position themselves. Attribution literature often remarks on the negative consequences of attributing life difficulties to personal characteristics. Thus,
helping the individual to attribute unfavourable situations to something one can change may help empower the individual.

6.4. REFLECTION

In this study, a small sample of people with brain injuries was studied by entering and participating in a natural setting, the day centre. The researcher, myself, was well known to these individuals as a caregiver. The data was obtained using semi-structured interviews which resembled conversations. However, the method of IPA requires that the researcher acknowledge possible bias and attributions that could have influenced the investigation.

The interviews in this study were design by me to tap ideas about brain injury and subsequent difficulties. What was reported and analysed in the study was what people with brain injuries said to me and these narratives formed, in the end, the focus of the investigation. And yet, to focus on these narratives alone would miss out on the fact that the narratives emerged from relationships situated in time and place.

During the interviews, the fact that I was a healthy, non-brain injured individual, talking to people with brain injuries made me feel like I was putting my participants in a restricted situation. That is, the scope they had to talk about their difficulties felt narrow as they could tell me about behaviours and capacities more effectively in other ways. For example, they could show me their work at the centre they attended or I could observe their behaviours during their time at the centre. Effectively, I felt that I was putting my participants in a situation where they had to present themselves to me as healthy as possible or in other words, as non-brain injured as possible.

However, what perhaps affected the study the most was the emotional labour of the interviews. Emotional labour is a type of work that involves feelings and can be contrasted with physical or task-orientated labour (Phillips, 1996). It involves the management of feelings while undertaking a job or task. In this study, the task of interviewing my participants included what I would say was a fair amount of emotional labour. This study required that I interview people with brain injuries with
whom I had worked as a carer, who had participated in my research previously and with whom I had developed a working experience. Therefore, by the time these second interviews came round I could say that I knew my participants relatively well. Managing feelings during these interview situations then involved two actions from me: managing risks for participants and managing my own emotions.

The emotional risks of participants during research is now a widely recognised issue (Lee, 1993) and in this instance, it required of me to adhere to ethical guidelines more strictly during this part of the research. For example, because of my previous experience in the first round of interviews I was more vigilant in anticipating problems and more ready to render appropriate support. If a participant broke down during the interview, I offered rest breaks, suggested therapeutic intervention when available or I arranged for appropriate referrals. At the end of each interview I debriefed my participants as carefully as I could and made sure that they understood the role they played as co-researchers in the investigation. On the whole, there were no major problems during the interviews but my efforts to be as professional as possible were perceived in many cases as more extensive that indeed they were. By this, I mean that a good number of my participants thought me capable of discussing brain injury issues and to be in possession of counselling skills. Empathy at the end of the day was the only thing that I could offer and to remark that my presence at the centre was due to the research of which they, themselves were co-authors. This reminder not only had an immediate positive effect on the participants but later when I went back to talk about the investigation with them, they commented how beneficial participation in the research had been for them. However, their conversations had the potential, and indeed did, arouse various emotions in me.

Managing my own emotions was the second action that I had to undertake during this part of the research. While listening to people with brain injuries, some of the negative and powerful feelings (like anger) and moods displayed by the participants were occasionally transferred on to me. I found that my participants did pass their depressions on to me on a great number of occasions. This, in turn, could have had an effect on my approach to transcribing and the analysis of their data. Similarly, there were some interviews, which I undertook with a sense of disgust towards the person
participating in the research. I experienced these feelings only on a few occasions and mainly towards participants well known in the centre for their disinhibitions or rudeness. In either case, the interviews were spent trying to hide my feelings as well as trying to appear professional which I think resulted in me showing less interest for the person and therefore perhaps, in poorer data. Alternatively, most times during or after interviews I felt a great impulse to help the participants in this investigation. Most times, there was a struggle for me between doing research and helping these individuals. The outcome of the struggle, more often than not, was the realisation that I could do both at the same time by completing my work. The idea may have driven the research towards presenting my participants in a more positive light than perhaps they were. Overall, awareness of these difficulties meant that there was an attempt to engage in what is call bracketing (Giorgi, 1985) of these feelings and biases. In addition, I put all my efforts into ensuring that the emerging themes and interpretations were grounded in and supported by the data.
CHAPTER SEVEN

STUDY THREE - THE OTHER IN AWARENESS OF BRAIN INJURY: NON-EXPERT HEALTH PROFESSIONALS TALKING TO PEOPLE WITH BRAIN INJURIES

7.1. INTRODUCTION

The first study of this thesis offered some explanations for the low salience of cognitive and emotional difficulties found in the accounts of people with brain injuries. These explanations were given in terms of the visibility of complaints, lack of communication between significant others and people with brain injuries in favour of protecting the person they supported and as a caring practice. The second study, compared the acquisition of knowledge about difficulties by people with brain injuries to a process of discovery and explained this process as a product of actor, social and physical environment. Furthermore, participants described understanding the implications of their difficulties as struggle between what they could control, what they could not control and what they could remember or not. However, and as discussed in Chapter Three, self-knowledge is socially constructed and therefore it is important to extend the search for explanations of self-knowledge in people's social environment. The aim of this study is then to investigate how information referring to sequelae of brain injury (cognitive and emotional in particular) is communicated to people with brain injuries by non-expert health professionals (i.e. day care centre workers).

As illustrated in Chapter Three, the development of the self depends partly on the views of others. The ways these views are transmitted, received, interpreted and acted upon have been discussed in relation to their importance to the development of awareness of difficulties following a brain injury in the mentioned chapter. However,
Chapter Seven - Study Three - The other in awareness of brain injury: non-expert health professionals talking to people with brain injuries

it is important to remind the reader here of two points. First, the way information is interpreted has been seen to depend, to some extent, on the importance given to a speaker. Second, how relevant the information is made to be by the person receiving it is also a factor in the interpretation of information from others (Garcia, Metthe, Paradis and Joanette, 2001). Conversation has been discussed as a collaborative process, usually between two people, whose target is to identify and respond to each other's intentions (Grice, 1975). To uncover this target, however, inferential processes must be at work in order to get at the true message and only then can relevant contributions be made. When communication lacks coherence, as in many cases after neurological impairment, the responsibility for determining relevance lies entirely on the healthy conversational partner (Garcia, et al., 2001). This may happen when "the partner with a neurological impairment is unable to identify the healthy speaker's intentions due to an incapacity to use contextual information" (Garcia, et al., 2001, p.18).

Further, identifying the speaker's intention is only one step. Judgements about the relevance of the content of the conversation must be made in order for a conversation to take place. Garcia, et al (2001) point out that the collection of such information depends on certain cognitive capacities, like attention and memory, which may not be entirely intact in certain populations with brain damage. When this happens, the healthy conversational partner may need to compensate for the speaker with the neurological impairment so that relevance may predominate. However, Sperber and Wilson (1986) propose that a speaker is interested in communicating only what the hearer needs to know to make the speaker's message relevant. And, according to Sanders (1983), what is relevant depends entirely on the hearer's ability and willingness to infer or invent a reason for the speaker's having made the statement.

However, interaction goals are only one example of factors that condition attention to one class of information rather than another. Factors that affect information in interpersonal encounters are also important, as emphasised in Chapter Three. Interaction context, which may be defined by such things as the power relationship existing between interactants or by the presence in the interaction of a particular category of persons, may play a role in regulating social interaction. For instance,
Kleck, Ono and Hastorf (1966), in an experimental situation, engaged participants in a brief interaction with a person who was physically handicapped, or they met a person who showed no sign of physical difficulty. It was found that participants ended the interaction more quickly when they were interacting with the handicapped person than when they were interacting with the non-handicapped person. Similarly, Farina, Allen and Saul (1966) gave participants a task to work on with a person they were led to believe was mentally ill or with a person about whom no such information was presented. The researchers found that participants talked less and initiated less conversation and expressed opinions less representative of their beliefs when they worked on the task with the supposedly mentally ill than did participants who worked on the task with the person who was not labelled mentally ill. More recently, Mwaria (1990) in a study of families of the severely brain injured reported that such patients found themselves in socially ambiguous and isolated positions due to the lack of cultural guidelines that dictate how to interact with these patients. Mwaria observed that medical caretakers and family members were often uncertain as to how to respond in the presence of these patients.

Finally, another factor that has been seen as influencing the communication between people with brain injuries and others is the content of this communication. Despite the prevalence of brain injury, it is a common complaint from victims of brain injury, their carers and professionals who work with people with brain injuries, that there is a lack of understanding of the problems of brain injury both amongst members of the general public and health professionals with no experience in this area. Research investigating misconceptions concerning brain injury amongst the general public and non-expert health professionals has revealed that inaccurate and inadequate knowledge about brain injury is common amid the general public and amongst health professionals without expertise in the field of brain injury (Swift and Wilson, 2001). Hux, Walker and Sanger (1996) examined the readiness of 494 school based speech language pathologists to provide services to students with traumatic brain injury. The survey responses provided evidence that school based speech language pathologists hold many misconceptions concerning traumatic brain injury and its consequences.
Hence, the study reported here examined the extent to which the explanations given by non-expert health professionals to people with brain injuries in their care, can contribute to explaining the struggle that coming to terms with difficulties represents for the patients. The term non-expert health professionals refers to health professionals who do not have specialist knowledge (i.e. academic or clinical) about brain injury but whose practice brings them into contact directly with people with brain injuries on a day to day basis. The material constitutes vital information for rehabilitation practice in the context of contemporary community-based services.

7.2. METHOD

7.2.1. Participants
Five individuals took part in one interview each. Participants were selected on the basis of having professional experience of brain injury (traumatic and/or non traumatic). Four were managers of three day care centres for people with brain injuries. The other was a deputy manager in one of the centres. Four were parental caregivers to people with brain injuries. The professionals all worked on a day to day basis with people with brain injuries, providing day care assistance and support for families and carers. The participants were aged between 40-70 years. Four were female and one male.

7.2.2. Procedure
Participants were contacted in the first instance by telephone, and a date for a face to face interview was arranged at their convenience at the day care centres or homes. Each participant was interviewed separately and audio-recorded. The length of the interviews varied from 30-45 minutes. Each interview consisted of both semi-structured questions and the presentation of vignettes.

The schedule (see Appendix 4) consisted of two sections, one concerning the experience of the non-expert health professionals with people with brain injuries facing cognitive difficulties, and the other addressing the experiences of non-expert health professionals with people with brain injuries facing emotional difficulties. Experiences of non-expert health professionals with people with brain injuries facing
physical difficulties were not addressed in this study. This type of difficulty is usually the first that people with brain injuries become aware of (Fleming, 1996) and it is not considered a problem by the time people with a brain injury attend day-care centres.

Two vignettes followed by semi-structured follow up questions were also used to elicit focused responses from participants. Vignettes or scenarios are descriptive sketches of incidents presented to participants to elicit opinions and reactions to their contents (Schoenberg & Ravdal, 2000). When carefully constructed, these simulate real life experiences. After participants have been read the stories, they are asked to respond to a few directed questions to involve them further in creating meaning.

In this study, the vignettes (see Appendixes 5 and 6) used were hypothetical and concerned fictitious others. Such depersonalization is considered advantageous in studies of social phenomena (Wolfson, Handfield-Jones, Cranley Glass, McClaran, & Keyserling, 1993) as removing personal disclosure may ease difficulty or embarrassment. For the purposes of this study, Vignette 1 introduced a brain injured person with memory difficulties. In Vignette 2 a story of a brain injured person with emotional difficulties was presented. Both Vignettes represented examples of lack of insight and were developed by the researcher, who drew from her own experiential and academic background to create context-sensitive, realistic scenarios. In addition to consulting existing literature, this background included long periods of voluntary work with people with brain injuries, leading to familiarity with the life circumstances of the brain injured, their carers and non-expert health professionals. This familiarity extended also to language, kinship patterns and relevant medical conditions. The vignettes were pre-tested on adults, colleagues of the researcher, for clarity, accuracy and relevance.

7.2.3. Analysis

All the interviews were transcribed and subjected to Interpretative Phenomenological Analysis (IPA) to identify recurrent themes. Central to IPA is an attempt to understand the content and complexity of beliefs and constructs being explained or suggested by participants, to investigate the meaning to the participants of the phenomenon in question. Themes emerge within individual interviews and across
different interviews. The process of identifying themes involves several steps. Each transcript was read a number of times. Consequently, the analysis of each transcript began, with initial thoughts, possible codes and anything of particular interest being highlighted. These were then coded with a key word or phrase which captured, broadly, the essence of the content. These represented emergent themes. The process was repeated for each of the transcripts. Following this, repetitions of these recurrent themes between the transcripts were taken to represent shared understandings. Each theme was then selected for more intensive analysis. This involved going back to the transcripts for further examination. First, all the transcripts were examined to identify all the extracts pertaining to each theme and to make sure that text previously not selected was included. The next stages of analysis were all directed to determine what exactly constituted the shared aspects of the participants' experience in relation to each theme. This involved looking at the extracts for each theme and re-coding them. Once this coding scheme had been created, each extract was then re-labelled. The next stage was to group the extracts according to these new coding categories. These categories were then used to explore patterns and relationships within and between the conceptual groups, thinking how different themes come together to help understand the participants' experiences.

7.2.4. Results
The findings in this study centre on three interrelated themes. The first theme, a lay theory of awareness of difficulties, refers to the experience of observing difficulties in people with brain injuries time and time again. The second theme, addressing cognitive difficulties and normality refers to how non-expert health professionals help people with brain injuries with cognitive difficulties and the perceived normality by people with brain injuries of emotional difficulties. Finally, the third theme, limiting progress, refers to factors that hinder the rehabilitation efforts of people with brain injuries.

A lay theory of awareness of difficulties
The first theme relating to commonality of experiences of difficulties draws on the observation that awareness of cognitive and emotional difficulties in people with brain injuries, or the lack of it, was a common occurrence for the participants. Most
participants observed that it was not a matter of knowledge about difficulties that created problems for people with brain injuries. Lack of knowledge and something more, like depth of knowledge, was problematic. That is, knowing about difficulties was not considered enough to come to terms with the challenges people with brain injuries had to face following their injuries. Most participants called this lack of knowledge and something more, insight or awareness or feeling. Ana commented:

*I actually, personally, don't think that there are many head injured people who actually have insight into their deficits, physical, emotional or mental or whatever, but I don't think that they have, and I am not a medical person so I don't understand why but I think they lose the finer edge on the understanding and the recognition of their disabilities.*

The observation was also made that insight or awareness could have different levels, and in the case of people with brain injuries, some of these levels may not be there. Again, Ana said:

*Well, awareness is knowing but awareness has many levels and head injured people have not got the finer edge of awareness. The depth is not there to emotionally hold on to that.*

This lack of depth was considered a natural protection for people with brain injuries by these participants, something that stops people with brain injuries from really knowing the bleak reality of their situations. Ana explained:

*I think if someone has, if you took one of our members, if you and I thought that we were going to be in that position, we would be totally devastated. I haven't come across a head injured person who is as devastated as, or not many who are as devastated, as you and I would be in our normal minds. I think that mother nature takes care and doesn't make them totally aware of their problem. It is a protection.*

However, this protection acted differently according to the nature of the injuries sustained by the individuals. Some participants had observed that traumatic brain injuries (i.e. injuries to the brain caused by accidents) showed less 'insight' than acquired brain injuries (i.e. injuries to the brain caused by tumours, strokes or Alzheimer's). Ana said:
I think we are talking about traumatic brain injury? Because acquired brain injury is totally different. People with acquired brain injury have much more insight, I think it takes traumatic brain injury to lose the insight. Most of the traumatics, they can verbalise what they have lost and they can say, you know my life is shit because I am not the same person I was. But the emotional bit isn't the same with the acquired.

You can actually pick out which ones are the acquireds and which ones are the traumatics. The acquired, if they know about what is happening to them they get emotional. The difference is very subtle but I can pick them out. The traumatics get emotional too but, they don't go on about it. They can verbalise it, but the intense emotional bit isn't there. After a brain injury, the traumatics cry as quick as possible, they get cross as quick as possible and they bring back all the emotions but the edge isn't there. If you look at our members, the traumatics, P., A., M., and P. and then you look at C., C. just whinges all the time. The traumatics just want to get back into the world, the others just want to sit around and moan. They don't help themselves. There are exceptions obviously. The acquired are totally different to the traumatic and I am not medically trained or anything like that but I can pick them out. In fact, I can even pick out the focal damaged ones to the diffuse ones. It was years before I could recognise that but there is a vast difference.

This protection was found to change by most participants with the passing of time. That is, lack of insight could be ameliorated with the passing of time. As Tom explained "I think that insight can be developed over a period of time with certain people. With an increasing insight the chances of coming to terms with the situation increase and therefore, able to plan a new life".

The biggest variability of lack of insight was found to be among the two most common difficulties, cognitive difficulties and emotional difficulties. Most participants observed that for people with brain injuries not to know about cognitive difficulties was fairly common. Not knowing about emotional difficulties seems to affect most people with brain injuries. This will be discussed below:

Cognitive difficulties. Most participants in this study found that by the time people with brain injuries attended the day care centre most individuals were "half way" to
knowing their cognitive problems. Zoe explained, "Those that come here to the centre are sort of almost half way to acknowledging the fact that there is a problem that we can help them with and try and improve things". Other people with brain injuries knew or suspected their difficulties at the time of admittance, but did not want this knowledge confirmed. Zoe remarked, "Some of them have some knowledge, probably, some deep down do, but do not want it confirmed". Other people with brain injuries were found by the participants to deny any involvement with the brain injury. Tom explained when talking about two members of the day care centre:

_They regard themselves as volunteers at our centre, they do not see themselves as head injured at all. They are there to help other head injured people and they consider themselves to be volunteers. For us it is part of their rehab because they do actually help other people. They don't take on responsibilities as many of the other volunteers._

Uncertainty of knowledge was also observed by the participants in some people with brain injuries. Zoe said:

_For some, I think that they are wavering, sort of not sure whether there is a problem or not. If they see someone else and they can actually see in that person problems that they have been experiencing, I think that sort of helps them recognise the fact and acknowledge it._

Other participants pointed to external factors, like severity of injury, as influencing the level of knowledge people with brain injuries have about their cognitive difficulties. Severity of injury means that memory problems sustained as a consequence of the brain injury do not allow the individual to retain knowledge. Zoe said about one of the centre's members:

_I think that his memory problems are so severe that, I genuinely think that he can't remember that he has got this problem. Which is why he needs to ask people frequently and which is why we try to get him to use his diary to reflect back and he has got photographs in there. I genuinely feel is not lack of insight, his memory is so severely damaged he can't remember that he has got a memory problem._
Living at home or living alone was also pointed at by some participants as influencing the level of knowledge people with brain injuries had of their cognitive difficulties. Zoe compared:

Some of them are less aware because if they don't have to do a lot of planning and organising in their lives, particularly those that, I think, particularly those that have gone back home and are living with parents and the parents continue to organise their lives, but not being unkind about it, but they think they are helping but they take over that role. They don't let the individual do it so, therefore, the individual himself does not have to worry about, you know, getting the washing and ironing done, making sure that they keep appointments on time, planning what they are going to have for dinner, making sure they have budget skills, you know. They do not have to do that; it has been taken over by the carers or the family. That is where there are problems sometimes because they cannot see that they have a problem, because they never have the chance to see it in a practical sense. I think that, I am trying to think of those that live independently, whether they are more aware of their problems that they have. Because they live independently, they have to face them. It is probably too general and there is no sort of research to say that someone that lives independently actually has greater awareness.

Thus, the knowledge that people with brain injuries had about their cognitive difficulties was perceived as being influenced by internal and external factors. However, for two participants in this study it did not mean that people with brain injuries even when aware of their cognitive difficulties, could understand them. That is, two participants thought that people with brain injuries were only verbalising their difficulties. Ana said, "It is the same as with physical deficits, they can verbalise them but no, they do not understand about them". Nevertheless, knowing about cognitive difficulties was regarded by all the participants as an advantage at the time of working with and developing strategies with people with brain injuries. For them it meant that the brain injured individual could progress further in rehabilitation. Zoe said, "For some of them the confirmation is good, because they think, "well, I am not going mad after all, yes it is a problem and it comes from my head injury and I can work on it". In other instances, knowing about cognitive difficulties was a first step to emotional reactions like depression and loss of motivation. Continued attendance at the centre,
however, meant for the participants that people with brain injuries had perhaps other reasons for attending. Ana said, "they may know, they maybe able to verbalise what problems they may have but don't do anything about them. They come here to socialise".

*Emotional difficulties.* All the participants in the study thought that most people with brain injuries had but did not know about their emotional difficulties. However, all participants observed that these difficulties were not considered a problem by people with brain injuries because, for them, it was their normal behaviour not a consequence of the brain injury. Tom commented:

*I can think of a hundred and one examples of such behaviour but I don't think they see it as a consequence of their brain damage, it is just normal to them.*

*Addressing cognitive difficulties and normality.*

Most participants observed that they could discern which people with brain injuries possessed knowledge of their difficulties because people with brain injuries talked about these difficulties. Participants when referring to talking about difficulties of the brain injured referred to cognitive difficulties. Emotional difficulties, participants remarked, tended to manifest behaviourally.

Cognitive difficulties were discussed with people with brain injuries members of the day care centres. These difficulties focused mainly on memory loss. Participants remarked that they were able to explore more difficulties once the brain injured individual had started to talk about them. Zoe commented:

*Some of them will come out right and say "I have got problems with this, this and that" and that makes it so much easier in the very beginning. You can start working on it straight away. Others are, may come and may not be able to tell that the memory is not that brilliant or they may be aware that the memory is not brilliant and perhaps they have already started to use a strategy without realising it and it is only when it is pointed out to them that the reason why they are using that is because they can't remember something.*
Exploring more cognitive difficulties experienced by people with brain injuries involved inference work from these conversations. Memory loss is only one disorder in cognitive functioning. The term itself, memory loss or memory problem, is commonly found in vocabularies. Other cognitive disorders, however, are not so well known and people with brain injuries can describe difficulties without using the terminology. As Zoe explained:

I can get a lot of information when they say "I forget" or "I can't think of what I need to use" or "I need to use a list to go shopping". They phrase things and I pick them up and also I may ask them about leisure activities and I can get so much from talking in a relaxed atmosphere just talking about their daily activities. They will not say "Oh, yes, I have problems with processing information" they will say "I can't work out that bus time table" and they will give you examples of what they are not able to do. I have not known, apart from the terminology of memory and concentration, they do not use words like processing information. What I tend to do is, I explain to them what it means, because sometimes with certain exercises they are given certain information and they have to formulate a response, whatever that is and you know, I try to explain that processing information is the speed. But they are not used to the terminology, they will say they have trouble with their memory and they will say that they cannot concentrate but will not say that they have got "poor planning skills". They use different terminology to recognise the problems other than memory.

Similarly, inferring difficulties from listening and conversing with people with brain injuries helped some participants empower brain injured individuals. That is, while talking to the brain injured, participants felt that the information received came directly from people with brain injuries, not via parties such as doctors, rehabilitation staff or family. When the participants needed to explore further the difficulties experienced by people with brain injuries they let this information guide their work:

What I always try to do is pull out what they have said and if they have been able to give a situation as well and just recount it back to them. I find that works because instead of me just saying "right, you have got problems with this or that" if I say "you told me that you had problems with this" I can put it into a more practical situation. If they have given me that situation and then explain that what we aim to
do is work with them in that area. I always try to use what they have said, it works better, unless they have memory problems, where they can't remember what they have said.

Communicating difficulties in this area was thus subtle and discreet. Tom said, "I would tell them but it would have to be done very carefully indeed. You can give little directional bits that would help them to achieve maximum recovery and you have to pick the time and the right person to do it."

Dealing with emotional difficulties required another perspective from the participants. As mentioned above, participants felt that people with brain injuries did not find emotional difficulties to be problematic. Their experience pointed to the normalcy of the behaviour for the brain injured. Participants felt that because of this, people with brain injuries, on the whole, did not talk about these difficulties. Not talking made it difficult to assess if brain injured people knew about these difficulties. Some participants felt that they knew. Lisa said, "some of them do know, others I don't think so" and what they did not know was that they had lost control of their behaviour. "On the whole I don't think that they know that they can't control themselves". Some participants remarked on the use people with brain injuries made of emotional difficulties to get attention. Lisa said, "I think some play on it, they rather like to be shocking, to get attention".

With emotional difficulties all participants felt that the only way to deal with them was through confrontation. Zoe explained why:

With behavioural problems we must make them aware of the fact that what they are doing is inappropriate. The thing is, if you namby-pamby around and try to be subtle with them, they don't get it, they don't understand. No point in being subtle with someone. You have to actually say to them: "OK, you've disinhibition" and they will probably answer "Oh I like to have a shag". But you have to tell them, you have to say "That, what you have just said to me is very inappropriate and I feel that you should not say that, here to me and you should not say it to other people, you would not normally say that to anybody if you had not had your head injury. I don't want you saying that". I actually try to tell them straight away.
This way of dealing with emotional difficulties was seen by the participants as appropriate and as a duty to the individual. Participants felt that if they did not act in this way there would be no one who would let the brain injured person know that their behaviour is inappropriate and thus, with untimely consequences for the self:

*If they have this type of behaviour they become isolated, because other people don't know about it, are embarrassed by it, don't know how to deal with it, don't know where the behaviour is coming from. So the person with the head injury who exhibits this type of behaviour can become isolated.*

Thus, communication plays an important part in how cognitive and emotional difficulties are dealt with by these participants. Most importantly, the way this communication takes place points to participants actually seeing these two challenges as different. Cognitive difficulties were accepted by participants as consequences of brain injury and therefore, organic in their aetiology and out of the control of people with brain injuries. People with brain injuries then required external sources of help: *With cognitive problems, they need professional help and helping themselves at the same time. And then some do and some don't. They need supporting.*

Emotional difficulties were also understood as consequences of brain injury but these were viewed as being more of a psychological nature and therefore, under the control of people with brain injuries. For instance, Lisa commented after giving a set of behavioural guidelines to the members of the centre: *It is up to them, whether they want to do anything about them. Many of them do not think about it, it is not important to them.*

**Limiting progress**

Caring has been described as an interpersonal process that connects those who care and those cared for (Jeon & Madjar, 1998). Thus the efforts of those caring for people with brain injuries are characterised by trying to see the person behind the injury. In this study, seeing people with brain injuries as individuals not only included the relation between the care givers and the cared for, it also involved the relation between the cared for and the world. All participants remarked on the role of the
family in limiting the progress made by their brain injured relatives. Zoe describes the experience:

*I think the family find it difficult because for some of them, particularly those with youngsters, you know, those in their twenties, that they have come back to live at home because of their head injury, the family sees them as their little boy or their little girl. We do not see them like that, we can stand back and see them as a twenty year old man with a head injury. It is very difficult. I have one family I have great difficulty with because they expect to know everything that happens here with their son. And although I am happy to work with the individual and help him with his diary, it is very difficult, the family can be very unhelpful.*

For these participants, therefore, the family of the brain injured was more often a hindrance to their efforts than a help. While participants saw themselves as promoters of progress, the family members were seen as protectors of the individuals. Ana said, "I think it is so to the point that relatives for example, stop the progress of the patient. The families tend to do things to protect them". Other reasons were also given for limiting the progress of the individual. One was lack of information within the family: *Dealing with the family is problematic because they often feel sorry for the brain injured patient, they are nervous about telling them what is right and what is wrong, that certain things are socially inappropriate. They do not recognise that most of the time they have to deal with someone that often has childlike reactions and that they have to re-educate the person.*

Another is the family's erroneous assumptions, as Ana, talking about her experiences with her own son explained, "In my case, when my son had his, it did not enter my head to tell him what he had. How did he know that he had a brain injury then? I assumed that he did know."

Medical professionals were also seen as partly responsible for limiting the progress of people with brain injuries. Ana said, "I blame the medical profession because they do not train the families to deal with the brain injury. They should inform the families to the best of their abilities and if they do not know how, they should give proper training. It's a major problem". One participant also explained that doctors were
responsible for misleading the family and people with brain injuries with overdiagnosis. Tom commented:

*The doctors are unable to explain to the relatives just what is going to happen in the future and my experience is that they are often much more pessimistic that they need be. Some give out too much hope but a lot of them, just say that the patient is going to be a cabbage or will never walk again and so on. And if you survive, the recovery is usually better than expected.*

Two participants expressed feelings of anger and frustration in relation to the general public. Ana said, "you know, Joe public out there does not understand head injury. Most of the brain injured people look totally normal, so they expect normal reactions", while Tom explained how gaining employment with a brain injury could be made easier if the understanding of brain injury was wider amongst the general public: *Some of them could hold down small jobs but it would depend on the boss or manager that would give them the job and the understanding of this person of the problems of head injury.*

However, external influences were seen as only one part of the problem. All the participants felt that internal causes played an important role in the progress made by people with brain injuries. One participant felt that the pre-morbid personality of the individual had to be taken into consideration. For instance, if the individual had been a motivated individual previously, this personality trait would still be activated after the injury and would contribute to the individual's progress after the injury. When the opposite was the case the same traits were seen as impediments to the rehabilitation progress. Laura explained:

*what makes things difficult for us is that some people were not achievers or had learning difficulties before the injury. We sit down and work with them but what works with one will not work for another. It is a matter of finding out at what level each person is at or be happy at.*

Another participant expressed that the level of education reached pre-morbidly also influenced the progress made post-morbidly. Ana said, "When I talk to them I talk considering their education. If the brain injured person used to be a cleaner or a
Chapter Seven - Study Three - The other in awareness of brain injury: non-expert health professionals talking to people with brain injuries

dustman and I say: "You have problems with your information processing" then that will mean nothing to them. They will not understand what it means to have problems with information processing because they did not know what information processing is before they had suffered the brain injury. When I explain things to them, I try to put it in terms that they may understand".

7.3. DISCUSSION
The findings in this study offer support for research pointing at lack of awareness of cognitive and emotional difficulties following a brain injury as problematic. However, while most research explains lack of awareness as denial of difficulties, participants in this study offered additional explanations for this phenomenon. Uncertainty of knowledge, severity of injury, refusal of confirmation, denial and normality, amongst others, were reasons given by non-expert health professionals for the difficulties experienced by people with brain injuries. These results also revealed that non-expert health professionals did not refer to difficulties using medical terminology, with the exception of memory and concentration, when they were with the person they supported. Non-expert health professionals referred to difficulties using the brain injured own descriptions of cognitive difficulties and in terms of what is appropriate or inappropriate for emotional difficulties. Rehabilitation progress in people with brain injuries was seen as externally limited and self limited. Family, medical professionals and general public were seen as imposing different demarcations on the brain injured. Pre-morbid personality characteristics worked as self-imposed limitations.

Overall, and in contrast to neurological and psychological theories of lack of awareness of difficulties following brain injury, participants' narratives implied an alternative theory to the subject under investigation. Participants in this study understood lack of awareness of difficulties as a combination of lack of knowledge of difficulties on the part of the brain injured plus something more, like "insight, awareness or feeling". This insight or awareness was then understood to be composed of many levels one of which, an "emotional depth" was found lacking in the people with brain injuries they supported. This lack of depth was then perceived as a natural protection for the brain injured so as "not be totally devastated" from the reality of
their injuries - something mother nature had given people with brain injuries to protect them from the truth.

Participants described this lack of awareness as malleable, changing with the passing of time, different in intensity depending on the type of injury and different according to the type of difficulty. Physical difficulties were perceived as the first difficulties people with brain injuries became aware of. This idea, which is congruent with academic and clinical theories of awareness of difficulties, was mentioned but not pursued by participants or researcher. Cognitive difficulties were described as the most amenable to bring into awareness as by the time people with brain injuries attended the day care centre, they were described as being "half way" to knowing that all was not well. According to these participants awareness of cognitive difficulties was affected by the brain injured self-characteristics (i.e self observation, denial) or through the influence of factors external to the patient (i.e living alone or severity of injury). People with brain injuries were then perceived as talking through their cognitive difficulties or trying to deny them. This perception, again is congruent with behaviours of the brain injured described in the literature.

Emotional difficulties were described by participants as different in nature to cognitive difficulties and as the most difficult for people with brain injuries to become aware of. The difference was described thus: that while people with brain injuries were perceived as having some knowledge of their cognitive difficulties, participants in this study described people with brain injuries as having no knowledge of their emotional difficulties. In other words, most people with brain injuries talked through their cognitive challenges but acted out their emotional difficulties. Similarly, while most people with brain injuries were perceived as having cognitive difficulties, all brain injured individuals were described as having emotional difficulties. The problem for people with brain injuries in becoming aware of this type of difficulty was that the brain injured themselves had not identified emotional difficulties as difficulties. People with brain injuries acted their normal selves. Thus, while the perception of awareness of emotional difficulties as being one of the most difficult to develop for the brain injured is not new, the carers in the present study explained this difficulty in terms of the self only.
Further, developing awareness of difficulties in people with brain injuries, for these participants, lead to two possible outcomes. Brain injured people either came to accept their difficulties or the incipient awareness led the brain injured to depression. This understanding of the development of awareness of difficulties in people with brain injuries is congruent with the model of development of awareness of difficulties illustrated in the psychological literature in Chapter Two.

Nevertheless, understanding lack awareness of difficulties after brain injury as a natural protection for the brain injured led participants in this study to describe two different perceptions of lack of awareness of specific difficulties and therefore, to address them differently. That is, while participants understood all difficulties to be a direct consequence of the brain injury, only cognitive difficulties were perceived to be outside the control of the individual affected by the brain injury. Emotional difficulties were perceived as psychological in nature and therefore, still under the control of the brain injured individual, even in cases where loss of control was obvious to them. In addition, when difficulties were perceived as outside the control of the individual efforts were made to empower the individual by talking about difficulties and offering strategies to help the individual gain control. When difficulties were perceived as under the control of the individual confrontation was selected to deal with what was perceived by the carers as problematic behaviour.

This finding helps answer the question why difficulties were perceived by people with brain injuries as different in nature. In Study Two participants described certain behaviours in terms of their brain injuries. Other behaviours were described in terms of personal characteristics or in terms of specific difficulties, mainly cognitive, which people with brain injuries were striving to manage. In the present study, participants' accounts constructed awareness of difficulties in terms of what could be controlled and what was appropriate. Their narratives pointed at two different ways of perceiving the difficulties of people with brain injuries, and therefore, at two ways of addressing them in the brain injured. One way was to help empower the brain injured individual so as to manage his or her difficulties and a second way was to confront people with brain injuries as to appropriate or inappropriate behaviours. In this way, the findings in Study Two correspond to the ways these particular difficulties are
addressed by these carers and this correspondence is evidence of how social interaction influences self-perception.

In addition, the findings of Tesser and Rosen (1975) that people avoid communicating negative evaluations of other people were only partly supported in this study. Participants felt that although it was important to talk about the challenges the people they supported had to face, this communication had to be done carefully so as not to "knock people further". However, this communication focused on particular difficulties, cognitive mainly, rather than emotional difficulties or global explanations in most cases. This finding then, also contributes partially to explaining why participants in the first study talked about specific difficulties as independent from their brain injury. Participants in this study managed and cared for people with brain injuries on a day to day basis, so referring to specific difficulties in this context makes more sense since it allows pragmatic solutions to everyday problems.

Nevertheless, in this study participants placed emphasis on how this communication took place. Careful communication was considered by carers when referring to cognitive difficulties. When dealing with emotional difficulties of people with brain injuries confrontation was chosen over other ways of communication. According to Shaugger and Schoeneman, (1979) people differ in their interpretation of others' feedback, particularly if the feedback is not explicit. This study revealed that non-explicit feedback was given to people with brain injuries when talking about some cognitive disorders. Participants used people with brain injuries' own terminology rather than medical terms to refer to afflictions (other than memory and concentration) which, arguably, could be arduous for people with brain injuries to interpret. Emotional challenges were dealt with more explicitly in that the communication entailed the appropriateness or inappropriateness of behaviour. This did not, however, entail explanations as to the cause of such behaviour. Therefore, it may not be clear for the brain injured how emotional difficulties can be a consequence of the injury.

In either case, the responsibility for the communication was seen as placed on the participant's shoulders. Garcia, et al., (2001) emphasised that the responsibility for
communication between the neurologically impaired and a healthy speaker relies on the healthy conversational partner. Sperber and Wilson (1986) added that a speaker is interested in communicating only what the hearer needs to know to make his or her message relevant. In this study, participants showed an interest in communicating information on cognitive difficulties with utmost care so as not to damage the self-esteem of people with brain injuries further. However, when the communication involved emotional difficulties, this consideration did not seem to be taken into account. This marked difference contradicts research on communication of negative information.

Participants in this study found it necessary to confront people with brain injuries because they were perceived as lacking in the skills necessary to understand subtle information. This contradicts the findings of Tesser and Rosen (1975) that people avoid passing on negative information when they think others may not understand this information, but supports the findings of Garcia, Metthe, Paradis and Joanette, (2001). These authors argue that when communication lacks coherence, as in many cases after neurological impairment, the responsibility of determining relevance lies entirely on the healthy conversational partner. That is, when "the partner with a neurological impairment is unable to identify the healthy speaker's intentions due to an incapacity to use contextual information" (p.18). However, Swann, Stein-Seroussi and McNulty (1992) found that when people were negatively evaluated people failed to realise that appraisals of them were indeed negative. Even when confronted, people perceive confrontation as either reflecting on the dispositions of others, or the context, rather than a reaction to particular attributes of themselves (Darley and Fazio, 1980) or they attend to such information selectively in order to maintain established self-conceptions (Swan, 1987). In addition, confronting a brain injured person with memory difficulties may mean that the confrontation may never be internalised, partly internalised or may be forgotten soon after.

Furthermore, the status of the participants may not be completely clear to the brain injured individuals who attend the day care centres. According to Holtgraves, Srull and Socall (1989) speakers' status affects memory of assertiveness. The authors found in three different experiments that under certain conditions the remarks of a perceived
high status speaker were remembered as more assertive than those made by a perceived lower status speaker. Participants in this study were managers of day care centres; they did not have medical training or expertise in the scientific fields of brain injury. How the members attending the centre perceive these managers could have an influence on how much of the communication that goes on between the participants and the people they support is attended to.

Thus, the knowledge people with brain injuries have of their cognitive difficulties at the time of attending day care centres may be maintained, if not advanced, as a result of the daily interactions to which they are exposed while attending the centre. Maintaining and advancing may be understood here as the ability to incorporate these difficulties into people with brain injuries vocabularies, whether or not the difficulties are understood per se. In addition, talking about this kind of disorder may carry overtones of helpful behaviour from non-expert health professionals, which may make negative communication less threatening to the self. On the other hand, knowledge of emotional difficulties cannot be seen in the same light. People with brain injuries do not perceive themselves as having these kind of difficulties and a one off confrontation may not lead the individual to see them as such. The overtone of a confrontation may provoke in the brain injured an emotional reaction and furthermore may only lead to an understanding that certain behaviours are not socially accepted, but without knowing why.

Indeed, carers in this study believed that the people with brain injuries they supported did not really understand the character of their difficulties. In most cases, carers thought that these individuals were "verbalising" their difficulties. However, they saw this as no obstacle for rehabilitation. On the contrary, being able to verbalise difficulties was seen as a starting-point in rehabilitation. This finding, which is in accordance with the learning without awareness literature, is also part of the framework of the carer. Participants in this study perceived themselves as promoters of progress. This role, was described by these carers as a continuous struggle between external and internal factors limiting the progress of people with brain injuries under their care. Getting to understand the person behind the brain injury demanded that carers work with what people with brain injuries communicate as a
difficulty. Carers did not expect to have to wait until the people they supported showed understanding of their difficulties.

7.4. REFLECTION

The method of IPA entails the explicit use of the researcher frame of reference to arrive at interpretations and conclusions. This is due to the fact that different researchers can bring to the fore different aspects of a data set. The interpretative framework of the researcher is then important to the research enterprise. In the present investigation, my interpretative framework was formed by factors such as knowledge of and practice in working with people with brain injuries. This framework could have influenced what was attended to in the interviews. In the analysis it may also have favoured a tendency to identify and prioritise certain themes over others through the extent to which they became familiar to me and hence, seemed true or important. Such bias could also have affected the way in which a critical approach was taken to different concepts. However, awareness of these difficulties meant that there was an attempt to engage in what is call bracketing (Giorgi, 1985) of these preconceived ideas and attributions. In addition, my efforts were directed into ensuring that the emerging themes and interpretations were solidly grounded in and supported by the data.
SUMMARY AND GENERAL DISCUSSION

8.1. SUMMARY
This thesis has investigated the link between awareness of difficulties following a brain injury and social interaction. The research examined the extent to which difficulties were salient for these individuals, and some of the sources of information available to these individuals. Explanations for the patterns found were sought at an intrapsychic level and social level. Interpretation of the findings was based on a concept of self-knowledge derived from an integration of a social interactionist approach to the self and a social constructivist model of consciousness. This concept recognises that self-knowledge is constructed during social interaction and that the information exchanged during these interactions is assimilated, internalised, and used in self reflection. In addition, the concept also recognises that self-knowledge involves selection from multiple sources of information used to form a united sense of self. The indicators of this selection process and the ones this investigation focused on were self-presentation and social environmental factors.

The major findings and interpretations are then summarised below:

- The narratives of participants with brain injuries mainly described brain injury and physical difficulties. Cognitive and emotional difficulties were found to be of low salience.

- People with brain injuries gave little indication that they could understand their difficulties. Instead, participants tended to present themselves as healthy and "normal" individuals.

- These findings were explained by various phenomena which did not include assuming that participants were reacting to knowledge of their difficulties. Explanations for the low salience of cognitive and emotional difficulties were given in terms of confusion,
memory loss and self-presentation amongst others, and lack of communication between people with brain injuries and significant others.

- Lack of communication between significant others and people with brain injuries was explained in terms of the physicality of the difficulties, in favour of protecting the individual affected by the brain injury and as a caring practice.
- Participants' narratives described gaining knowledge of their difficulties as a process of discovery, which was the product of actor, social and physical environment.
- Redefining the self after brain injury was described by people with brain injuries as a combination of behaviours they could control and information they could remember. Behaviours that could not be controlled were attributed to brain pathology. These narratives introduced a "second agent" to the sense of self.
- Narratives from non-expert health professionals in Study Three mirrored the findings in Study Two in terms of attributing behaviours to the brain injury and in terms of what people with brain injuries could control and remember. Thus, self-knowledge in people with brain injuries can be explained, partly, by the local discourses of this particular social environment.

8.2. PAST RESEARCH

It was seen in Chapter Two and Chapter Four that the existing literature concerning awareness of difficulties following brain injury assumes these difficulties to be problematic for people with brain injuries. It has often been claimed that people with brain injuries try to disassociate themselves from the negative implications of being affected by a brain injury (Prigatano, 1999). That people with brain injury battle to maintain their self-esteem. However, when these assumptions are not validated people with brain injuries are perceived as denying their difficulties. Their behaviour is also interpreted in this way and it is judged problematic for rehabilitation purposes. It was also seen then that denial was not a consistent coping mechanism. It did not extend to all difficulties that can be experienced following a brain injury. The label of denial was applied by researchers to only a few difficulties, and then only in the cases where people with brain injuries had failed to fit into the categories that have been designed for them by researchers.
The idea of denial, usually found in health and social psychology and stigma literature, has been put forward by writers trying to identify the way members of a low status group respond to the threat of belonging to it (Goffman, 1963; Tajfel, 1978). These responses have been described as denial, withdrawal and self-stereotyping, amongst others. The descriptions, which are convenient at the time of explaining the behaviour of individuals belonging to low status groups, can help rehabilitation, social and health workers in comprehending reactions to particular situations and in designing interventions. However, and although these descriptions are valuable, they are usually "over-emphasised" (Finlay, 1999). That is, any behaviour which coincides with these responses tends to be interpreted as being the result of belonging to the low status group or to a minority group. Thus while a low salience of certain difficulties was found in this thesis, it was also found that this could be explained by lack of information about those difficulties, lack of understanding of them and severity of memory loss. Responses like lack of information and lack of understanding of difficulties are not found in the health, social psychology and stigma literature on membership of low status groups.

For these reasons, it is important not to assume that because something has been found not to be problematic for someone, the person is in denial. If people with brain injuries are found to want to return to work it does not meant that the person affected by the brain injury is trying to disassociate from the injury. If people with brain injuries have unrealistic plans for the future, it does not mean that these individuals did not have these plans before the injury. If the person affected with a brain injury exhibits disinhibition it does not mean that these behaviours were fully under control previously to the injury. This prominence is partly the result of using experimental paradigms that investigate cause and effect and exclude the complexities of the situations of real life people with brain injuries. In this investigation, the ways participants constructed their knowledge of their difficulties resulted in a struggle involving an understanding and a remembering of their difficulties rather than in attempts to disassociate themselves from these difficulties.

Research on the implications of lack of awareness of difficulties needs to approach this subject from different perspectives which do not assume that what is important
for the researcher is applicable to the participants in such research. The cause of the problems found in the research literature is the failure to recognise that interpretations of this kind of research are made according to the framework of reference of the researcher not that of the participants. For example, if a researcher sets out to find how much awareness of difficulties a person with a brain injury has, then this is assumed to be important. In this context, it is the researcher who is moving the goalposts deciding how much awareness of difficulties people with brain injuries should have. However, people with brain injuries may be more concerned with specific difficulties that affect their everyday living rather than their measured amount of awareness of these difficulties. Differences between the frame of reference of the researcher and participants need then be taken into consideration and only then can the effects of lack of awareness of difficulties in people with brain injuries be better analysed.

To accomplish this researchers may need to take as a point of departure a self-knowledge model of awareness, not simply a definition of awareness (as seen in Chapter Two). Since self-knowledge involves multiple sources of information, this entitles phenomena to be interpreted in different ways and not simply categorised in one way. Thus, awareness should be understood in the context of other aspects of self-knowledge and the way this context is construed.

8.3. THE SOCIAL CONSTRUCTION OF CONSCIOUSNESS

The studies in this thesis have explored how awareness of difficulties can be a product of social interaction. Some points can be made concerning the application of a social constructionist theory of consciousness to the study of awareness of difficulties following a brain injury.

The findings in Study One and Two point to the all embracing physical reality of the brain injury and the physical difficulties that in some cases follow a brain injury. Social constructionism with its foci on agency and structure drives attention away from the body. Nevertheless, the importance of the body for the self and social life can be seen in this study and in a number of areas. For example, a central prerequisite for the development of a human being is the control of the physical body and its capacities.
Chapter Eight - Summary and general discussion

Such control and the knowledge it brings provide a sense of constancy of the embodied self. Bodily sensations provide the initial way of knowing and learning about the world and provide the first experiences from which self-awareness develops. Arguably, and although this control was described as interrupted by the brain injury by some participants, what the narratives of people with brain injuries pointed at was a divergence between body and self. That is the bodily demands were conflicted with self demands. This point can be problematic from a social constructionist perspective because it does not clearly account for the occasional primacy of the body over self. More fundamentally, the body is central to the social process because the biological bases of experience as perceived by self have important effects in the construction of self and identity (as discussed in Chapter Three). The relation between self and identity in brain injury is a social process, which can alter through time, as the bodily contingencies change. These bodily contingencies may be cyclical, intermittent and unpredictable. It is necessary to remember at this stage that living organisms are not static. Neither are their manifestations, nor the sensations and experiences of these manifestations. These experiences are not only socially constructed, they are contingencies exercising varying degrees of salience for self and others through time and space.

For example, visible physical difficulties, like being in a wheelchair, may be difficult to hide and whatever the salience of the difficulty may be for the self, the public identity of the individual will always be constrained by the wheelchair. Less visible difficulties, like epilepsy, at the other extreme may not be salient for the public identity of the person with a brain injury but they may be salient to the private identity of the person due to his or her management of these less visible difficulties. Thus, and in this way, the body and whatever happens to it is central to the experience of brain injury and in the social processes involved in its management. Any social constructivist theory applied to the study of brain injury must then consider this occasional primacy over other processes.

In Study One it was also found that the correspondence of complaints between people with brain injuries and their significant others was evidence that people with brain injuries benefit from a discursive environment. However, the finding that there
was little understanding of difficulties was not. Explanations for the absence of this
discursive environment were given in terms of lack of information, memory loss and
perceptions of significant others of "invisible" difficulties. In this respect, the
theoretical constructionist background fails to account for the consequences of a
social interaction that does not carry a content relevant to self-knowledge. It could be
assumed then that individuals engage in an active search of relevant information from
other sources as the findings in Study Two indicate.

In Study Two it was found that people with brain injuries overall equated the process
of acquiring knowledge of their difficulties to a process of discovery in which
information obtained during social interaction played only a part. Knowledge acquired
while interacting with the physical environment and observations of the self were also
sources of information. In this sense, the social interactionist perspective that was
taken as a base for this research was found too narrow for the study of awareness of
difficulties in people with brain injuries. Widening the social interactionist perspective
with a social constructivist theory of consciousness thus allowed a wider
interpretation of the results. However, the process of discovery or the "sorting of the
puzzle" described by the participants in this research was found to be obstructed by
the severity of memory loss in many cases. Whilst Burns & Engdahl (1998) suggest
that individuals vary on the amount of information which they attend to, assimilate
and interpret, it is argued here that differences in memory capability is a determinant
of this variability.

In addition, it was found that memory loss was described by many participants as a
loss of phenomenological experience. People with brain injuries could name some of
their conditions and explain their difficulties. In other words, they could verbalise
their difficulties without having the phenomenological experience of their knowledge.
These differences in memory, which were not accounted for by Burns & Engdahl but
are congruent with the cognitive studies of Tulving (1985) discussed in Chapter
Three, arguably pose a serious threat to the understanding of awareness and
consciousness as a continuum. Burns and Engdahl (1998) and philosophers like
Zahavi and Parnas (1998) theorise awareness as a part or level of the conscious
experience. To be conscious is to "illuminate" the contents of awareness (Zahavi and
Parnas, 1998) or to reflect on the contents of awareness (Burns and Engdahl, 1998). For Burns and Engdahl the contents of awareness are made up of "experiences, images, representation of objects, concepts" and so on, which are recorded in memory. Arguably, when the neural or physiological mechanisms that record these data malfunction, or stop recording data or only record certain types of data, the contents of awareness are incomplete. By implication then, consciousness illuminates or reflects empty parts of awareness; or in the words on one participant "the holes of life". By further implication, consciousness cannot illuminate anything. Therefore, it cannot be conscious of nothing. However, the participants in this investigation were conscious of this emptiness. Thus, memory impairment maybe an example of empty or disrupted awareness which may cast doubts over the theory proposed by Burns and Engdahl.

Study Two also found that people with brain injuries attributed some behaviours to brain pathology. This narrative, which sounds sensible and beneficial for self-understanding, and may be used by people with brain injuries to protect self-esteem, was used in this context to explain unintentional behaviour. People with brain injuries were then describing themselves as not responsible for the consequences of the brain injury. That is, brain injury was defined as something, a disorder or disease, which possessed the person, not the other way round. In Part One of Study One the narratives of people with brain injuries also gave an early indication of this sense of possession. Participants in the study presented themselves as healthy individuals, the brain injury was not then considered a part of the self. Furthermore, it should also be noted that these kinds of attributional explanation were also found among the non-expert health professionals in Study Three.

The attributional relationship between brain and behaviour corresponds to a contemporary, scientific view of human beings. According to Martin (1998), for example, neuropsychologists assume that human behaviour and experiences are governed by the physiological, mechanical or neural activities of the brain. Studies on the social conceptions of brain injury have also indicated that the attributional relationship is also a common belief amongst the general population (Willer, Johnson and Rempel, 1993) and health professionals (Swift and Wilson, 2001). Thus relying
on this idea, individuals can easily accept the explanations of behaviour of people with brain injuries.

However, and as discussed in Chapter Three, agency is a defining property of the self in a person's narrative. The individual is likely to incorporate into the self image a link between his or her intentions and actions. This sense of agency forms the basis of the belief in one's power to be effective in the environment. The narrative of causal relationship from brain injury to behaviour can threaten the apparently natural link that represents the person's agency. That is, when one assumes that damage to the brain can influence one's mind and self, one holds a second agent within one self. It is beyond one's control, although it exists inside one's body. The individual then carries something unfamiliar in his or her sense of self. Furthermore, when the individual explains intentional behaviours in terms of own abilities these explanations can serve to reconstruct self-esteem. In this sense having a brain injury is a struggle of the self for people with such injuries.

Overall, the application of a social constructivist theory of consciousness has been found beneficial to the study of awareness of difficulties in people with brain injuries. It may be remembered (Chapter One) that social constructionism asserts that the apparent scientific basis on which most neurological, neuropsychological and psychological practice (amongst others) is founded is only one way of interpreting the world. The application of a social constructivist perspective, with its emphasis on many realities, has allowed this research to draw from various and, in some cases, very different interpretations of brain injury. The study has invited interpretations from social psychology, cognitive psychology, physiology, neurology and philosophy to complement the interpretation of the data. For example, when participants' narratives included descriptions of memory loss, knowledge of cognitive psychology theory and research guided the interpretation of memory loss as autobiographical memory or semantic memory or episodic memory. If participants' narratives included descriptions of loss of feeling on the left side of their bodies, lessons from physiology and neurology were applied to understanding these descriptions as outcomes of right hemisphere lesions. In this way, the application of a social constructivist theory of
consciousness to the subject of awareness of difficulties after a brain injury is an example on how different disciplines can inform each other.

A final point concerning the application of a social constructivist theory of consciousness to something as tangible as brain injury, addresses the accusation of relativism often made towards social construction theories in general (Burr, 1998; Raskin, 2001). As seen in Chapter Three and Chapter Four, social constructivism shifts the focus away from independent realities (i.e., discovered truths) and towards socially constructed realities (Burr, 1995). If notions of selfhood, one of the foci of psychology, are constructed rather than pre-existing entities open to scientific enquiry, then who is to say which constructions of selfhood are the best? (Raskin, 2001). In relativising knowledge, it is often argued that social constructionism stands for epistemological and ethical nihilism, reducing any real world basis for knowledge claims and social intervention.

For example, Matthews (1998) critiques social constructivism as relativism. The author argues that the social constructionist position is that truth is only relative and has no general applications given that such truth is a mere construction developed in a given social context. For Matthews social constructivism as relativism is an attack on science because it makes no distinction between objective knowledge and superstition. Held (1998) also believes this position to be problematic. From Held's perspective social constructionism fails to explain why social constructionism is better than more traditional approaches to science. Why would the social constructivist ask us to accept their reality claims when they themselves admit that all reality claims are equivalent? She also criticises the idea that people can choose to believe in those social constructions of reality that they prefer.

However, and based on the preceding arguments which are not going to be addressed at length at this point, it is argued here that relativism, at its worse, is of no importance because it has never led to the disastrous consequences its opponents claim it does (Rorty, 1979). At its best, relativism can be advantageous (Gergen, 1994a). For example, Rorty (1979) argues that understanding human perception as a mirror that reflects nature produces a philosophy that demands a preoccupation with
grand theories of truth. His goal is to change the rules of the intellectual playing field, altering the standards by which knowledge schemes are judged. Rorty claims that the point of his philosophy is to keep the conversation going rather than to find an objective truth.

In a similar way, Edwards, Ashmore and Potter (1995) reject what the authors call "death and furniture" arguments, which claim that relativism cannot account for the real nature of human suffering, pain, misery and (death) or the materiality of concrete objects such as rocks, chairs, pens and so on (furniture). Edwards et al. (1995), reject the death and furniture arguments by claiming that relativism does not paralyse scientists.

With regards to "furniture", and coming back to the subject of this thesis, even the seemingly physicality of a brain injury can be seen as a "perceptual category": a matter of what a brain injury seems to be like to people. In other words, people know about tables, chairs, pens, brain injuries only indirectly through our construction of them. That is, there may be alternative ways to construe any given object. A brain injury, which can be very physical and visible to one and others, is likely to be construed differently by a person living in a western society to that of a person living in an eastern society. The multicultural research into awareness of difficulties following a brain injury carried out by Prigatano and colleagues reviewed in Chapter Two is evidence for this point (also work by Simpson, Mohr & Redman, 2000).

Furthermore, even when people are familiar with particular types of ontological "furniture" their precise boundaries can be called into question and reconstituted using alternative constructions. Does the brain injury finish with the physical signs of the injury? Does the brain injury mean that a person affected by it is no longer fit as a member of society? This does not mean that people have to stop trying to understand brain injuries in all possible ways possibly human. It simply means that the social constructions of a brain injury are not final or perfect. In this way, social constructionism can see relativism as advantageous, because it encourages creativity. In other words, the approach may lead to new ways of looking at something (in the
present case, brain injury) or thinking about something and new ways, as in the present case, of designing interventions.

8.4. LIMITATIONS OF THE RESEARCH

The sample of people with brain injuries participating in the research represents a cross section of the brain injured population attending day care centres in the South of England. The findings identified in this research require further validation in other brain injured populations attending similar centres. The relevance of the findings for people with recent injuries, people with more severe injuries or for those who do not attend such centres cannot be assumed but further research with such populations may prove useful. However, the qualitative design throughout the research arguably may compensate for the small sample sizes (N=30 in Part One of Study One and N=24 in Study Two).

The methods adopted in Study One and Two were constrained by the difficulties described in Chapter Four concerning the use of semi-structured interviews and where it was seen that the this type of interview was the most appropriate for the purposes of the research. The interviews designed for people with brain injuries were found to be too directive in both studies. Although every effort was made to let the participants talk extensively, the precise nature of the questions could have resulted in poorer quality of data.

The validity of the data for Study One was checked at various points. These included the use of code-re-code and inter-rater reliability checks for the content analysis. Studies Two and Three contain the reflection section prescribed by the phenomenological method. The use of two different methods under the same paradigm was found to be advantageous for the analysis and interpretation of the data. The method used in the first study provided data, which in turn was used for the design of the semi-structured interview in Study Two. However, the combination of methods from different paradigms may also be beneficial in the research of awareness of difficulties following a brain injury.
8.5. IMPLICATIONS FOR REHABILITATION AND FUTURE RESEARCH

A number of implications for clinical practice are suggested from the findings. Some researchers have suggested that it is important for rehabilitation efforts to focus on developing awareness of difficulties (Kay and Silver, 1989). Other researchers have argued that a prerequisite level of awareness is not necessary to utilise compensatory strategies following a brain injury (Sohlberg, Mateer, Penkman, Glang and Todis, 1998). These authors suggest that people with brain injuries can be trained to use compensatory strategies even in cases where patients do not understand why or believe that they need them. The authors explained that for people affected by a brain injury it might be more productive to tap into implicit learning that into declarative knowledge as to why these strategies are important. The findings in this thesis however, point to the ability of people with brain injuries to learn about their difficulties even if the understanding of those difficulties is not there in some cases. Therefore, while accepting that implicit learning may be productive for the rehabilitation of people with brain injuries, teaching them to verbalise these difficulties may also prove productive.

Learning to verbalise difficulties, through repetition for example, may be useful to the person with a brain injury as these expressions can be used to "position" the person with a brain injury during social interaction in the way already described in Chapter Six. However, what may prove more useful, and perhaps more difficult, would be to help the patient or client change the narrative of the causal relationship brain-behaviour. Although health professionals may believe that there is a causal relationship between brain injury and the behaviour of people with brain injuries, this is only one perspective. For instance, it is difficult to find the cause of mood swings after a stroke. They may be a direct consequence of the trauma or they may be a secondary reaction to the experience. Even if there is much scientific evidence connecting behaviour with brain injury, it is still very difficult to find the true causes of behaviour.

Thus, rehabilitation and health professionals may help people with brain injuries to construct alternative explanations of behaviour that are more empowering for the individual. How this may be achieved, can be the object of further research, but
rehabilitation staff and carers of people with brain injuries need to first take into consideration the contextual and personal characteristics of the person with a brain injury. It is a well illustrated point in the brain injury literature that patients or clients with brain injuries may experience depressive states upon learning about the incurable nature of their difficulties (Prigatano, 1991; Malec and Moessner, 2000).

Attributional theories often remark that locus of causality of difficulties in life makes a difference in interpersonal relations and not just a cognitive difference but also an affective difference, a difference in feelings (Brown, 1986). When a person attributes difficulties in life to stable characteristics of the self, the person becomes more easily depressed. Conversely, an attribution of difficulties to situations the person can change can empower the individual.

Rehabilitation staff, health workers and carers of people with brain injuries may help change the narratives of these individuals by offering new narratives or helping construct alternative narratives with their patients or clients. Further research may then inquire into the usefulness of the new narratives for the sense of self in people with brain injuries. Alternatively, or as well as, rehabilitation staff, health workers and carers of people with brain injuries may invite their patients or clients to compare pre-injury-post-injury attributional narratives. Temporal comparisons may help dispel the persistence of inaccurate beliefs about the self. Further research may then inquire into the usefulness of temporal comparisons for the sense of self in people with brain injuries.

8.6. CONCLUDING REMARKS

Traditionally, social and health psychological research into adjustment and adaptation to brain injury has revealed "unrealistic" self-appraisal as problematic for people with brain injuries and the people in their social environments. This unrealistic self-appraisal has been described as reduced awareness of physical, cognitive and/or emotional difficulties, which occur following neurological damage. The development of a realistic self-appraisal, under this perspective, is seen as important if people with brain injuries are to engage in rehabilitation and live fulfilling and meaningful lives. In this thesis, this point of view has been challenged. Instead, the research has explored the link between awareness of difficulties following a brain injury and social
interaction. Brain injury happens in society and when the difficulties that are experienced after this brain injury appear beyond the self-control of the individual affected by the trauma, they are a challenge to society in general. The social and health psychology literature illustrated in Chapters Two and Three is witness to this.

The thesis, while not trying to minimise the problem of brain injury for the people affected by it, their families and carers, has introduced another perspective to the study of lack of awareness after brain injury: that of the social interactionist-constructivist thesis. It is hoped that this framework will provide a corrective balance to the interpretation of behaviour, which ascribes neurological, neuropsychological or psychological causes to phenomena, which thus shift them from the individual domain to the public. For example, certain characteristics experienced after brain injury become "syndromes" of the brain injury, with the result that specific episodes in a person's life come to be constructed as "symptoms". Instances when people with brain injuries appear to disassociate from their brain injuries are synthesised as denial of difficulties and adopted by researchers and reconstituted as lack of awareness of difficulties. Furthermore, it is also hoped that the introduction of this framework to the study of brain injury will help understand people with brain injuries needing to see themselves as a solution waiting to happen rather than a burdensome problem difficult to solve.

Finally, and as Fleck (1935) argued many years ago, it is necessary to remember that scientific facts are socially constructed by distinct thought collectives, each composed of individuals who share a specific thought style incommensurable with others. Training in one style hampers the ability to look at the same object from a different perspective, therefore neurologists, neuropsychologists or psychologists tend to observe the same phenomena. Only a combination of historical, sociological, psychological and philosophical points of view into a multi-disciplinary approach, called by Fleck "comparative epistemology", could allow for a proper study of complex phenomena.
REFERENCES


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APPENDICES
APPENDIX I - Interview schedule for people with brain injuries (Part One of Study One)

<table>
<thead>
<tr>
<th>Sex</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Occupation (now or/and in the past)</td>
</tr>
<tr>
<td>Education</td>
<td>Interview n.:</td>
</tr>
<tr>
<td>Type of injury</td>
<td>Duration of coma</td>
</tr>
</tbody>
</table>

1) What is this place called?
2) How far is this place from your home?
3) Why do you come to...?
4) Any other reasons?
5) How long have you been coming here?
6) What made you decide to come here?
7) Do you enjoy coming here?
8) Why?
9) What sort of activities do you do here?
10) What do you enjoy the most?
11) What do you enjoy the least?
12) Do you live on your own?
13) What other activities do you do when you are not here?
14) Do you do these activities on your own/friends/family?
15) Are you employed at the moment?
16) Have you always had the same job?
17) Are you seeking employment at the moment?
18) What do you think you are good at?
19) Could you improve?
20) In the past, what do you think you used to be good at?
21) About your health, how are you feeling today?
22) Do you consider yourself healthy?
23) Would you say that you have always been healthy?
24) How do you keep in good health?
25) Do you think about your health?
26) In general, would you like to tell me about you and your life?
27) Do you think your life has changed for you?
28) When did it change?
29) Would you like to talk about it?
30) Is life for you better now or in the past?
31) What makes you happy?
32) What makes you sad?
33) Do you think life for you will be different in the future from what it is now?
34) Have you got any plans for the future?
35) Given the chance, what would you like to do?
36) How do you feel you cope with life at the moment?
37) Do you worry about yourself?
38) Do you feel people respect you?
39) Do people upset you?
40) Would you say that you upset others?
41) Who would you say is the most important person in your life?
42) Why?
43) Who do you dislike the most?
44) Why?
45) How do you think others see you?
46) Do you think you get on with people?
47) Do you think about what you do and what you can do?
48) Before we finish, would you like to tell me the time and the date?
49) What did you do before you came here?
50) What will you do tomorrow?
APPENDIX II - Interview schedule for significant others (Part Two of Study One)

Sex:                                               Status:
Age:                                               Occupation:
Education:                                         Interview n.:
Knowledge of duration of coma/amnesia:             Relation to the Patient:

1) Would you say that ___ used to be an active person?
2) Do you think ___ is as capable now as before the injury?
3) Would you say that there is room for improvement?
4) How do you explain to ___ this shortcomings?
5) What do you think ___ used to be good at?
6) What do you think ___ is good at now?
7) In your opinion, is there room for improvement?
8) Do you try to encourage ___?
9) How do you do that?
10) In general, do you think that ___ knows what happens from day to day?
11) How do you think ____ gets on with other people?
12) In your opinion, do ___ thinks about what he/she does and what he/she can do?
13) In the past, did ______ use to worry about the things he/she did or could do?
14) How do you explain to ____ this shortcomings?
15) To what degree do you think ____ knows/understands about his/her injury?
16) After the event, how much do you think ______ knew/understood about the injury?
17) Do you think ___ knows/understands the implications of the injury?
18) To your knowledge, does ___ worry about the physical consequences of the injury?
19) Do you talk about them?
20) How do you talk about them?
21) In the past, did ______ used to worry about health?
22) Do you think ___ has changed since the injury?
23) How has ___ changed?
24) Could you tell me a bit about ___ before the injury?
25) Do you think ___ has noticed any changes (if any) in himself/herself?
26) How do you explain these changes to ___?
27) In your opinion, is ___ motivated in his/her daily activities?
28) What motivates ___ now?
29) What used to motivate ___?
30) To your knowledge, does ___ has any plans for the future?
31) Do you think ___ worries about himself/herself?
32) Did ___ use to worry about himself/herself?
33) How do you think people, in general, treat ___?
34) How would you say ___ feels about other people?
35) Would you say ___ has changed his/her social habits?
36) Does ___ worry about how others see him/her?
APPENDIX III - Interview schedule for people with brain injuries (Study Two)

- **Familiarity with brain injury.**
  Have you known brain injured people in the past?
  What are your experiences of brain injury, apart from your own?

- **Knowledge of own problem in hospital/rehabilitation/at home.**
  What happened to you?
  Did you know in hospital what was happening to you?
  Did you know during rehabilitation?
  Did you know when you got back home?

- **Reasons for not knowing.**
  Who told you what had happened to you?
  What did you think at the time?
  Who told you about the problems that you were likely to have after the injury?
  Did anybody explain to you what you could do to help yourself?
  Did you follow the advice?/ Why?

- **Emergence of knowledge.**
  When do you think you realised that you had a problem?
  Are there any particular instances when your problems maybe clear to you?

- **Reaction to problems.**
  What was your reaction to knowing what was happening to you?

- **Situation now.**
  Do you know about your problems now?
  What do you do about them?

- **Remember/know. (Explain both terms first)**
  Would you say that you remember about your problems or would you say that you just know about them?
Has it always been this way?

- *Who explains what.*

  With whom do you talk about the problems you have?
APPENDIX IV - Interview with non-expert health professionals (Study Three)

-Familiarity with brain injury

How long have you been working with people with brain injuries?
Have you known any brain injured person previously to you working here?
Have you received any training previously to working with people with brain injuries?

-Knowledge of the problem (finding how the staff at the centres refer to the problem and experiences of it)

Have you ever come across a brain injured person that did not know about his/her physical deficits? (if yes, proceed, if not, go to questions about cognitive difficulties)
Did you think that he/she knew what was happening to him/her?
What makes you think that a member/client knows about his/her physical deficits?
What makes you think that a member/client does not know about his/her physical deficits?
How common do you think this problem is? In your experience, is this problematic for the brain injured person?
In your experience, is this problematic for other people?
Do you think that people that do not know about this problem can come to know this or know this better?
In your experience, people that know about this problem, what do you think they do about it?
In your experience, are there any situations that are a direct consequence of the problem?

If by cognitive deficits, we understand memory, perception and reasoning problems, then:

Have you ever come across a brain injured person that did not know about his/her cognitive deficits?
Do you think that they know about them?
What makes you think that a member/client knows about his/her cognitive deficits?
What makes you think that a member/client does not know about his/her cognitive deficits?

How common do you think this problem is?

In your experience, is this problematic for the brain injured person?

In your experience, is this problematic for other people?

Do you think that people that do not know about this problem can come to know this or know this better?

In your experience, people that know about this problem, what do you think they do about it?

In your experience, are there any situations that are a direct consequence of the problem?

*If by emotional deficits, we understand excessive aggression, excessive cursing, excessive sexual talk, frequent and inexplicable change of mood, misreading social situations, then:*

Have you ever come across a brain injured person that did not know about his/her emotional deficits?

Do you think that they know about them?

What makes you think that a member/client knows about his/her emotional deficits?

What makes you think that a member/client does not know about his/her emotional deficits?

How common do you think this problem is?

In your experience, is this problematic for the brain injured person?

Has it been you experience that it is problematic for other people?

Do you think that people that do not know about this problem can come to know this or know this better?

In your experience, people that know about this problem, what do you think they do about it?

In your experience, are there any particular situations that are a direct consequence of the problem?
-Dealing with problems

If you suspect a member/client to not know about a deficit, what do you do about it?
How would you explain this problem to the member/client?
If a member/client gets into trouble because of not knowing about a particular deficit, what do you do about it?

*If they do not say specifically*, ask if they talk about the problems with the relatives of the member/client? / Do you find this effective?
APPENDIX V - Vignette 1 (Study Three)

Sylvia is 56 and has had two strokes. The first stroke happened five years ago and was very mild. Sylvia recuperated from it with hardly any consequences. She went back to work after a recommended period of rest.

A year ago Sylvia was affected by a second stroke. Since, she attends a day care centre where she continuously approaches the staff with questions like, why is she attending the centre, when will she be allowed to go back to work, how many children has she got and is she still married. Her husband collects her at the end of each day from the centre. Sylvia does not seem to have any problems recognising him and greets him warmly. On the way home, Sylvia proceeds to ask her husband questions like, why is she attending the centre, when will she be allowed to go back to work, how many children have they got and if they are still married.

Do you think that Sylvia’s behaviour is unusual/inappropriate? / Why?
Do you think that Sylvia knows about this behaviour?
Why do you think that Sylvia wants to go back to work?
What do you think is in Silvia's mind?
In your opinion, is Sylvia ready to going back to her old job? Any job?
Do you think that she can go back to work? / Why?
What would you recommend she does? / Why?
What would you call Sylvia's condition?

(Probing wherever necessary)
APPENDIX VI - Vignette 2 (Study Three)

John is a young adult who has suffered a brain injury. During rehabilitation and while attending a day care centre, he was observed once ordering a meal from the centre's canteen. While queuing up, he was standing next to an attractive therapist and begun to engage her in conversation. As the woman walked in line, John stood next to her staring at her in a rather inappropriate manner. He began to walk next to her and began to comment about her attractiveness. The woman was obviously uncomfortable. John continued to make comments and the woman acknowledged those in a brief manner. It was obvious to all around her that she was not interested in further dialogue. John persisted in making more comments until she walked away from the line indignant and angry. John was left standing and wondering what he had done to cause such negative reaction.

Do you think that John's behaviour is unusual/inappropriate? / Why?
Do you think John knows what has caused the therapist to walk away? / Why?
If the woman had not walked away, would you think that John would have persisted in his efforts? / Why?
What do you think is in John’s mind?
Would you say that John has a problem?
What would that problem be?

(Probing wherever necessary)