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The Experience of Neuropsychological Assessment:
An Interpretative Phenomenological Analysis

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Salomons

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Abstract

Objectives. This study investigated the experience of neuropsychological assessment from the patient's perspective. It sought to gain an understanding of how the patient viewed the purpose of assessment and how the patient experienced the assessment process. It explored the impact of the assessment of the patient's sense of self and elicited patients' views about what was particularly helpful or unhelpful about the assessment process.

Design. A within-group qualitative design was employed to investigate the experiences of nine men and women who presented for neuropsychological assessment in the context of an outpatient assessment clinic or as part of an evaluation for a rehabilitation programme.

Method. Verbatim transcripts of semi-structured interviews were analysed using interpretative phenomenological analysis.

Results. Six master themes were identified: Expectations of assessment, context of referral, experience of process, impact on self, components of a good assessment and experience of illness/disability. The findings indicated that patients are poorly prepared for assessment but come with positive expectations for information that will help them understand and cope with their impairments. Their relationship with the psychologist is central in determining the quality of their experience and in facilitating improved self-esteem, coping and better awareness of cognitive strengths and deficits.

Conclusions. It is concluded that neuropsychological assessment can have an educative and therapeutic function that should be further exploited in a diagnostic and rehabilitation context. The findings are considered in relation to the literature on sharing a diagnosis, coping with illness and the client-clinician relationship. The implications of the research findings for clinical training and neuropsychology service provision are discussed and consideration given to future research opportunities.

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Chapter One

1.0 Introduction

This study explores the experience of neuropsychological assessment from the perspective of the person undertaking the tests, in this context, a person presenting with a neurological impairment or injury. Neuropsychological assessment is a core component of clinical neuropsychologists' work with people who have acquired cognitive impairments as a result of a neurological illness or injury. The discipline of clinical neuropsychology seeks to further our understanding of brain-behaviour relationships and to apply such knowledge in clinical decision-making and in the planning and delivery of patient care (Groth-Marnat, 2000). Standardised psychometric measures derive from an empirical research base (Spreeen & Strauss, 1998) and are used in neuropsychological assessments to make objective judgements about the nature and causes of cognitive dysfunction.

The standardised administration of neuropsychological test instruments is of vital importance in ensuring the reliability and validity of the measures used and the robustness of the interpretations made on the basis of test findings. Thus, interaction between the clinician and patient during neuropsychological assessment is of a highly structured format. Care must be taken to adhere to the same administration and scoring procedures that were used during test standardisation. Evaluative feedback is discouraged during the testing session and the supportive functions of the clinical neuropsychologist's role must be carefully balanced with a high degree of impartiality (Kaufman & Lichtenberger, 1999).

The assessment of brain-injured populations poses particular challenges in standardised assessment as people with cognitive impairments may have particular difficulty remembering instructions, understanding nuances of language and sustaining concentration. Clinical neuropsychologists attempt to strike a balance between testing their patients under optimal conditions to assess their level of capacity and standardised conditions to assess their level of current functioning in relation to specific normative standards (Lezak, 1995).

Lezak advises that neuropsychological assessment should be a constructive experience for clients, which leaves them feeling better about themselves rather than being 'a hit-and-run examination' (Lezak, 1995, p.127). In practice however, the interaction between clinician and client is likely to be an idiosyncratic process, and, as evidenced by a systematic review of the literature, has been subject to very limited investigation. Whilst it is accepted that patients' performances will be affected by anxiety, fatigue, noise, memory defects and motivational variations (Lichtenberger, Kaufman & Lai, 2002), the experiential aspects of neuropsychological assessment from the perspective of the patient, or indeed, the testing clinician, has received little formal investigation.

This study will focus on the experience of neuropsychological assessment from the patient's perspective. The interest in this topic derives from a paucity of existing research into the qualitative aspects of the assessment experience and specifically its impact, if any, on the patients' view of their presenting problems. In the following sections, the contextual relevance of the study will be outlined, the literature pertinent to the area will be reviewed and a case made for the timeliness of a qualitative

investigation of the experience of neuropsychological assessment. Finally, details of the research methodology and the research questions will be presented.

1.1 The Practice of Neuropsychological Assessment

People undergoing investigation or treatment for a neurological condition may find themselves referred for a neuropsychological assessment for three principle reasons. Neuropsychological assessment is used to aid diagnosis; to identify cognitive strengths and deficits to guide treatment planning; and to monitor changes in functioning over time and in response to treatment (Groth-Marnat, 2000). Typically, a neuropsychological assessment will involve between two to six hours of psychometric tests, administered under controlled conditions, often in the clinician's office. The clinician is encouraged to support the patient to do their best to complete the tasks to the best of their ability, but essentially, the psychologist must take a neutral and detached approach to test administration in order to ensure objectivity (Lezak, 1995).

On completion of the testing session(s) the tests are scored and interpreted by the neuropsychologist. A report is prepared for the referrer, frequently a medical practitioner or clinical team, and the findings incorporated into the patient's care plan. At this stage the patient may receive feedback on their test findings, either by the psychologist themselves or indirectly through the referring agent. Currently there is no requirement for patients to receive copies of their reports but this practice will be changed as of April 2004, when Department of Health guidelines on copying letters to patients are implemented (Department of Health, 2000).

Research conducted in Australia (Bennett-Levy et al., 1994) and America (Donders, 2001a; 2001b) suggests that feedback of test findings to patients is infrequent or inconsistent (Bennett-Levy et al., 1994) and likely to be dependent on clinician preference and contextual issues related to the age and capacity of the patient and the nature of the referral (Donders, 2001a). Findings are most frequently communicated through a formalised report, sent principally to the referring practitioner, and, only occasionally shared with patients (Donders, 2001b). These findings may not, of course, reflect the dominant practice in the UK.

It is likely that in everyday clinical practice the nature and content of information sharing between clinician and patient varies according to the style, beliefs and clinical constraints of the practitioner (Keightley & Mitchell, 2004). It is undoubtedly an area worthy of investigation, however, the interaction between psychologist and client proved too broad for the scale of the proposed study and one element of the experience, the view from the consumer's perspective, became the focus of investigation.

1.2 Why explore the patient's experience?

The emphasis on the standardised administration of neuropsychological tests has led, it can be asserted, to a failure on the part of the profession to fully appreciate the interactive nature of the test experience.

There are a number of reasons why the dynamic aspects of assessment are not fully exploited in neuropsychological practice. One is the time taken to administer and score neuropsychological tests. A full neuropsychological assessment and preparation

of a report may take between five to 10 hours of clinical time. Busy clinicians may find it difficult to make time to book additional appointments for test feedback to their clients and consequently, the evaluative and experiential aspects of assessment are inadequately explored.

Secondly, many services now employ assistant psychologists to administer neuropsychological tests, freeing up valuable clinical psychology time for the more challenging aspects of assessment such as client interviews and report preparation. Although the use of assistant psychologists in neuropsychological assessment is governed by a clear code of practice (DCP, 2001; National Academy of Neuropsychology, 2000) and may indeed provide an important time saving service, clinical neuropsychologists may be in danger of losing valuable opportunities to gather qualitative data about the ways in which their patients pass or fail on standardised tests. This information is of great importance in evaluating the performance of people with acquired cognitive impairments. It supports a hypothesis testing approach to assessment, allowing clinicians to assess specific impairments in more depth, and feeds directly into problem solving and rehabilitation planning (Lezak, 1995).

Finally, clinical neuropsychologists, may, in some circumstances, lack confidence in addressing the issue of test feedback (Rice & Warner, 1993). Until recently, there was no mandatory qualification in Clinical Neuropsychology (DoN, 2002) and many practitioners worked alone, in split posts, with variable levels of supervision and with limited access to specialist BPS training opportunities (Goldstein, 1994). The BPS has done much to increase access to specialist training and develop codes of

professional practice, which hopefully will raise the confidence levels of practitioners. A follow-up to Goldstein's (1994) survey would be most welcome in profiling current clinical neuropsychology practice in the UK.

The term 'assessment' or 'testing' is likely to conjure up associations for patients of being examined or placed under scrutiny and, except in cases where patients have limited awareness of their own performance, most will make some evaluation of their performance (Keady & Gilleard, 2002). Such judgements, in themselves, may affect performance. The discipline's concern with objectivity often fails to take account of the patient as someone who actively construes their experience and makes judgements about their performance. Rather than being passive recipients of objective procedures, it can be argued that participants in neuropsychological testing engage in problem-solving processes where success or failure is often self-evident.

Accurate self-evaluation can be very beneficial in the management of neuropsychological conditions as it encourages realistic goal setting and the adoption of compensatory coping strategies (Prigatano, 1999). The judicious use of neuropsychological test feedback and reflection on the patients' perceptions of the testing process may not only help to optimise performance in testing but can also be seen as a means of educating the patient on the nature and management of cognitive impairment (Gass & Brown, 1992). This can contribute to the development of collaborative therapeutic relationships, particularly in the context of rehabilitation and adjustment to disability.

The professional practice literature, in its more recent publications, endorses the broadening of the remit of neuropsychological assessment to look at its role in treatment planning (Lemsky, 2000). With the growth in professional accountability to patients as consumers of health care (Department of Health, 1999) it is no longer appropriate to view patients as passive recipients of testing procedures, but as active collaborators in the management of their care (Department of Health, 2001). Recently the BPS produced a Code of Good Practice for Psychological Testing (2002) that formalises the responsibilities of clinicians in the testing process. It therefore seems timely, both for ethical and clinical reasons, to open up neuropsychological assessment to more scrutiny; to explore what participants understand of the experience and how they incorporate this understanding into the experience of their illness or disability.

1.3 Review of the Literature

As a first step in researching this topic, key texts in the neuropsychology literature (Groth-Marnat, 2000, Lezak, 1995, Spreen & Strauss, 1998) were consulted to identify guiding principles in the practice of neuropsychological assessment. A search of the literature was then carried out, using Psych. Lit, ClinPsych, Cinahl, Medline and Web of Science to search for references between 1980-2003 for articles relevant to patient experience of neuropsychology assessment. A small number of key references (less than 10) emerged through this search, which facilitated a process of identifying other cited references and tracking the development of thinking and research on the topic.

The literature search identified a number of key themes, which will be explored in more depth. These themes relate to: the professional practice literature, empirical

studies on the experience of neuropsychological assessment, the impact of providing feedback to patients and literature on sharing a diagnosis. The conclusions drawn from these studies led to a consideration of the theoretical issues that help illuminate our understanding of the nature and impact of the patient's experience of neuropsychological assessment. In this regard, the literature on the clinician-patient relationship will be briefly reviewed. This will be followed by a consideration of the nature of coping and adjustment to acquired neurological impairment and the broader role of assessment as part of the rehabilitation process.

1.3.1 The Professional Practice Literature

The assessment literature has been cognisant of the dynamics of the patient-clinician encounter for at least 50 years (for a useful review of the area see Berg, 1985) with much of the early writings coming from the psychodynamically influenced field of diagnostic personality assessment. The literature draws our attention to the emotional factors that influence how a patient responds to assessment tasks and suggests that performance related feedback facilitates a collaborative diagnostic relationship that fosters self-awareness in the patient (Pope, 1992).

Gass & Brown (1992) applied these concepts to the process of neuropsychological assessment, focussing on the particular responsibilities inherent in working with clients who are cognitively impaired. This paper draws our attention to the therapeutic and rehabilitative benefits of integrating neuropsychology test feedback into the ongoing treatment process. In particular, neuropsychological test feedback can be used to develop the patient's awareness of their strengths and weaknesses, and can be of help to family members in explaining problem behaviours and providing

guidance about future decision-making. The paper also highlights some important contextual issues governing the nature and timing of feedback to people with cognitive impairments, such as capacity to comprehend feedback, and diagnostic and prognostic issues that may more appropriately be taken on by, or shared with medical colleagues.

These concepts are clearly endorsed in core neuropsychology texts (Lezak, 1995, Spreen & Strauss, 1998). However, these principles are primarily based on clinical experience and intuition about the importance of the clinician-patient encounter. The process of neuropsychological assessment has been the subject of surprisingly little empirical investigation.

1.3.2 Empirical Studies

A small number of studies have evaluated the experience of neuropsychological assessment either directly (Bennett-Levy et al., 1994; Keady & Gilleard, 2000) or as part of a more general evaluation of consumers' experiences of services for people with brain injuries or memory disorder (Hill et al., 1995; McMordie et al., 1991, Wackerbath, 2001). Two core themes emerge from these studies, namely the communication of information and the impact of assessment on the patient.

Bennett-Levy et al. (1994) carried out a comprehensive postal survey of 129 participants who had undergone neuropsychological assessment in the previous six months. They were asked to complete a 48-item questionnaire detailing aspects of their experience of assessment. Three different psychologists assessed patients from five different centres in the region, thus reflecting different personal styles and

professional contexts of assessment. This study found that a positive evaluation of the assessment experience was associated with good preparation for the assessment and good quality feedback. Two thirds of the sample received no information in advance of the assessment, though nearly 70 per cent did receive feedback.

Of those who received feedback, half reported that this feedback was memorable and useful and that it changed their view of themselves or the future. Unfortunately the study did not explore the ways in which the patients' views were changed as a result of the assessment nor could it speculate on what aspects of the assessment experience contributed to this change of self-view.

A desire for information is similarly reflected in Hill et al.'s (1995) and Wackerbath's (2001) evaluations of user expectations of memory clinics, and McMordie et al.'s (1991) survey of consumer satisfaction with services to people with head injuries. In particular, users of services expressed a desire for information that explained the nature and causes of cognitive impairment and gave practical advice on how to cope with its consequences.

There is some support in the literature for the view that neuropsychological assessment is a stressful experience that can have an impact on the person's self-view. The most common reports centre on feelings of vulnerability and discomfort in the face of failing tasks that hitherto would previously have been well within the participant's competence (Benziman & Toder, 1993; Keady & Gilleard, 2002). In the Bennett-Levy et al. (1994) study, patients who initially expressed anxiety about presenting for neuropsychological assessment were most likely to experience a

change in confidence levels as a result of the assessment. Most of these patients reported feeling better about themselves as a result of the assessment but about one in six patients reported feeling worse. The study did not identify the factors that predicted deterioration in patients' confidence levels.

Keady & Gilleard (2002) used a qualitative methodology to explore the experiences of 15 patients with a possible diagnosis of Alzheimer's disease, presenting for neuropsychological assessment at a memory clinic. Their study cast light on the stages of the assessment process; the decision to seek help and the meaning of the referral to neuropsychology; the experience of testing or, in their terminology, "playing the game" of assessment; and the process of moving on or adjustment. Their study highlighted the uncertainties and sense of anxiety associated with the testing process.

It emerged that the assessment experience was an uncomfortable mixture of validation of the patients' own fears about their condition, and the threat associated with evidence of their failing memory and what that might mean for their future. Where participants were given little information about the nature and purpose of the assessment process, they constructed their own meaning, sometimes erroneously believing that attendance at the clinic meant they were "going mad". Against a background of ignorance of the real purpose of testing, patients were highly threatened by failure on tasks deemed "childish" or irrelevant. They sought out defensive strategies that helped them work out "the rules of the game", as they clearly took their performance seriously. Keady & Gilleard (2002) point out that this uncomfortable mixture of threat and validation is an inherent part of the diagnostic

process in dementia and needs to be addressed during assessment and as part of the follow-up process.

These studies suggest that patients come to assessment seeking an explanation of their difficulties and advice about how to cope with their problems. They are frequently poorly prepared for the experience. They can find the experience stressful and personally challenging and their confidence and self-view may be changed, for better or worse, depending on the quality of their experience. Patients want feedback on their test performance but do not routinely receive it. We remain unclear about what elements of the assessment process contribute to making it a helpful experience and unclear about how feedback is used and what makes it helpful to the patient.

1.3.3 Providing Feedback to Patients

Two studies that explored the effects of feedback on awareness of memory performance (Schlund, 1999) and behaviour (Schlund & Pace, 1999) postulated that quantitative feedback, delivered close to performance, increases awareness of deficit in brain-injured patients. Lack of awareness of deficit in brain injured patients poses particular challenges for treatment (McGlynn & Schacter, 1989), as inaccurate assessment of cognitive strengths and impairments can lead to a lack of participation in rehabilitation, poor judgements in decision making, and difficulties in maintaining everyday roles and responsibilities (Prigatano, 1999).

These studies lend support to the view that neuropsychological test findings can be used as part of a multi-disciplinary treatment approach to educate patients about discrepancies between their self-perceptions and their performance on objective

measures of functional and cognitive ability (Hibbard et al., 1992). They suggest that feedback can maximise the learning opportunities inherent in the testing situation.

Patients, who come to assessments eager for information and advice about their conditions, may be particularly sensitised to hearing constructive feedback that can enhance their self-awareness and capacity to cope realistically with their difficulties.

It appears that current practice fails to fully capitalise on the educational and therapeutic opportunities of the assessment experience.

1.3.4 The Literature on Sharing a Diagnosis

There is strong and consistent evidence in the medical literature that patients want to be provided with information about their diagnosis and prognosis (Jenkins et al., 2001; Meredith et al., 1996). Research also suggests that well-informed patients experience reduced psychological distress and better treatment outcomes (Fallowfield et al., 1990).

Much of this research has been carried out in the cancer field, an area where sharing the diagnosis of a potentially life-threatening, debilitating and painful condition is associated with anxiety and uncertainty for both the patient and clinician. Coulter et al. (1999) explored the challenges and therapeutic opportunities of sharing information with patients. They stress the importance of providing patients with good quality information about their illnesses, tailored to their individual needs, as this enables patients to engage in decision making about their treatment options and feel more empowered in managing their illnesses.

Recently, researchers in dementia care have begun to investigate the practice of sharing a diagnosis of dementia (Keightley & Mitchell, 2004; Vernooij-Dassen et al., 2003), and to explore its impact on patients (Husband, 1999; Wilkinson & Milne, 2003). The National Service Framework (NSF) for Older People (Department of Health, 2001) has emphasised the early diagnosis of dementia in enabling sufferers and their caregivers to respond effectively to the challenges posed by the condition, and regards the sharing of the diagnosis as being an essential part of this process.

In practice clinicians are often reluctant to share the diagnosis of dementia directly with the patient, citing concern that this may cause psychological harm to the patient, or result in the loss of hope (Husband, 2000). However, the results of an interview based study with 24 people with dementia (Pratt & Wilkinson, 2001, cited in Wilkinson & Milne, 2003) indicates that the participants were overwhelmingly in favour of being told their diagnosis and felt that it should occur as soon as possible in the diagnostic process. The advantages associated with such disclosure were that it provides opportunities to validate and appropriately label concerns about cognitive failings, it facilitates the process of coping and adjustment, it permits early contact with support and information services and enables individuals to make decisions and choices about the future.

A study on the effects of early intervention with people with dementia suggests that intervention impacts positively on memory functioning and use of compensatory strategies at 18-month follow-up. Furthermore, it is associated with improved carer well-being and less breakdown of home care (Moniz-Cook et al., 1998). Three feedback sessions were held with patients and their families subsequent to diagnostic

neuropsychological assessment. Eighty-six per cent of carers rated the feedback meetings as the most helpful aspect of the intervention. Moniz-Cook et al. (1998) suggest that a significant aspect of the value of these feedback sessions lies in the development of a therapeutic alliance with the patient and caregivers, where the clinician commences an engagement with the family that leads on to education in specific intervention strategies.

The dementia literature reflects a concern with raising clinicians' awareness of the benefits of sharing diagnostic information with patients. It acknowledges that clinicians need to acquire skills that will foster increased confidence and competence in working collaboratively with patients who face deterioration in their cognitive and physical functioning (Pinner, 2000). Dementia is a stigmatising condition that is associated with fears of a loss of self-integrity (Keady & Gilleard, 2002). Sufferers of many other neurological disorders, such as head injury, stroke and multiple sclerosis, that result in the loss of cognitive functioning, share this potential loss of integrity (Nochi, 1998) and struggle to fully comprehend the implications of their diagnosis (Calderwood, 2003; Cant, 1997). The issue of collaborative, treatment-enhancing information sharing has equal relevance for practitioners in neuropsychology and related disciplines.

Until recently, clinicians working in dementia and neuropsychology may have underestimated the capacity of people with cognitive impairments to benefit from collaborative information sharing but a growing body of research challenges these beliefs. It is likely that the discipline of neuropsychology has much to learn from the example of other areas of medicine that have recognised the therapeutic value of

Carefully timed and targeted information sharing between clinician and patient. The literature on the therapeutic benefits of the clinician-patient relationship will now be, briefly, considered.

1.3.5 The Clinician-Patient Relationship

The power and mysteries of the doctor-patient relationship has long fascinated the medical profession and has generated a huge literature in its own right (Ong et al., 1995; Van Dulmen & Bensing 2002). Researchers have looked at components of communication between doctors and patients and the impact of communication on satisfaction and compliance with treatment (Ley, 1988). Broadly, the results of these studies indicate that good doctor-patient communication is associated with improved patient satisfaction, reduced psychological distress, improved compliance with treatment goals, and better outcome on short-term measures of health improvement (Ong et al., 1995). More recently, Van Dulmen & Bensing (2002) have summarised the literature on the doctor-patient encounter and conclude that a good relationship promotes improved health by reducing anxiety, facilitating better sharing of information, and raising self-esteem and self-efficacy as a result of improved expectations about coping.

Different styles of relationship have been identified in the literature (Roter & Hall, 1992, cited in Ong et al., 1995), with the 'paternalistic' style of relationship, where control is held by the doctor acting as an agent on behalf of the patient, being associated with traditional medical practice. The growth in awareness of the patient as a partner in health care has led to a move away from the paternalistic doctor-patient relationship towards a more egalitarian, patient centred approach to medical care

(Department of Health, 1999). This type of doctor-patient relationship will be much more likely to value shared decision-making, with doctors fulfilling a facilitative role that allows information to be targeted to the needs and preferences of the individual patient.

Consumer research indicates that patients are clear about what they want from their relationship with their doctor. Studies consistently tell us that patients want doctors to be humane, to have time to listen to their needs and concerns, to share information with them and involve them in decision making (Coulter, 2002). They expect their doctors to be well informed and technically competent but primarily patients want their doctors to treat them as individuals within a relationship based on trust (Wright et al., 2004).

Involvement in decision-making does not necessarily imply that all patients want to take responsibility for decision-making. Many factors, such as age, sex, cultural variations and illness specific variables will influence the degree of patient autonomy and active involvement in decision making (Robinson & Thomson, 2001). The implications of the patient centred approach require doctors to develop better skills in assessing patient preferences for involvement in their own care, whilst not relinquishing their role in diagnosis and guiding treatment options.

Outcome studies in psychotherapy research indicate that the quality of the “therapeutic alliance” between patient and therapist is likely to be the most important factor, alongside therapist technique, in determining outcome, accounting for up to 29 per cent of the variance in therapeutic success (Roth & Fonagy, 1996). The impact of

the therapeutic alliance between clinician and patient is of undoubted significance across a range of health disorders and it underscores the puzzling lack of attention within neuropsychology to the domains of the assessment encounter.

Consumer studies in neurological rehabilitation (McMordie et al., 1991; Sabari et al., 2000) indicate that patients and their carers express similar needs to medical patients in terms of a desire for practical advice and information about diagnosis and treatment options. Furthermore, the quality of the relationship between patients and their therapists assumes a crucial role in patient evaluations of treatment experiences (Darragh et al., 2000).

Van Dulmen & Bensing (2002) suggest a model for understanding how a good therapeutic alliance between physician and patient facilitates improved health outcomes. They suggest that a trusting, collaborative relationship enables the physician to access better information from the patient, who by virtue of being less anxious, is less defensive and shares more evidence of symptomatology. This facilitates better diagnosis by the physician. A shared process of decision-making about treatment options leads to better compliance with treatment. In addition, a positive relationship allows for more hopefulness and a greater likelihood of positive expectations for coping.

Though as yet untested, this model fits well with the theoretical literature on coping and adjustment to chronic illness, which emphasises the role of appraisal, illness perceptions and access to a repertoire of adaptive coping resources in determining an individual's response to illness and disability (Maes et al., 1996). A brief review of

the literature on coping with neurological impairment will now be considered in light of the above formulation.

1.3.6 Coping with Neurological Impairment

People who develop a neurological illness or sustain injury or damage to the brain will experience a range of physical, cognitive and emotional sequelae that frequently impair their abilities to maintain essential life roles (Morton & Wehman, 1995; Murrell, 1999). Frequently the process of adjustment to neurological impairment will involve substantial revisions of the person's sense of self (Nochi, 2000), and the deployment of a range of coping strategies that help compensate for acquired deficits (Curran et al., 2000).

Theories of coping and adjustment to illness suggest that the individual's response to illness will be determined by their beliefs about the nature of the illness (Leventhal et al., 1980) and their responses to the demands and threats imposed by it (Lazarus & Folkman, 1984). These models have been adapted for understanding coping and adjustment in brain injury by Godfrey et al. (1996). They suggest that the nature of the coping process will be influenced by the interaction of pre-injury characteristics with the unique stressors posed by the injury, the person's appraisal of the threat associated with these injuries and the availability of coping resources to mitigate against acquired impairments and disabilities.

For people with acquired cognitive impairment, deficits in awareness and cognition may significantly impair their capacity to realistically assess the degree of threat associated with their limitations and in so doing, hamper rehabilitative efforts to

employ meaningful compensatory strategies or alter life goals (Port et al., 2002). The Godfrey et al. (1996) paper explored a number of factors, in addition to organic impairments, that may contribute to deficits in awareness. They suggest that pre-injury expectations of functioning (or sense of self), are highly overlearned and that many features of the person's environment and circumstances (friends, family, familiar home surroundings, possessions) serve to maintain a sense that previous abilities are preserved. Onset of impairment is often sudden and prognosis uncertain at the early stages of recovery. Professionals attempt to maintain a sense of hope and optimism and this sometimes can delay the full impact of long-term disabilities for up to two years post-injury (Ponsford et al., 1995).

This model suggests that the nature of the patient's illness appraisals will influence their willingness to employ (or learn to employ) appropriate coping strategies and resources to accommodate to their limitations. Evidence suggests that brain-injured patients who engage in passive or avoidant coping strategies experience more depression, anxiety and lower self-esteem than patients who endorse more problem oriented ways of coping (Curran et al., 2000). Deficits in insight occur partly in response to poor information about the nature and consequences of impairments (Prigatano, 1991). Thus it can be argued that providing the patient with objective and individually tailored information about their strengths and weakness can play an important role in helping patients adopt realistic and problem-focused coping strategies that facilitate better rehabilitation outcomes.

1.4 Gaps in the Literature to Date

An examination of the literature to date gives us some clues about the essential features of the patient's experience of neuropsychological assessment but there remain many gaps in our knowledge. All but the Keady & Gilleard (2002) study use survey type methodologies to investigate consumer views and many report a mixture of carers and patients opinions due to the variable capacity of cognitively impaired patients to respond to questionnaires.

The Bennett-Levy et al. (1994) study was designed to directly access the patient's viewpoint and provides a very comprehensive overview of the area, but tantalisingly leaves us with many questions about process issues that influence patient experience. For instance, the study reports that 67 per cent of patients learned something useful about their problems areas. Similarly, half of the sample learned something useful about coping with their difficulties but the study could not specify what was learned or in what ways patients found the assessment to be helpful in their everyday lives.

Furthermore, the paper suggests that the "system" or context of assessment may have had an effect on the patients' experience of assessment and on neuropsychology practice, but could not elaborate on these issues. The findings could not speculate on how the patients' views of themselves or the future had changed as a result of the assessment, or how the interaction between the patient and psychologist may have influenced this process.

The literature on coping suggests that an individual's response to a neurological injury will be influenced by their beliefs about the nature of their injuries/illness and their

use of problem-focussed coping strategies. The process of neuropsychological rehabilitation attempts to educate the patient about the nature and consequences of their acquired impairments and advocates a coping approach to the management of enduring deficits (Prigatano, 1999). The Bennett-Levy et al. (1994) study suggests that the process of neuropsychological assessment influences the person's self-image in relation to their illness and that the patient presenting for assessment seeks information that will guide them in how to cope.

Some of the limitations of the Bennett-Levy et al. (1994) study arise from its design. It utilised a fixed choice, yes/no format to facilitate its use as a postal questionnaire with a cognitively impaired population. This methodology did not allow for a more in-depth, qualitative exploration of process issues that may have cast light on some of the more interesting findings, such as how the process of neuropsychological assessment contributes to an improved understanding of illness, to the process of coping and to the maintenance of a positive self-image in the face of neurological disability. These issues require elaboration and this study proposes to investigate these questions in more depth.

1.5 Rationale for the Current Study

This study hopes to build on the findings of the Bennett-Levy et al. (1994) study and gain a more in-depth understanding of the experiences of patients who present for neuropsychological assessment. Drawing on the literature outlined above the study will explore patients' expectations and understanding of the purpose of neuropsychological assessment, which may cast light on how the assessment experience contributes to patients' understanding of their presenting problems. It will

explore how patients experience the process of assessment and consider the findings in relation to the existing literature on consumer experiences of assessment and the clinician-patient relationship. Drawing on the coping literature it will explore how the assessment experience impacts on the patient's sense of self in the context of their illness or injury and explore if, and how, the experience is perceived to have been helpful or unhelpful in the management of their condition.

The design of the current study will take account of the methodological weaknesses of previous research, in particular by considering the specific issues that arise when conducting research with people with cognitive impairments. People with cognitive impairment are more likely to have difficulty in the use of structured questionnaires or complex forced-choice measures due to linguistic, processing or attentional difficulties (Paterson & Scott-Findlay, 2002). This tends to limit the researcher to using simpler self-report measures that fail to answer questions in sufficient depth, as with the Bennett-Levy et al. (1994) study, or results in research that is unreliable in assessing the consumer's viewpoint (Hill et al., 1995).

People with cognitive impairments have better opportunities to express the uniquely individual aspects of their experience using a qualitative interview based methodology which follows a semi-structured format but allows some flexibility in following the data emerging from the interviewee (Paterson & Scott-Findlay, 2002). This study will adopt a qualitative methodology to investigate the patient's experience of neuropsychological assessment. The research will systematically explore the themes that emerge in response to open-ended questions from the interviewer and elaborate on novel or unanticipated issues that emerge from the research conversations.

1.6 Rationale for Interpretative Phenomenological Analysis (IPA)

A qualitative methodology, Interpretative Phenomenological Analysis (IPA), (Smith, 1996) was chosen to investigate these questions for two specific reasons. Firstly, the primary focus of the study is in discovering the personal meaning of the assessment process for patients who undergo assessment. This suggests a phenomenological, rather than an experimental methodology. IPA seeks to systematically explore the personal meanings and perceptions of an event or experience from the individual's perspective. Previous research has generally used survey type methodologies to produce summaries of patients' responses to fixed choice questions about the experience of assessment. This study will seek to explore participants' own accounts of neuropsychological assessment and through a process of systematic data analysis, identify and consider the themes that emerge from an interpretation of the data.

Secondly, the researcher comes to this study with assumptions about how participants may react to neuropsychological assessment. Her clinical experience and reading of the professional and research literature has influenced these assumptions. It is therefore explicit that the researcher will seek to meaningfully interpret the responses of participant's in the context of existing theory and research findings and in an attempt to build on existing knowledge. IPA methodology overtly acknowledges the interpretative role of the researcher and allows that process to be scrutinised by means of an audit trail and a detailed description of the interpretative process (Smith et al., 1999).

1.7 Relevance to Clinical Psychology

It is anticipated that the findings will raise clinicians' awareness of the therapeutic and educational aspects of neuropsychological assessment. It is anticipated also that the findings will contribute to our understanding of clinician-patient relationships within the context of neuropsychological assessment. The findings will have relevance for how clinicians construe the value and purpose of neuropsychological assessment and may indicate changes in how clinicians conduct their practice.

1.8 Research Questions

In keeping with the exploratory and inductive nature of research enquiry in IPA, four open-ended questions were chosen to direct the study:

1. What is the participant's understanding of the purpose of neuropsychological assessment?
2. What was the participant's experience of the process of assessment?
3. How does the experience of neuropsychological assessment leave the participant feeling about him or her self?
4. What do participants find helpful or unhelpful about the process of assessment?

Chapter Two

2.0 Method

This chapter will describe the author's "research journey", illustrating the natural history of the research process (Silverman, 2000, p.236) from its earliest conceptualisations, through its search for an appropriate methodology to answer the research questions, and ending with a detailed explanation of the methods of data collection and analysis. Mays and Pope (1995) state that "systematic and self-conscious research design, data collection, interpretation and communication"(p.2) ensure rigour in qualitative research. In keeping with this premise, the author will adopt a reflexive position in describing the evolution of the research methodology.

2.1 Context of the Research Questions

I came to this research as an experienced clinician who had worked for twelve years providing a clinical neuropsychology service in a district general hospital. The main emphasis of the work was in conducting neuropsychological assessments to aid diagnosis and treatment planning. In the course of my clinical practice I became more aware of the broadening of my role within neuropsychological assessment. Time was spent exploring patients' worries and concerns about their memory and cognition. Time was spent explaining the results and implications of the test findings. The assessment process frequently concluded with an exploration of the meaning of the assessment findings for the individual concerned and providing advice on ways to cope with the identified difficulties.

As a clinician I was convinced of the importance of this broadened role but wondered if I was unusual in the focus of my neuropsychology practice. Traditionally the practice of neuropsychological assessment sits at the “harder” end of psychological enquiry, requiring the use of standardised psychometric measures, administered in an objective manner. This can challenge the establishment of rapport in the neuropsychology consultation (Kaufman & Lichtenberger, 1999). Much emphasis is placed on the interpretation of test profiles and the production of neurologically meaningful reports (Donders, 2001b). Less is written about what happens in the clinician-patient encounter.

I became interested in exploring the perceptions of patients and clinicians of the assessment process, and when I embarked on post-qualification doctoral training resolved to explore this issue from a research perspective. Initially I hoped to use a triangulated design (Redfern, 1994), exploring the perspectives of both clinicians and patients, believing that it would lead to richer findings. I planned to carry out a large-scale, survey based, quantitative investigation of clinicians’ views, complimented by a qualitative study of the experiences of a small group of patients.

In reflection I was naïve about the complexity of the research questions and about the time scale of a research project of this nature. Feedback from academic supervisors led me to question if triangulation would actually lead to converging evidence on the same issues rather than incomparable snapshots of different expectations and experiences. This led me to redefine my aims and research questions. An extract from my research diary illustrates this change of focus:

“... I’ve reflected on the feedback I received on my original research proposal...and tried to build on that. All this leads me back to my original rather simple research question. What is the personal experience of neuropsychological assessment? My primary interest is to gather data in a systematic way that will contribute to psychological knowledge of processes experienced by clients undergoing neuropsychological assessment...I think the best way to do this is through a qualitative exploration of the personal experience of neuropsychological assessment” (19.08.02).

2.2 Matching Research Questions to Methodology

As a neuropsychologist, embarking on a qualitative research project was a frightening prospect. I worried about the “respectability” and credibility of conducting a qualitative investigation in a discipline predominantly allied to a positivist, experimental research paradigm and was concerned about the scepticism I might encounter from peers and colleagues (Morgan, 1998). I was aware that I had some personal investment in the assumptions and beliefs that underpinned the research questions and very much wanted to produce a piece of research that was theoretically driven, empirically grounded and methodologically robust, that could be critically evaluated and would hopefully be of a publishable standard.

A period of reading and discussion with colleagues and academic and clinical supervisors ensued. I decided that my research questions suggested a primarily phenomenological study. For a period of time I debated the relative merits of a Grounded Theory approach (Strauss & Corbin, 1994) and Interpretative Phenomenological Analysis (Smith, 1996; Smith et al., 1999). The incremental case-

by-case, theory–building approach of Grounded Theory seemed a less appropriate method of data analysis in view of the focussed nature of my research questions exploring specific aspects of experience. I was aware that I came to the research with clear assumptions about the nature of the assessment process that influenced my choice of research questions and that would, in turn, influence my interaction with and interpretation of the data.

The systematic method of data analysis developed by Smith (1995) with its explicit ownership of the interpretative process resonated with my developing awareness of my own epistemological position. I tentatively saw myself as a “subtle realist” (Mays & Pope, 2000), grounded in empiricism but appreciative of the dynamic nature of research into human experience where meaning is shared and constructed as part of the interactive research process (Mathieson, 1999). I attended two workshops led by Jonathan Smith (Smith, 2002a; Smith, 2002b) and my confidence grew that the methodology was right for my research questions. I also felt confident that I could access good supervision through my peers and academic tutors. Interpretative Phenomenological Analysis was therefore chosen as the methodology to guide the collection and analysis of the research data.

2.3 Research Design

The study used a within group qualitative design to investigate patients’ experience of the process of neuropsychological assessment. Rather than testing theory using a hypothesis testing approach, the aims of the study were exploratory and descriptive and sought to contribute to our understanding of the meanings of neuropsychological assessment for those people undertaking testing. In the qualitative research tradition,

an in-depth exploration of the perspectives of a small group of participants can be a means of deepening understanding in an incremental way (Buston et al., 1998). Data was gathered in face-to-face semi-structured interviews and the data analysed using Interpretative Phenomenological Analysis (IPA) (see Smith et al., 1999).

2.4 Participants

Nine participants, six women and three men, were recruited from the caseloads of four clinical neuropsychologists in a neighbouring Trust. They experienced a range of neurological conditions. The sample size was judged to be large and diverse enough to gather meaningful findings, yet small enough to facilitate analysis in the time scale available for the study. Five participants undertook neuropsychological assessment in an outpatient assessment service and four participants were assessed with a view to participation in a cognitive rehabilitation programme. Three qualified clinical psychologists assessed five of the participants and an assistant psychologist conducted the assessments on the remaining four participants. A participant profile is provided in section 3.1.

2.4.1 Sampling

Qualitative research does not aspire to produce statistical representativeness or broad generalisability to other populations. Rather it seeks to reflect diversity and communalities within a given population who share the experience of the phenomenon under investigation (Mays & Pope, 1995). Purposive sampling was chosen as a means of obtaining the perspectives of a diverse group of participants, with different neurological conditions and assessed by different clinicians. This would ensure that contradictory experiences were heard and facilitate “deviant case

analysis” (Mays & Pope, 2000) that ultimately adds to the rigour of the thematic interpretations and research conclusions.

2.4.2 Selection criteria

The following selection criteria were used.

Inclusion Criteria

- i. Age between 18-65 years inclusive at interview (this age group was representative of patients normally seen in the population under investigation).
- ii. Experience of neuropsychological assessment in the past eight weeks.
- iii. Ability to recall details of the assessment experience.
- iv. Knowledge of English sufficient to give informed consent and participate in the interview without the need for an interpreter.
- v. An awareness of their cognitive impairments that is wholly or partially consistent with the results of their cognitive assessment (judged by the clinician who conducted the assessment).

Exclusion Criteria

- i. Evidence of amnesic deficit that would preclude recall of the assessment experience.
- ii. Evidence of significant denial or unawareness of cognitive impairments that would preclude insightful participation in the interview process.
- iii. Evidence of a severe language/ communication disorder.
- iv. Significant problems with fatigue, distractibility or emotional inhibition, likely to hamper the interview process.

- v. Evidence that the participant is likely to suffer significant distress at the content of the interview.

2.5 The Interview Schedule

A draft interview schedule was drawn up following guidelines outlined in Smith (1995) and Rubin & Rubin (1995). The aim of the interview schedule was to provide a structured focus to questioning that would nonetheless allow participants to elaborate on the themes of importance to them. It was important to use a language and structure that accommodated any cognitive difficulties participants might experience (Paterson & Scott-Findlay, 2002). The draft schedule was shared with impartial clinical psychology colleagues and a neuropsychology colleague. On the basis of their feedback amendments were made that included a simplification of language in some instances and the inclusions of a question about the participant's understanding of the context of their referral to neuropsychology.

The final interview schedule (Appendix 1.1) comprised an introduction to the purpose and planned structure of the interview, questions exploring participants' expectations and understanding of the assessment, their experience of the process, their feelings and reactions to testing, their experience of feedback, and their general evaluation of the experience.

2.5.1 Piloting the interview schedule

The interview was piloted on a colleague who worked as a counsellor in the field of disability and had personal experience of head injury and neuropsychology

assessment. This was a valuable opportunity that confirmed the relevance and pacing of the questions in the planned format and sensitised me to the need to relax and allow the conversation to deepen as the interview progressed:

“Did a pilot interview with S. today which went really well...what was interesting was how the data got richer and deeper as the interview progressed – it didn’t feel as if I was going from broad questions to specific, but rather as if we were going from descriptive to insightful...initially I asked the questions in order and I thought I would be finished in fifteen minutes – then as I went more from topic to topic things began to connect together”. Extract from research diary (15.05.03).

In addition, the first two participants were asked for feedback on the content and structure of the interview schedule. The participants were comfortable with the format and had no suggestions for change. Consequently no further modifications were made and the data from the first two interviews were included in the analysis.

2.6 Procedure

2.6.1 Ethical Issues

Ethical committee approval was sought from and granted by the Local Research Ethics Committee (Appendix 1.2). The study adhered to the BPS Code of Conduct, Ethical Principles and Guidelines (2000). A number of important ethical issues were considered in view of the characteristics of the participant group studied, which are discussed below.

2.6.2 Selection of Participants

The participants were considered to be vulnerable by virtue of having some impairment of cognitive functioning. Thus it was imperative to ensure that they fully understood the nature of the research and the requirements of their participation in the study.

When considering the inclusion and exclusion criteria, I judged that the psychologist carrying out the assessment would be in the best position to select suitable participants and offer them pre-prepared reading material that would enable them to consider participation. Keady & Gilleard (2002) used this method of selection in their study of people with suspected Alzheimer's disease and it appeared a good model to follow. Thus, I was not aware of any participant details (other than demographic and contact details) that would hinder my hearing the participants' story telling in their own terms. This, hopefully, would minimise my sense of being in the role of clinical neuropsychologist, rather than researcher. This method of recruitment may of course have led to some selection bias, an issue that will be addressed later when the findings are discussed.

2.6.3 Recruitment Procedure

Each participating psychologist was individually briefed about the research. In addition to a verbal explanation of the study, an information sheet (Appendix 1.3) was given to each psychologist, outlining the recruitment procedure, which briefly, was as follows:

- At the end of an assessment suitable candidates were invited to participate in the study, using a prepared text (Appendix 1.4) and supplementary explanation as necessary.
- If the patient expressed an initial interest, the psychologist would pass their details on to me to arrange a pre-interview meeting or telephone conversation. Interested participants were given an introductory letter and information sheet to take home and consider further (Appendix 1.5).
- Undecided patients were asked if I could contact them by telephone after one week to check their interest in the study.
- Patients unwilling to participate received no further communication about the study.
- Participating psychologists agreed to provide any follow-up psychological support that might ensue from their patients' participation in the research.

Twelve potential participants were identified. I failed to ask if any participants were invited but refused to participate in the study. One willing person was over sixty-five years, and thus excluded on the grounds of age. One person was uncontactable and a third person was not available for interview within the necessary time scale because of holiday arrangements.

2.6.4 Consent Issues

Nine people were contacted by telephone and had a preliminary discussion with me about the study. We then met in person, where the study was further explained and issues of confidentiality assured. I read the consent form (Appendix 1.6) aloud to each participant and checked that each question was understood. All these steps were

followed before the participant was invited to sign the consent form. This ensured that information pertaining to the granting of informed consent was tailored to the participant's level of understanding (Wager et al., 1995).

2.6.5 Confidentiality Issues

The procedures for ensuring participant confidentiality were clarified with the psychologists and research participants prior to the commencement of the interviews. Participants' names and identifying characteristics were changed on the written transcripts. All data, discs and audiotapes were stored securely away from the hospital environment. Participants were assured that information was given in confidence and would not be fed back to their clinicians in any way that could personally identify them. An information sheet was sent to referring consultants as a matter of courtesy (Appendix 1.7). All participants agreed to be interviewed immediately after signing the consent forms.

2.7 The Interview process

Participants were interviewed alone, either in the participant's own home or in an office in the rehabilitation centre. The interviews were all conducted over a four-month period. Steps were taken to build rapport and re-orientate the participant to the nature and proposed structure of the interview process. The structure of the interview schedule was broadly followed, with probes, summarising statements and occasional re-orienting to the questions occurring depending on the responses of the participants.

2.7.1 Reflexivity

A number of participants displayed problems sustaining attention on the interview topics, particularly towards the end of the interview schedule. At times they wandered from the topic of conversation into tangential areas of interest, then lost their train of thought, asking, “What was I talking about again?” Others displayed language difficulties that hampered their ability to articulate their thoughts clearly. These are characteristic manifestations of cognitive impairment associated with neurological disorders (Lezak, 1995). As a result, I was aware that my skills as an experienced neuropsychologist came perhaps to my advantage, but this may have influenced, albeit in a facilitative way, the evolution of the participants’ stories. The implications of my role as clinician/researcher will be further explored in the Discussion section.

Thoughts, feelings and observations on process issues were recorded in my research diary (Appendix 2). These records were incorporated into later analysis of the data and the development of themes.

2.7.2 Debriefing

I was aware that the interview process explored sensitive issues. However, participants were able to talk about topics that they acknowledged were painful to them without undue distress. At the end of each interview the tape was switched off and the interview session closed by checking that all issues were adequately covered, that participants felt emotionally ready to leave the interview, and if there were any issues I needed to pursue on their behalf with their clinicians. Full details of the debriefing are provided at the end of the Interview schedule in Appendix 1.1.

2.8 Data Management and Analysis

IPA provides a step-by-step framework for the analysis of interview transcripts that was followed in this study (Smith et al., 1999). Smith's approach combines a systematic and auditable method of working iteratively through individual transcripts, acknowledging that the process is of necessity creative and dynamic, as ultimately the work is a reflection of the researcher's interpretative framework (Smith et al., p.220). The method advocates that close reading of each individual text is followed by preliminary identification of themes. Themes are then clustered into higher order categories that connect together meaningfully, first within individual transcripts then across all cases. These master themes allow for the development of new or unanticipated understandings of the phenomenon under investigation.

In this study, an idiopathic case-by-case method was followed (Smith et al., 1995). Each tape was listened to immediately after the interview and preliminary thoughts noted. I personally transcribed tapes one to seven but not the final two due to time pressures. The following steps were then taken in the analysis of each transcript:

- Each interview transcript was read a number of times and key items of interest noted on the left margin of the transcript. I considered the question, "What are they saying?"
- The transcript was read again, this time considering "What does this mean?" These preliminary themes were noted on the right hand margin of the transcript.
- I then constructed a list of preliminary themes. For each theme I sought to reference it with a quote from the text, thus "grounding the example"(Elliott et al., 1999). As a result some themes were discarded and others became more prominent.

- A list of master themes with constituent sub-themes evolved from this process, though a cyclical process of sourcing references to support emerging interpretations and connections.

This was a challenging process, illustrated by the following extract from my research diary:

“[I am] struggling to ...move forward...I am plagued by anxiety ...anxiety that I am not doing it right, that I haven’t got enough time to do it thoroughly enough, that I’m missing something important, that I’m being too interpretative without basing it enough on the data.

Part of me knows, however, that this is my own personal reaction to this process of research. It is very personally challenging, it makes us question and doubt our insights as researchers, and that is scary and time consuming and difficult. However another part of me is hugely enjoying the process, finding it really *fascinating and rewarding...*” (20.11.03)

I returned to Smith’s writings, endorsing the discipline of sourcing quotes to support themes. This liberated the interpretative process as I felt I was guided by the text.

- I moved on to produce a thematic summary for each participant (Appendix 3.1). This helped in the development of my thinking about overarching themes for the combined analysis. The master themes from individual transcripts were combined into a table of master-themes and sub-themes and checked for commonalities and connections.

- This process was subjected to a number of revisions, facilitated by the comments of a colleague experienced in qualitative research who conducted an audit trail on one transcript, and the discussion of the coherence of the proposed connections with my academic supervisor. Elliott et al. (1999) recommend these methods of credibility checking to ensure rigour and legitimacy in qualitative research.
- To facilitate the communication of my finding I returned to my research questions and asked, “how does this information answers my questions?” and “what are participants telling me that I did not anticipate?”

A summary table of master themes and sub-themes is presented in Section 3.2.

Quotations from each participant to support master themes and constituent sub-themes are provided in Appendix 3.2, and extracts from two interview transcripts in Appendix 3.3, to facilitate independent scrutiny of the interpretive process.

2.9 Validity Issues

Elliott et al. (1999) recommend a number of criteria for evaluating the quality and rigour of qualitative research studies. Their quality criteria reflect the specific aims of a qualitative research paradigm, where the meaningfulness of the data is judged according to its “trustworthiness” which is achieved through transferability to similar samples, credibility or resonance with the reader, and transparency or auditability (Stiles, 1993). The following criteria from Elliott et al. (1999) were adopted in this study:

2.9.1 Owning One's Perspective

The context of the study is described in a manner that discloses the interests and assumptions of the researcher and makes transparent their role in the planning and conduct of the study. This is described in depth in sections 2.1 and 2.2.

A reflexive research diary outlines the researcher's presumptions and tracks the development of analytic thinking (Silverman, 2000). It is regarded as an essential tool in ensuring transparency of thinking and method in qualitative research (Stiles, 1993).

A detailed research diary is provided in Appendix 2.

2.9.2 Situating the Sample

A profile of participants, as provided in section 3.1, details the life contexts and characteristics of the participants. This allows the reader to make judgements about the transferability of the research findings.

2.9.3 Grounding in Examples

The analytic process is described in detail by providing examples from the text that illustrate the development of themes and interpretations. In Appendix 3 examples are provided of the steps taken in data analysis.

2.9.4 The Audit Trail

The research diary, coupled with a detailed description of the process of data analysis facilitates an audit trail that enables the research to come under independent scrutiny, and makes explicit how conclusions were reached. This is one of the most important

ways in which the issue of reliability or rigour is addressed in qualitative research (Mays & Pope, 1995).

In this study a colleague experienced in IPA conducted an audit trail. She tracked the development of thinking and interpretation in the case of participant 7 (Barbara) and concluded that it was:

“...extremely clear how I had come up with the themes and how and where they were related to the transcripts” Extract from research diary (29.01.04).

2.9.5 Respondent Validation

The participants were offered a summary of the main themes emerging from their interview once the analysis of individual transcripts was completed. All participants expressed an interest in receiving a copy. Their feedback was invited as a way of checking that my interpretations were broadly consistent with the perspectives of the people I listened to, that the conclusions reached had some credibility and coherence (Turpin et al., 1997). Examples of participant responses to the summaries are provided in Appendix 3.4.

Participant validation also served an important closure function, which for me as a clinician/researcher assumed an importance that may well have been driven by my own need to “end things well” for participants, but which also addressed an emergent theme concerning the importance of feedback:

“I am very conscious that the interview process is an interactive process – that the experience of being interviewed also has an impact on how the participant

feels, and perceives their experience. Participants have said that it has felt like debriefing, that it has helped them think *about things they haven't thought about before*. *I am anxious to give them feedback, to help "close" the interview as I'm aware that they have not been unaffected by participating in the experience...*"

Extract from research diary (22.07.03).

2.9.6 Generalisability and Resonance with Readers

Good qualitative research does not attempt to make broad generalisations about the representativeness of its findings. Rather it seeks to draw conclusions from the specific research tasks it sets itself and looks to see if the findings resonate with readers, if the findings tell a contextually meaningful story (Elliott et al., 1999). It does not seek to tell absolute truths but to add to our understanding of complex phenomena in an incremental way. Thus the findings aim to be transferable to similar populations or case examples in clinical practice, to add to the body of research evidence already gathered and contribute to developments in theoretical understanding and clinical practice (Buston et al., 1998). These issues will be further explored in the discussion section.

The results of the analysis will now be presented.

Chapter 3

3.0. Results

3.1 Participant Profiles

Defining characteristics of each participant are given below to “situate the sample” (Elliott et al., 1999). In order to maintain participants’ confidentiality, pseudonyms have been used and identifying information modified throughout the dissertation.

Participant 1: Rachel (interviewed at home, duration approximately 45 minutes)

Rachel is a 25-year-old office worker who lives with her partner, Tom. She experienced a brain haemorrhage five months prior to being interviewed and had initially been treated for three weeks in the Stroke Unit of the local hospital. She was now living at home with her partner and had not yet returned to work. At the time of interview she was undergoing a three-week assessment at a local rehabilitation centre and had participated in a battery of neuropsychological tests, administered by an assistant psychologist. At the time of assessment Rachel was awaiting feedback on her test results from a qualified clinical neuropsychologist. This would happen at the end of her period of assessment.

Participant 2: Denise (interviewed at the Rehabilitation Centre, duration approximately seventy minutes).

Denise is a 54 year-old public servant, who lives alone. She has a history of a severe head injury that occurred 40 years previously, whilst living abroad. Despite her injury she had established a successful professional career and was very distressed to find herself the subject of a competency dispute with her managers three months into a

new job. She was referred for neuropsychological assessment by her Occupational Health Department, at the request of her managers. She participated in a battery of neuropsychological tests routinely administered to patients by an assistant psychologist. A formal report would be sent to her managers but she was given the opportunity to meet individually with the supervising neuropsychologist to discuss the test findings. At the time of interview she was still awaiting this feedback.

Participant 3: Danny (interviewed at the Rehabilitation Centre, duration approximately seventy minutes).

Danny is a 45-year-old man who lives with his partner Simon. He has a history of severe epilepsy and numerous skull fractures. In the past he was also a heavy drinker. His specialist nurse referred him for assessment as he had been having memory problems and episodes of disorientation subsequent to his seizures. He has had numerous experiences of medical investigations in the past. For Danny it was very important that his homosexuality was acknowledged and accepted by those with whom he came into contact. Danny was assessed by a qualified clinical neuropsychologist, who provided him with test feedback at the end of his assessment.

Participant 4: Rosa (interviewed at the Rehabilitation Centre, approximate duration, 50 minutes).

Rosa is a fifty-year-old lady who lives with her daughter. Rosa has significant memory impairment and needs considerable support and supervision in the management of everyday activities. She is very close to her Mother, who, along with Rosa's teenage daughter, has provided Rosa with a great deal of practical and emotional support since having had a stroke four months previously. At the time of

interview Rosa was attending the local Rehabilitation Centre for a period of therapy, and like Rachel, had participated in a battery of neuropsychological tests, administered by an assistant psychologist.

Participant 5: Paul (interviewed at home, approximate duration one hour, ten minutes).

Paul is a 38-year-old man who was diagnosed two years previously with the autoimmune disease Lupus, which causes joint pain and in addition, can cause cerebrovascular haemorrhages. Paul had experienced a stroke nine months prior to the interview, which left him with a significant visual impairment, in addition to speech and memory impairments. Paul is no longer at work and lives with his brother, his sister and her two young children. He was referred for an outpatient neuropsychology assessment by his consultant neurologist, as part of his follow up care at the local hospital, and was assessed by a qualified clinical neuropsychologist. Paul received feedback from his psychologist on the day of his assessment.

Participant 6: Frances (interviewed at home, duration approximately one hour and fifteen minutes).

Frances is a 61-year-old married lady who lives in her own home with her 18-year-old daughter. She has three older sons and, prior to the road traffic accident that caused her head and orthopaedic injuries, she worked in mental health services. She is an outgoing and sociable person who is actively involved in her local Church. Her community neuro-rehabilitation team referred her to the local rehabilitation centre and prior to the interview Frances had completed an assessment with an assistant

psychologist. She awaited the results of her assessment and a decision about her suitability for the rehabilitation programme.

Participant 7: Barbara (interviewed at home, approximate duration, one hour).

Barbara is a 56-year-old married lady who lives with her husband and two grown up children. Prior to her recent stroke, Barbara worked in the family printing business. In her spare time she writes poetry and short stories and has had a number of pieces published. Barbara had her [second] stroke nine months previously and had spent six months in hospital. She had recently completed a period of rehabilitation. She had undergone an assessment as part of her rehabilitation programme, conducted by a qualified clinical neuropsychologist.

Participant 8: Alistair (interviewed at home, approximate duration, one hour and fifteen minutes).

Alistair is a 22-year-old University student who sustained a severe head injury nine months previously after falling from a height. His condition at first was critical and his parents were told on at least two occasions that he would die. He was in hospital for six weeks and then had a period of, mostly physical rehabilitation, in his University town. He then spent a period of time in his local hospital. His consultant neurologist referred him for a neuropsychology assessment to check out concerns about his memory and cognitive functioning prior to his return to University. A qualified neuropsychologist conducted Alistair's assessment and provided feedback to himself and his parents on the day of the assessment.

Participant 9: Julia (interviewed at home, approximate duration, one hour).

Julia is 43 year-old married lady with a four-year-old daughter. She works in the computer industry. She has a diagnosis of multiple sclerosis and has noticed a worsening of her symptoms since the birth of her daughter. She requested a review with her neurologist, as she was concerned about deterioration in her cognitive functioning. She noticed that she could not think of a number of things at once and this was affecting her at work. Julia was assessed in an outpatient neuropsychology assessment clinic by a qualified clinical neuropsychologist. She was expecting to get the results of her assessment from her neurologist.

3.2 Results of Data Analysis

This section will present the results of the data analysis on the nine participant interviews and consider the themes identified, in the light of the four research questions. Each research question will be considered in turn, then any emergent themes, not anticipated at the planning stages of the research process, will be considered separately.

Six master themes emerged from a detailed analysis of the transcripts: Expectations of Assessment, Context of Referral, Experience of Process, Impact on Self, Components of a Good Assessment and Experience of Illness/Disability. Table 1 presents the master themes and their constituent sub-themes and indicates how many participants shared in experiencing each sub-theme.

Examples of extracts from which the themes emerged are presented, showing the pseudonym of the participant speaking and reference to the page and line number in

the transcript. Where phrases are truncated by pauses in speech or where parts of the text have not been included in the quote this is indicated by dots (...), and where the subject of a sentence was not referred to in the transcript reference, this has been added in square parenthesis [].

Table 1: Matrix of Master Themes and Sub-themes

	Rachel	Denise	Danny	Rosa	Paul	Frances	Barbara	Alistair	Julia	Total
1. Expectations of Assessment										
Fears and Uncertainties		✓	✓	✓	✓	✓	✓	✓	✓	8
Information and Clarification	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
Advice on Coping	✓	✓				✓	✓	✓	✓	6
2. Context of Referral										
Trust in Professionals	✓		✓	✓	✓	✓		✓	✓	7
Coerced Assessment		✓					✓			2
3. Experience of Process										
Emotional Engagement	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
Relationship with Psychologist	✓	✓	✓	✓	✓	✓	✓		✓	8
Awareness of Performance	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
Feedback Process	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
4. Impact on Self										
Self-Awareness	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
Self-Esteem & Validation		✓	✓	✓	✓		✓	✓		6
Use of Strategies			✓	✓	✓	✓	✓		✓	6

Table 1 (continued)

	Rachel	Denise	Danny	Rosa	Paul	Frances	Barbara	Alistair	Julia	Total
5. Components of a Good Assessment										
Providing Information	✓	✓						✓	✓	4
Good Preparation for Testing		✓	✓				✓			3
Providing Feedback			✓			✓		✓		3
Acknowledging the Emotional Impact	✓	✓						✓		3
Facilitating Coping and Adjustment			✓	✓	✓	✓	✓			5
Support Structures						✓			✓	2
6. Experience of Illness/Disability										
Accessing Information/Services		✓		✓		✓		✓	✓	5
Being Heard as a Person			✓		✓		✓	✓		4
Power imbalances		✓			✓		✓			3
Coping and Adjustment	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
Social Support	✓	✓	✓	✓	✓	✓	✓	✓	✓	9

3.3 Research Question 1: What is the participant's understanding of the purpose of neuropsychological assessment?

The participants' understanding of the purpose of assessment will be considered in relation to two master themes: Expectations of Assessment and Context of Referral.

3.3.1 Expectations of Assessment

i) Fears and Uncertainties: All but one of the nine participants was uncertain about what to expect from their neuropsychological assessment. In general they had been given little advance knowledge or preparation:

“To be quite honest, I didn't know what to expect, because nobody told me anything about it...it was just a psychological assessment.” (Alistair, 7:12).

Barbara was fearful about the prospect of referral to neuropsychology as she associated it with the detection of psychopathology:

“I was horrified when I saw it on my programme and wondered if I'd done something strange...I had an adverse effect on the drugs... and I wondered if it was after I'd had those drugs that they thought I'd been strange, still strange” (Barbara, 1:7).

Danny was anxious as he expected the assessment to be similar to traditional medical investigations, which in his experience had been distressing and impersonal:

“I feared it, because ...I wasn’t familiar with what it would mean...and I kept getting thoughts of...” Oh, my God, is it going to end up like scans I’ve had at X. Hospital ...I was afraid it might mean just coming in and being thrown on a couch, twenty little attachments to my head...” (Danny, 4:21).

Rachel’s experience was the exception to the general case. She had been assessed once before whilst in the acute stroke unit, so her expectations of assessment were more realistic:

“The types of tests that were used were similar but obviously more extensive...um, but they were similar to little ones that were done while I was in hospital...It would be lots of memory testing and things like that...” (Rachel, 1:28).

ii) Information and Clarification: Despite their uncertainty about the assessment process, participants expressed a desire for information about the nature of their difficulties and clarification of why they experienced problems in particular areas of their lives:

“...but at least if I’m struggling with something then I know why I’m struggling, ‘cos maybe that bit was killed in the bleed...or whatever...” (Rachel, 4:36).

“I wanted to understand ...why...em... I might find doing certain things rather more difficult than other things, because I used to be able to do them without any problem at all” (Julia, 5: 31).

iii) Advice on coping: Six participants clearly expressed a desire for help and advice in coping with their difficulties. Frances was relieved to be referred to neuropsychology:

“I wanted to be helped to get myself better. I didn’t know how many of the areas that I now have weaknesses in, em, how many I could strengthen but I knew that I needed professional help” (Frances, 1:7).

Denise, too, appreciated the opportunity to reflect on the nature of her difficulties and hopefully learn something from the experience that would influence the direction her life might take:

“What can I do about it? What can others do about it? How’s this going to impact on my...on, you can call it my career and what I’m doing?” (Denise, 14:36).

3.3.2 Context of Referral

i) Trust in Professionals: Despite their uncertainties, participants accepted their referral to Neuropsychology frequently out of a sense of trust in the judgement of the professionals who had instigated the referral:

“So, it was a bit of a mystery but... I didn’t mind ...because I believe that... you are looking after my best interests...the point is, you’re in your field and you know what you’re doing...” (Paul, 4:19).

For Julia and Alistair, their consultant neurologists played an important role in facilitating the referral and explaining its purpose:

“[Dr.X] pushed me to have a em...psychological assessment because he was slightly worried about my short term memory” (Alistair, 3:9).

“Dr. X. had said to me that, eh, Mr P. is very good because he can work on, em, doing various... mental exercises to eh, determine which bits of the brain were working ok and which bits aren't ...” (Julia, 3:25).

In Julia's case, it was expected that her consultant neurologist would also be the one to make sense of the findings and advise her on the implications of the results for important life decisions:

“ I need to go back and see Dr. X when he's in receipt of the report... to be able to... work out what, what I'm still going to be good at... and... those types of things... I don't find ... as easy to do...” (Julia, 27:23).

Rosa, Barbara and Frances were referred for neuropsychology assessment in the context of a multi-disciplinary assessment for a rehabilitation programme:

“I had different assessments, different therapists, I think it was quite...I think it was a team” (Rosa, 6:9).

For Barbara the referral was unexpected and seemed unconnected with her everyday experience of rehabilitation:

“With the psychologist you have no daily contact with them... we don’t actually know one another. Whereas with the nursing staff and the physio... you’re in daily contact with them and they actually know your personality” (Barbara, 2:19).

However, she acquiesced to the referral out of a desire to please her rehabilitation therapists and not challenge the expectations placed on her as patient in a rehabilitation programme.

“I didn’t want to appear awkward and that... I wasn’t being co-operative ...you know, as was expected of me... but ...if they had said, do you want to do this, and it wouldn’t have affected their opinion of me, I would probably have said no...” (Barbara, 17:22).

Here Barbara reflects an innate understanding of the power imbalances operating within healthcare relationships where, in order to ensure the specialist help she required, she opted not to challenge the system. This sub-theme will be explored further in section 3.5.

ii) Coerced Assessment: For Denise and Barbara the referral to neuropsychology was associated with a certain element of coercion:

“I’ve...been hitting problems in work... I understand that I am “kakhanded”, clumsy, and slow ..I told [my manager] ... as far as I’m concerned there was no medical... mental problem... but she kept on and on... and so I said...I will go to the Occupational Health Department, who in turn referred me here, because I have a history of head injuries...” (Denise, 1:3).

This, in Denise’s case, led to feelings of disempowerment and detachment from the assessment process, which she acknowledged was associated with the circumstances of her referral:

“... I’ve held responsible positions, and yet, I actually felt, I couldn’t ask...but ... the situation I’ve been finding myself in at work has been very disempowering...so I don’t know how much of that has been following me into the situation.” (Denise, 7:11).

In summary, participants, generally, were poorly informed in advance about assessment process but accepted the referral nonetheless, either out of a sense of trust in their referring practitioners, or because they did not feel they had a great deal of choice. The context of their referral influenced their expectations, in that they either went in with an open mind or approached the assessment with apprehension and defensiveness. All participants wanted information about the nature of their difficulties that had relevance for their everyday lives. They hoped the test findings would help solve problems and improve functioning.

3.4 Research Question 2: What was the participant's experience of the process of assessment?

3.4.1 Experience of Process

i) Emotional Engagement: Participants found neuropsychological assessment to be an emotional experience in a variety of ways. Julia found it a physically and emotionally demanding experience:

"I'd almost felt that, em, my brain had been, been through a wring... through a mangle...or something...because... it was hopeless, absolutely hopeless" (Julia, 13:27).

Rosa felt:

"... stupid, although that's not a nice word ...but that's how it makes you feel, it makes you feel stupid, is that...a little child would know that, how comes you don't know?" (Rosa, 12:27).

Frances poignantly described her distress at not being able to recall historical facts or recognise designs, skills that were previously particular talents of hers:

"I knew that I knew them and it upset me greatly that I couldn't do them...that night in bed at three o'clock in the morning I was still going over it...even now it's upsetting me to think I couldn't do it" (Frances, 8:22).

Rachel approached the tests in a matter of fact way:

“I didn’t think anything of it, I suppose...I thought the tests were quite nice to do ...at least it’s getting your brain in gear...” (Rachel, 5:3).

She acknowledged however that she had not always found it so easy and that the context and stage of recovery make a big difference to one’s reactions:

“When I had the tests done [first time], I think it was three weeks since...I’d got ill, so it was all new to me ...and it was absolutely devastating to be given these simple things to do, like to be asked to name some animals, and I could say, probably one... that was awful.” (Rachel, 6:28)

Alistair, on the other hand was “*chuffed*” (Alistair, 45:16) with the experience:

“...it is so simple, and you are comfortable with failure, em, you get your feedback straight way... I don’t see how it’s a traumatic process” (Alistair, 45:27).

He was particularly pleased that his parents were involved:

“The interview bit at the beginning was super...the way it was set up and with my parents being there” (Alistair, 9:1).

Denise and Barbara found the experience more distressing. Denise was extremely anxious due to “*the whole situation that precipitated it*” (Denise, 4:39). She felt “*patronised*” (Denise, 6:17) and scrutinised:

“...I actually felt a little bit like...like an insect on a pin” (Denise, 16:32).

She reported that throughout the assessment she was “functioning practically on auto-*drive*” (Denise, 4:24). She felt exhausted afterwards and had to take two days off work subsequently to recover her equilibrium:

“I just felt totally exhausted...it actually triggered off a whole lot of feelings regarding the accident ...” (Denise, 10:39).

“It was a lot more than I expected... I really didn’t anticipate that kind of reaction” (Denise, 13:36).

Barbara was left feeling let down and somewhat resentful about her experience:

“Well...if it’s like you said, we’ll find out your strengths and weaknesses and you can help me... well... it’s too late to give me the results when I’ve left. I need them at the beginning...I don’t think it’s very professional that I don’t get the results” (Barbara, 12:15).

This lead her to minimize the value of the assessment, something that was quite out of keeping with the rest of her experience in the rehab unit:

“Everything else has been so positive ...here I haven’t really benefited at all” (Barbara, 16:17).

In summary, participants displayed a strong sense of emotional engagement with the process of assessment, ranging from situational feelings of frustration and embarrassment through to quite enduring experiences of distress.

ii) Relationship with Psychologist: The vulnerability of being exposed to evidence of loss of functioning touched many participants deeply but most still emerged with a sense of having benefited from the experience. What appeared to make the difference in many instances was the quality of the participant's relationship with the psychologist. For some, the nature of their encounter with the psychologist was the defining element of the whole experience and transformed their view of themselves and their difficulties:

“I was being helped... towards helping myself, and I felt very comfortable about that, and em... to be able to walk down the street, put my shoulders and say, ‘well, I’m as good as the next one!’ and...I am dealing with the little problems that I have in my way and under guidance from a professional, P” (Danny, 19:34).

Danny, a homosexual man, with a history of severe epileptic seizures, was made to feel comfortable and accepted in the assessment, which led to him to approach testing without concern:

“Within a couple of minutes I felt comfortable in that area of my life...to break down any concerns that I have, or might have had with the consultants etc...that I might have seen previously” (Danny, 7:31).

“...he made me comfortably aware of what was going to be happening and eh...that I’d feel one hundred percent comfortable if I got the whole damn thing wrong” (Danny, 15:18).

Here Danny captures the essence of good rapport in the testing relationship, which for many bolstered them against the more threatening aspects of the testing experience. The psychologist was sensitive to Danny’s previous experiences of medical care, which for him, were depersonalised and frightening.

Paul’s narrative also bears witness to the powerful effects of the clinician-patient relationship. He was very appreciative of the attention paid by the psychologist to all his needs, as a patient and as a person. He was greatly touched by the personal approach of the psychologist who telephoned him in advance to confirm the appointment, welcomed him on arrival, and offered regular comfort breaks. This seemed quite unusual in comparison to his previous experiences:

“I found the whole experience with P. very good...he was so down to earth, he wasn’t really like a doctor, he, he, spoke to you like a person... not, you know, another case...” (Paul, 31:34).

Another characteristic of the psychologist’s role appeared to centre on holding and supporting behaviours that facilitated the participant working to the best of their ability. Participants appreciated psychologists giving clear instructions and

preparation for tasks, gentle encouragement to persist in the face of challenge and demonstrating an understanding of when to abandon tasks:

“P. ...did say which ones are timed and which ones, em, take more time to do, but... said... just do as many as you can as quickly as you can. You won't get them all done...so don't even think you're supposed to... just do the best you can...” (Julia, 8: 26).

iii) Awareness of Performance: All participants were sensitive to their performance on tasks:

“ I tried to recall listening to the story, and what the hell the story was about...and I had no recollection whatsoever...” (Danny 9.31).

Even those with very disabling memory deficits, such as Rosa, could reflect on their test performance:

“... and things that I could remember from the picture...what was different about the picture, that was it... what was missing from the picture?” (Rosa, 9: 13).

This indicates that participants display an active intellectual engagement with the process of neuropsychological assessment, over and above any objective feedback they may receive about their performances. The impact of their emotional and

intellectual engagement with assessment is strongly influenced by the relationship established with the psychologist.

iv) Feedback Process: All participants took the testing process seriously and were eager to receive feedback on their test performance. Participants valued the opinion of their psychologist:

“Because you think, oh, she’s qualified...she’s the one who knows. I mean I’m talking to her, I’m here for her help...” (Rosa, 27:28).

Many hoped that the test feedback would guide their decision-making about important life issues and offer advice in coping with their difficulties:

“I’d like to go back to work very, very soon...but I’m holding off until I get all the test results back...” (Rachel, 9:5).

Only Alistair, Danny and Paul had received verbal feedback at the end of their assessment. They were assessed in an outpatient assessment clinic, by a qualified and experienced clinician. For them receiving feedback was a positive experience:

“We all went back in, my parents as well, which again was good because otherwise they would feel disjointed from the whole thing..., [he] just went through the results and ...he hadn’t found any major problems, em, he just sort of filled me with confidence and them with confidence.” (Alistair, 27:11).

Julia's results were to be sent to her neurologist:

“He said he would em...write an official report and send it to Dr. X...what P. suggested was that...make the appointment with Dr. X and ...he'd [the neurologist] probably give me a better idea as to ...what...you could do to improve in whatever area is wrong...” (Julia, 24: 10).

Those seen within a rehabilitation setting had, in all but one case, been assessed by an assistant psychologist, who was not in a position to feed back test findings. This would be deferred until the multi-disciplinary team considered their results in the light of other assessments. This was not a problem for Rachel who had an understanding of the nature of the tests and was aware of the organisational timetable that clearly established what to expect and from whom:

“...it's obvious, the tests are so in-depth... you appreciate that it takes time...to get all the information back out of them...I was told that I...would get some results ...when I meet at the end of my assessment... I think the Chair tells me right at the end of the assessment” (Rachel, 9:49).

Denise's test findings were sent directly to her Occupational Health Department and subsequently shared with her managers. She received some feedback from Occupational Health but the experience was impersonal and threatening to her self-view and, potentially, to her career:

“[The results] were given by the occupational health doctor...who wrote to me...the word [she] actually used, because it went to my manager as well, was that I have a learning difficulty... that’s quite a thing to hear, learning difficulty...” (14:19).

Frances was awaiting her feedback with some trepidation, admitting she was “half afraid of getting it” (Frances, 17:14). She highlighted the vulnerability of patients receiving feedback of test results and had some suggestions for ways in which it should be managed:

“...it’s a vulnerable situation because part of you is frightened of knowing the results... and part of you wants to know... if there’s someone knowledgeable with you and you can say to them, well, is there any possibility that I can do something that will help myself with this or, how long will it take and is there a chance that I’ll regain something here, em...or, or if I can develop my strengths...” (Frances, 22:17).

For Frances, as with the other participants, the feedback of test results was a crucial element of the assessment process, but sadly it was something that was sometimes delayed or poorly managed, leaving participants like Julia to hope that she would receive the advice she needed:

“...hopefully if I need to get in touch with him I can leave a message on the answer phone, because he must have an answer phone... I’m rather hoping that

we will be able to come up with... something to build on from the outcome of the report...” (Julia, 31:22).

The shared experiences of the participants leave us in no doubt that the process of neuropsychological assessment is a meaningful one. It impacts on the participants’ emotional vulnerabilities and exposes them to evidence of their cognitive impairments and limitations. It facilitates self-evaluation and raises hope that they will receive expert advice that may cast light on their difficulties. They have a desire for meaningful feedback but this process is often delayed or unsatisfactory. Patients find themselves at the end of channels of communication, raising questions about the ownership of the results of neuropsychological testing. The personal impact of assessment will now be considered in more depth.

3.5 Research Question 3: How does the experience of neuropsychological assessment leave the participant feeling about himself or herself?

3.5.1 Impact on Self

i) Self Awareness: The participants’ sensitivity to their own performance during testing led to numerous references in participant transcripts to a heightened level of self-awareness subsequent to the testing process:

“It makes you aware of the problems you’ve got” (Rachel, 5:45).

In Danny's case it helped him to become aware of patterns of behaviour that had hampered his relationships with people; patterns he had developed to avoid his embarrassment at his memory failures:

"...because of fear of embarrassment...I would wriggle away...or I would change the subject as quickly as possible...and they made me...much more aware of the way I have developed ... prior to that, I was not able to identify what specifically, and why I was doing it" (Danny, 16:2).

This awareness led participants to reflect on how they had changed:

"Before...I could do like, multi-task stuff, like three things at once ...I was really like, ...on the ball, you know, before everything happened... but now, today... I can only do one thing at a time" (Paul, 14:22).

For Frances the test experience confirmed what she was already beginning to accept:

"I couldn't, couldn't possibly do the sort of work I was doing before...I'm not the same anymore. I've changed" (Frances, 19:13).

This was an issue about which Frances was sad though nonetheless realistic:

"...I wanted to, to get it done and I was actually very pleased to be able to do them [the tests] because I suppose they were things I had to come to terms with myself and I'd never done things like that before" (Frances, 11:16).

For Denise, the experience of neuropsychological assessment led to a fundamental review of her life and her career:

“...it’s been a whole, almost, paradigm shift for me... I’ve had to do a lot of reflection and think, now...now where? I’ve got a lot of experience; I’ve got a lot of skills, what am I going to do?” (Denise, 17:39).

The experience, it appears, fostered a thoughtful, sometimes sad, yet realistic consideration of how the participants had been affected by their illnesses and injuries. This enhanced sense of personal awareness was helpful in the context of problem solving and planning for the future.

ii) Self-Esteem and Validation: All participants, except for Barbara, found their confidence and self-esteem to be in some way boosted by the experience of neuropsychological assessment:

“It boosted my confidence, yes, definitely...when I left..., I was on a high, definitely” (Alistair, 45:11).

“I do distinctly recall ...feeling...confident, and a little proud...being able to walk out into the fresh air and just enjoy it, as opposed to... struggling away, cautiously... confident, that ...they were minor details and ... there’s no reason why I can’t ...largely, deal with them” (Danny, 23:9).

Even Denise, who found the assessment experience to be challenging and emotional, acknowledged an increased sense of personal agency:

“...by understanding what’s happening, by looking at my strengths and limitations, it does give me more, more control in one way” (Denise, 23:42).

This boost in self-esteem and personal agency was accompanied by a sense of validation; a feeling that frequently arose from the new understanding participants had gained of their condition:

“...it did make me feel..., yes, Rosa, you were really sick ...you’re not 100%, you’re still sick” (Rosa, 15:28).

The verification of genuine illness- related difficulties, by a professional person, made a considerable difference to how participants viewed their problems:

“...I feel more positive with myself...even more so now I realise that there is a bigger problem, that... I can’t fight on me own” (Paul, 24:9).

Barbara, in contrast, did not find the experience affirming in any way; rather she found that the test experience undermined her confidence:

“I was getting on alright and you’re kind of making me think, ooh...when I get home I won’t be able to do all these things...I know what I’ve got now and

you're sort of saying I might have more things... and I thought, I don't like this"
(Barbara, 5:35).

The absence of a trusting, supportive relationship between herself and the psychologist meant that, for Barbara, discussion of the likely implications of her deficits was highly threatening, and undermined the progress she felt she had made in her rehabilitation thus far. Far from feeling that the psychologist validated her experience of her condition, Barbara discredited the psychologist's capacity to make a credible evaluation of her future functioning:

"They said...it's been suggested by the psychologist you may not be able to multi-task. I said, well, how does she know? She asked me a question and I answer her... she's never seen me trying to do two things at once..." (Barbara, 27:14).

Barbara's experience reflects the opposite pole of the theme cluster to most of the other participants. Her negative view of the assessment, which, from her perspective made her feel worse about herself, bears witness to the potential of the assessment experience to influence the participant's perception of themselves and their condition.

iii) Use of Strategies: An increased sense of validation and self-esteem led a number of participants to consider modifying their behaviour in some way in the future in order to compensate for particular areas of difficulty. Rosa illustrated this planned use of coping strategies as she explained how she had decided she needed to slow down and focus on doing one task at a time:

“ You know, the best thing is...if it’s coming, it will come, but gradually, you just have to be patient...if you’re doing something and you can’t do it as fast as you used to, you’re going to do it anyway. Take your time” (Rosa, 13:4).

“So if you are setting the bath, set the bath. And if you are cooking, just cook”
(Rosa, 14:35).

For Paul, a significant outcome of the assessment lay in his improved communication with his family. Paul learned it was important to maximise his capacity to concentrate and absorb information by slowing the rate of input of information and reducing distractions in his immediate environment, a point he shared with his family:

“... [the psychologist] said... tell them what is actually happening...because they probably don’t know. And then I said to me sister ...you talk to me and then you talk really fast and P. said...slow her down and...just tell her, too much information’s coming out at one time” (Paul, 15:1).

Danny’s new found sense of validation enabled him to openly endorse strategies such as the use of a diary to support his poor memory, something of which had been ashamed in the past:

“... P. was very supportive of ...accepting there was a benefit in keeping diaries...and why not, beneficially, continue to do that” (Danny, 18:3).

He also felt confident enough to openly acknowledge his forgetfulness, a coping strategy that would reduce unnecessary embarrassment and enable Danny to elicit additional reminders or prompts from his conversation partner rather than use diversionary tactics:

“...it made me realise that if I was speaking with anybody ...that I could solidly say, I honestly don’t remember that, rather than say...well isn’t it amazing that I don’t remember that... that confidence to be able to do that” (Danny, 22:33).

It is clear that, for many participants, the assessment experience had an impact on how they coped with situations; either in modifying the way they approached tasks in order to accommodate their deficits, or in educating their families and friends about how best to help them.

3.6 Research Question 4: What do participants find helpful or unhelpful about the process of assessment?

3.6.1 Components of a good assessment

Question 5 on the interview schedule asked participants to reflect on the positive and negative aspects of the experience of neuropsychological assessment, and invited constructive feedback on ways the service to patients could be improved. While there was less consensus expressed in this aspect of the findings, the themes identified by participants suggested six essential components of a good assessment. These were:

- Providing Information
- Good Preparation for Testing
- Providing Feedback

- Acknowledging the Emotional Impact
- Facilitating Coping and Adjustment
- Good Support Structures

i) Providing Information: Rachel appreciated how the assessment experience identified her areas of difficulty, which, in turn would help her get better:

“...I know that it’s essential to do the tests and it’s a good thing to do because if it helps you get better, if it highlights things you struggle with, then it’s important...” (Rachel, 8:19).

For Julia, the test experience confirmed her own sense of her strengths and weaknesses; something she hoped could be built on for the future management of her difficulties:

“I was happy I’d done ok on things which were related to ... with what I do, yes, with what I’ve always done...what I wasn’t keen on...was that on the things that I’ve never been so good at...I ...came down even worse than I thought... I would... I’m rather hoping that we will be able to come up with something... to build on from the outcome of the report...” (Julia, 32:3).

ii) Good Preparation for Testing: Barbara’s difficult experience of assessment led her to emphasize the need to explain the nature and purpose of assessment:

“...I think just the awareness at the beginning... to make it very clear that... you are going to be tested at some point...and however good or bad we think you are you’ll still be tested. I think they really should emphasise that” (Barbara, 18:1).

For Barbara, the crucial point was that the tests should be presented as something routine and not evaluative of the person’s progress in rehabilitation.

Danny, who found the Block Design task difficult and somewhat humiliating, suggested ways of ensuring that participation in such tasks did not make the person feel foolish:

“...to encourage the psychologist ... to say, well they might seem... like eh...typical toy building, or whatever the terminology, but there is a reason... to justify it, and just make it less awkward” (Danny, 24:38).

Denise felt that anxiety had hampered the development of rapport with her psychologist and consequently, her capacity to assert herself in the assessment process. She recommended that psychologists pay more attention to preparing people emotionally for the process:

“I would have appreciated...being given time just to calm down” (Denise, 25:34).

“...it would have given me a little more command of myself...I would probably have been able to ask more questions...if you’ve got a highly anxious person in

front of you and you're working with them you can't really connect..." (Denise, 26:30).

iii) Providing Feedback: Barbara felt let down by the failure, in her view, of the psychologist to provide meaningful feedback in the immediate aftermath of the assessment. She made some specific recommendations in this regard:

"I think quick feedback would be good. And then if they...find something, this is how we were going to re-address it..." (Barbara, 22:16).

She further suggested that test feedback should be constructive, problem focussed and meaningful to the person's current life situation:

"...you've got to think... of how it relates to your everyday life now rather than what may happen in the future... what ...are they experiencing with their problems now" (Barbara, 31:12).

Danny particularly emphasised the value of supplementary written feedback that would help him explain his difficulties to others using credible, "clinical" terminology:

...to be able to define and ... to be able to clinically put it into terms or words that would ...make sense" (Danny, 26:30).

iv) Acknowledging the Emotional Impact: Denise felt strongly that patients should have an opportunity for de-briefing after the testing session and that the emotional impact of the experience is underestimated:

“One thing that came to me when we were talking, and you were saying how did I feel the next day, the one word that kept coming to me was debriefing, debriefing, debriefing...” (Denise, 27:13).

Rachel, for the most part, approached testing with a matter-of-fact attitude but she, too, appreciated the emotional consequences:

“...the only bad things are when you're ill ...things are all quite shocking to you at the time because you're struggling with why you're ill and the reasons why you're doing these tests...I suppose they're the bad things...” (Rachel, 8:23).

The context and stage of adjustment to illness were, for Rachel, particularly salient points for psychologists to consider.

v) Facilitating Coping and Adjustment: Rosa particularly appreciated that the test experience helped her to accept her memory problems:

“...it helped me to be patient and it helped me to accept things. You might not remember, there's nothing wrong with that” (Rosa, 26:34).

Paul was positive about having learned some new strategies that he planned to use in his everyday life:

“...you know, switching the tele off, and em...doing something positive, think about things before you actually do something” (Paul, 28:1).

Alistair had a very good assessment experience but pointed out that not enough time or attention was paid to how he was personally coping with his head injury. For him, the ideal assessment would have involved:

“...[the psychologist] to do the testing, this is the very medical side...right? And this is the side that would be documented. Then I could also do with a psychologist on a, on a level such as this one [interview] so we can sit and talk for an hour about...about how the process has affected me ...” (Alistair, 46:17).

vi) Support Structures:

Frances and Julia specifically mentioned elements of the organisational support structures that made a positive impact on their experience. For Julia, who has multiple sclerosis, the location of the psychology office was important:

“...it was a good experience to at least, em, be in somewhere quiet, because I’m used to going to St. X Hospital...sometimes it’s just so busy...” (Julia, 34:11).

Frances gave a special mention to the reception staff that welcomed her to her assessment. They appeared able to anticipate, with considerable sensitivity, the difficulties that brain injured people might encounter when visiting a new location:

“...there was a lady there...and she was good to me. She walked with me when she was showing me where the canteen was. She didn't just say, it's there, there and there 'cos I'd have forgotten. She walked with me and she said, will you be able to find your way back?” (Frances, 26:1).

Frances, Danny, Paul and Rosa, remembered how they were made to feel welcome and understood when they presented for neuropsychological assessment. Simple, courteous attention to individual need stood out for these participants who were surprised and touched by the experience, which contrasted with their previous experiences of medical care. In the final section, the experience of being a patient will be considered in greater depth.

3.7 Emergent Theme: The Experience of Illness/Disability

A number of sub-themes emerged as the analysis of the texts progressed that seemed to cluster together around the issue of being a patient living with an illness or disability. These were strong themes that emerged in some form in each interview and seemed to transcend and yet still have an influence on the experience of neuropsychological assessment. Indeed it seemed that some of the interview questions brought more general themes into focus for the participants. This facilitated either a direct comparison between neuropsychological assessment and other

experiences of medical care or, it encouraged them to reflect on issues they had not actively thought about before.

Question 1 on the interview schedule (Why were you sent to have a neuropsychology assessment?) frequently prompted the participant to tell the story of their illness or injury. This raised common issues centring on difficulties accessing information/services, difficulties being heard as an individual, and the power imbalances the influence the experience of being a medical patient.

i) Accessing Information/Services: Frances, for example, struggled to access appropriate medical care, telling a story of poor and disorganised follow-up post-discharge:

“They told me they didn’t have a neurosurgeon, but they did, it was Dr.X...and my records had all been lost, my file was missing, my doctor [GP] had not received it and he didn’t know what to do...but when I went to see Dr.X, em...that appointment was made because of a lot of pressure that everybody put on...[he] couldn’t do a lot either because ...there was no file, he didn’t know anything that had happened to me...” (Frances, 1:27).

This led Frances to conclude:

“I think I should ...have got the proper treatment ...I think I was entitled to that really” (Frances, 13:35).

Alistair had difficulty accessing the information he needed to feel involved in decision-making about his care and reflected on the curious changes and imbalances in communication flow that occur for a head injured person who experiences changes in consciousness:

“When I first went in my parents were given complete rights of counsel...and had every piece of information that was available for that period... and then as soon as ... I was sort of deemed conscious again that right was taken away. But as soon as that happened they didn't find out a single thing. And I wasn't being told. So then we went through a total dead period where nobody knew anything” (Alistair, 11:8).

ii) Being Heard as a Person: Once Alistair was well enough to think about and understand what had happened to him he was frustrated by the lack of communication between himself and his doctors. Whilst he understood this might stem from a general sense of doctor-patient protectiveness, he would have preferred to be consulted about his own preferences:

“...the only thing that annoyed me about that was... I mean, I know that they have to give people hope, em, but I would have preferred to hear the truth, personally, but then obviously I am a case and they have to treat the majority...”
(Alistair, 9:31).

iii) Power Imbalances: The nature of power imbalances in the referral process was explored earlier in Barbara and Denise's experiences of referral to neuropsychology

(see 3.1.2). The well meaning but often patronising and uncollaborative power imbalances that can feature in doctor-patient communication was further illustrated in the story of Paul's referral to Neuropsychology:

"I said I wasn't really happy about certain things...and he said, oh well, don't worry, I'm very pleased with you and em...that was the end of it... it felt like I was only in there like two seconds... and nothing ...well, I can't remember anything being discussed to say that he was going to refer me to anywhere."

(Paul, 4:10).

Paul did not feel "heard" in this consultation with his doctor, an experience that strongly contrasted with his experience with the psychologist, which stood out in his mind as being an experience where he was cared for as a person.

iv) Coping and Adjustment: Participants were asked if the assessment experience had taught them anything useful to help them cope with their illness or injury. Some participants, such as Rosa, Danny and Paul, did acquire some useful strategies as a direct consequence of their assessment experience. Others, however, had clearly been engaged in a process of adjustment to their illnesses and disabilities for some time, and this question prompted them to share their experiences of coping and adjustment:

"After my English Degree I was going to go into theatrical publishing...that's not going to happen... I know that and I've come to terms with that...my goals have completely changed...I think I might go and teach English in non-English

speaking countries, or I might go and dig oil wells for the Red Cross...I'd quite like to do something that's a bit good, you know...?" (Alistair, 35:31).

Participants demonstrated a range of coping strategies in coming to terms with their circumstances, ranging from a realistic assessment of their losses and a resolve to focus their energies into new and constructive opportunities, to a determination to focus on the positive in their situation:

"I've ...just continued with being grateful for the fact that I'm not in my grave or on, on a, a life support machine...do you know? So, em, I want to be around whilst my daughter finishes her education...she's going to University in September and I want to be here for her for that" (Frances, 17:31).

v) Social support: This was perceived as a significant factor influencing participants' adjustment to the experience of living with illness and disability. Rosa drew on the example of a person she had known previously who coped with his disability in an inspirational way:

"...There was this blind man, [at home] ...he could walk for miles, just with his walking stick, the things he used to...the stories he tell us...he was such a positive person, and we keep forgetting he's blind..." (Rosa, 21:4).

Another source of support came from meeting with other people who shared in their experience of illness or disability:

“There’s very good camaraderie among the patients as well. One of them invited me over on Sunday. She’s been over here so we’re keeping in touch and that”
(Barbara, 33:26).

Families and friends were perhaps the primary source of encouragement and support for many people:

“You have to have someone to talk to. I find that out...if I didn’t have anyone to talk to, what would happen? How would I feel? How would I manage...it doesn’t have to be your parents...it could be friends...”
(Rosa, 17:2).

Personal faith and being a member of a Church group was also an important source of support:

“I think it was basically because of my faith...that’s what I had, and very good friends that kept me going...” (Frances, 14:12).

Denise explained how the experience of neuropsychological assessment had triggered off memories associated with the accident that caused her head injury forty years previously. It would appear that for many participants, the interview experience, of being asked to reflect on a specific experience of care, triggered reflections on the nature of their experiences since becoming ill, and of their coping and adjustment.

3.8 Summary and Conclusions

This chapter has presented the six master themes and sub-themes that emerged through analysis of the data. The themes reflect the experiences of a group of people from different backgrounds, who presented for neuropsychological assessment in different contexts. The participants shared many concerns and experiences. They all sought clarification of the nature of their difficulties and wanted advice and information that would help in living with their condition. Their relationship with the psychologist was an important element of their experience. Participants engaged emotionally and intellectually with assessment and their experience influenced their view of themselves and their approach to coping. Their feedback generated suggestions for what makes a good assessment. Participants reflected on the experience of having an illness or disability and shared some of the issues that influence that process.

This story is interpreted and told by a researcher however, who comes to the research with a knowledge base and set of expectations about the process of neuropsychological assessment that is influenced by her experience as a clinician. This will have had an impact on how questions were formulated, how the interviews were conducted and how the data were “heard”. The association of the researcher with the profession being discussed in the participant interviews will also have had an influence on the data generated.

In the following chapter, these methodological issues will be explored. In addition the results will be discussed in the light of previous research findings and conclusions drawn as to their implications for clinical practice and further research possibilities.

Chapter 4

4.0 Discussion

This study chose Interpretative Phenomenological Analysis (Smith, 1995) as a method of exploring the patient's experience of neuropsychological assessment. In the following sections, the major themes uncovered during the process of analysis will be considered in relation to the research questions and the existing theoretical and empirical literature. The helpfulness and suitability of the methodology will be considered, with an emphasis on what has been learned in this research exercise and how future research might be conducted differently. The implications of the research findings for clinical practice will be explored. Finally, this chapter will evaluate the contribution of this study to the research literature and consider opportunities for future research.

4.1 Consideration of the Findings in relation to the Research Questions

4.1.1 Participants' understanding of the purpose of assessment

The participants in the study were all uncertain about what to expect from a neuropsychological assessment, except in the case of one participant who had prior experience of assessment. They were generally poorly prepared for the assessment, in that few of the participants received explanatory information in advance of their appointment. Many participants expressed anxiety about the procedure, particularly those who had experience of distressing or uncomfortable neurological investigations in the past.

The case for preparing patients for medical encounters and procedures is well supported in the research literature (Deane et al., 1992). A clear recommendation to arise from the Bennett-Levy et al, (1994) study was for patients to be sent explanatory leaflets prior to assessment to facilitate their understanding of its purpose and process. However, participants in this study were not routinely informed about the assessment procedure, which suggests that clinical neuropsychology, as a profession, should examine its practice in information sharing and preparation for assessment. An up to date survey of clinical neuropsychology practice in the UK, similar to that conducted by Sweet et al. (2000) in the USA would be very timely.

Despite their uncertainty about what to expect from their neuropsychological assessment, all participants expressed a desire for information and practical advice that would help them understand and cope with their difficulties. This was an unequivocal message to emerge from the participant transcripts, suggesting that these patients had a very strong need to understand their cognitive impairments and find meaningful solutions to everyday problems. It suggests that people with neurological disorders affecting their cognitive functioning express similar information needs to patients experiencing other chronic and challenging medical disorders (Meredith et al., 1996).

An interesting theme to emerge from the data indicates that the nature of the referral process to neuropsychological assessment plays an important part in determining patients' expectations. Though few participants had a clear idea of what to expect from the assessment, many accepted the referral "on trust", as they expressed faith in the judgement of their referring practitioner. This sense of trust played an important

role in facilitating acceptance of the referral process, almost unquestioningly in some cases:

“...I trust em, you know, the doctors and nurses and everything, em... to look after me...” (Paul, 8.16).

This finding supports evidence in the literature on clinician-patient relationships indicating that patients seek collaborative and trusting relationships with their doctors (Wright et al, 2004), but once this trust is established, many patients are happy to accept guidance from their doctors about treatment decisions (Robinson & Thomson, 2001).

It was evident however, that a “coerced” referral for neuropsychological assessment set the scene for a more threatening and less satisfactory experience. Denise came to the assessment under threat of an incompetency claim from her employers. She felt disempowered and patronised in the patient role, but reclaimed some of her autonomy by finding personal meaning in reviewing the impact of her head injury and re-appraising the assessment to enable her to revise her personal goals (Taylor, 1983).

Barbara unfortunately did not achieve a similar resolution to the conflicts inherent in her role as a dependent, yet articulate patient (De Ridder et al., 1997). She felt let down by the psychologist and, as a result, found the experience personally threatening and demeaning. Barbara’s distressing experience indicates that in the absence of a collaborative and trusting relationship, neuropsychological assessment will be an unproductive encounter.

The data on the patient's understanding of the purpose of assessment suggest that, similar to more traditional doctor-patient encounters, the patients in this study had clear information needs and a strong sense of what they expected from their psychologist, in their role as experts in cognitive functioning. Furthermore, their acceptance of the procedures and feedback arising from the encounter was, to a considerable extent, influenced by the relationship that developed between themselves and the psychologist during the assessment (Ong et al., 1995). The strength and influence of the clinician-patient encounter will be considered further in subsequent sections.

4.1.2 Participants' experience of the process of assessment

Participants in the study experienced a strong emotional engagement with the process of neuropsychological assessment. For many it aroused feelings of anxiety, frustration and a sense of stupidity as they confronted their areas of cognitive weakness and failed on tasks that were previously within their sphere of competence. The findings support those of Keady & Gilleard (2002) indicating that, far from being passive recipients of neuropsychological procedures, patients with neuropsychological impairments are acutely aware of their performance on standardised testing.

The data suggest that the participants adopted a self-evaluative stance in relation to their test performances. Frequently they could reflect on patterns of response during testing, indicating that learning had taken place:

"...No, Rosa, you can't do that, because you tried that, look, it doesn't work out..." (Rosa, 14.31)

The evidence that participants retained salient memories of their test performances, sometimes more than four weeks after their assessment experience, suggests that patients with cognitive impairments can benefit from discussion of their test performances and appear open to consideration of the learning opportunities inherent in the test situation. Schlund (1999) demonstrates in his study on the effects of verbal feedback on appraisal of memory performance, that people with memory impairments retain feedback that is delivered close to actual performance more effectively. The evidence to emerge from this study lends support to the assertion that concise, meaningful feedback, delivered directly to the patient, close to the assessment session, can facilitate learning and self-awareness. This can be incorporated constructively into the rehabilitation process (Hibbard et al., 1992).

The strong sense of engagement on the part of participants with the process of assessment was, not surprisingly, linked with an unequivocal desire for feedback on their test performance. The delivery of test feedback was very variable however. At the time of interview, which was, on average, within a month of assessment, only Barbara had received a written summary of her test results. She felt she had waited an unnecessarily long time for feedback and had to seek it out very assertively. She was dissatisfied with the findings as she felt they lacked ecological validity, failing to resonate with her own experience of her illness and disability:

“ My fear about going to work is how I’m going to do things with one hand, rather than am I going to forget things...her emphasis was different” (Barbara, 2.23).

Paul, Danny and Alistair had received verbal feedback immediately after their assessment. Frances, Rosa, Denise and Rachel were still awaiting feedback appointments. They did not appear concerned about the delay in formal feedback of test findings, as they had been informed about the structure and timing of the feedback process and consequently understood the organisational context in which they had to operate as patients (Radley, 1994).

Julia was unsure when and how she would receive feedback, but understood that it would be through her consultant neurologist. Though she had undergone assessment with an experienced clinician, the protocol for test feedback in the organisational context in which she found herself dictated that the test results were relayed through the referring clinician.

In her response to her interview summary, Julia reported that she had been denied an opportunity to meet with her neurologist to discuss the test findings, as her GP had received a copy of her report (implying, one presumes that the GP was supposed to take on this role). This illustrates the haphazard nature of the dissemination of neuropsychological test information and seriously calls into question whether current practice is meeting the desired code of conduct for testing outlined by the BPS (2002), which states that persons who administer tests should...

“...provide the test-taker and other authorised persons with feedback about the results in a form which makes clear the implications of the results, is clear and in a style appropriate to their level of understanding.” (Code of Good Practice for Psychological Testing, 2002, p.3).

Julia's experience suggests that neuropsychologists may mirror the concerns of other professionals about sharing a diagnosis of cognitive impairment with their patients (Keightley & Mitchell, 2004) and may prefer to adopt a traditional model of patient care where the medical consultant is the central authority figure, acting on behalf of the patient (Roter & Hall, 1992, cited in Ong et al., 1995). Unfortunately modern healthcare services often fail to deliver the protective benefits of this paternalistic model, which relies on continuity and a sense of personal care (Oliver, 2001). As a result, the patient fails to be informed and supported, and ultimately becomes disconnected from being an agent in their own care.

The pattern of test feedback confirms findings in the literature that direct test feedback by psychologists to their patients is inconsistent (Donders, 2001a) and that the style and nature of professional practice is influenced by the organisational context of the neuropsychology service (Donders, 2001b). Patients may need to assertively seek out the information they require and not all patients, particularly those with acquired cognitive impairments, possess the requisite skills or confidence in this role (De Ridder et al., 1997).

The reluctance of psychologists to share test findings with their patients is all the more puzzling as the data from this study suggest that the rapport developed between patients and psychologists during the testing session is powerful and influential. It is possible that busy neuropsychologists avoid the therapeutic responsibilities that may arise in response to the sharing of test feedback. The separation of assessment from on-going management is common practice in many neuropsychology services. The splitting of assessment and rehabilitation services perpetuates the sense that

assessment is a non-therapeutic exercise, a position that is challenged by the results of this study.

A number of participants reflected a sense that the psychologist played an important part in providing them with validation and legitimation (Bury, 1991), by defining the nature and consequences of their cognitive impairment using appropriate clinical terminology. Participants, such as Danny, who received feedback directly from his psychologist, experienced an enhanced sense of mastery in coping with their condition. These facilitative aspects of the neuropsychological assessment encounter bear strong resemblance to the health promoting features of the physician-patient relationship proposed by Van Dulmen et al. (2002).

In contrast, assessment encounters that were devoid of a strong therapeutic alliance, as portrayed by Barbara and Denise, were characterised by feelings of disempowerment and personal threat. The expertise of the psychologist was discredited or minimised in response to the anxiety and distrust generated by the exposure of the patient to their cognitive weaknesses, leaving the patient feeling angry, undermined and emotionally exhausted:

“ ...It just left me feeling...I won't even say the word is vulnerable...it's em...bewildered...yeah...” (Denise, 13.4).

There was no evidence that the level of qualification or experience of the psychologist made a difference to how participants viewed the assessment encounter. Participants spoke uniformly of the courtesy, warmth and professionalism of the psychologists

conducting the assessments. The difference seemed to centre on the extent to which the psychologist made a connection with the patient in terms of the personal context of the assessment and, whether the psychologist personally communicated the test results in a practical and meaningful way.

4.1.3 The impact of neuropsychological assessment on the participant's sense of self

The assessment experience clearly had an impact on various dimensions of the participant's sense of self. This was a particularly interesting theme to explore as it offered opportunities to cast light on the earlier findings of the Bennett-Levy et al. (1994) study, which suggested that the process of neuropsychological assessment changed the way patients viewed themselves and the future. This can be linked to Beck's (1976) formulation of the importance of the cognitive triad of self, the world and the future in the understanding of mood disorders.

Through a process of self-evaluation, most participants formed new insights about their strengths and weakness, which, in many cases led to a more focussed evaluation of problem situations and how they might cope differently. This was certainly facilitated by direct conversations with the psychologist about test findings and coping strategies, but perhaps more interestingly, the process of testing in itself led participants to re-evaluate their own performances, and in some cases, to re-evaluate their appraisal of themselves in relation to their illness (Leventhal et al., 1980).

For some participants the experience of testing brought the comparison between their old selves and new selves into sharp relief, particularly for people like Frances who

was coming to terms with the consequences of a severe head injury. She was greatly distressed at her failure to recognise line drawings, as she had been a talented artist, yet she too displayed evidence of cognitive re-appraisal of the meaning of this loss by reminding herself how things could have been worse and focussing on what was still positive in her life (Taylor, 1983):

...we're alive for God's sake. We've been given another chance, do you know?"
(Frances, 29.3).

Nochi (2000), in a qualitative investigation of the coping processes of people with acquired brain injuries, suggests that the process of adaptation requires sufferers to reconstruct a view of the self that incorporates the changes imposed by the injury. This process reflects stages of adjustment as people struggle with the loss of their old selves, both in their own eyes and in the view of society in general (Nochi, 1998). Positive adjustment is facilitated by a revised sense of self that remains intact in spite of the brain injury or worthwhile because of the brain injury. Hence, the illness experience is incorporated into a new sense of self, which reflects the changes and compromises wrought by the illness. The data in this study suggest that the experience of neuropsychological assessment can act as a trigger to explore these issues and contribute, in the longer term, to the process of adjustment to loss and disability (Miller, 1993).

For the majority of participants, the experience of assessment was positive and validating. It boosted their confidence and raised their morale and self-efficacy (Bandura, 1977). It facilitated consideration of a range of coping strategies.

It appeared that positive reappraisals of self and coping capacity were mediated by the nature of the assessment experience, and in particular, by the presence of key psychologist behaviours. In situations where the information was targeted to patients' concerns, and advice regarding coping strategies was transmitted in positive ways, participants were eager to adopt clinical recommendations and experienced a greater sense of legitimacy and self-efficacy. In the absence of trusting, collaborative relationship, where little attention paid to contextual issues relating to the patients' individual concerns, the participants felt hostile about the information imparted and struggled to incorporate the findings into their self view.

Moos & Schafer (1984) suggest that there are key adaptive tasks associated with illness that vary with the nature and stage of the illness. Successful adaptation involves fitting specific coping skills to match the particular demands of the situation. At all stages the meaning attached to these adaptive tasks will influence the nature of the coping response by any individual. This study concludes that the process of neuropsychological assessment, by virtue of its high degree of threat in many instances to the person's sense of cognitive integrity, can provide opportunities for significant learning and self-appraisal. When mediated by an educative and supportive relationship with the psychologist, this can facilitate positive reconstructions of the self.

4.1.4 What participants find helpful or unhelpful about assessment?

Six components of a good neuropsychological assessment were identified through analysis of the participant data. These consisted of: providing information, good

preparation for the assessment, providing feedback, acknowledging the emotional impact of assessment, facilitating coping and adjustment, and support structures.

Participants recommended that patients should be told in advance what the assessment would involve and why it was being conducted. It was felt that this would help people to feel less anxious and foolish and foster better rapport earlier in the test session.

Participants found it beneficial when testing identified their specific strengths and weaknesses, particularly if this was coupled with practical advice on coping strategies and with decision-making. They suggested that feedback should be delivered quickly, and targeted to the everyday needs and concerns of the patient. It should not primarily reflect the psychologist's agenda. A number of participants commented that a written summary of the test findings would be particularly welcome as it could be shared with significant others and used to reinforce advice regarding coping strategies.

It was considered important that psychologists appreciate the emotional impact of assessment, and that some patients might need an opportunity to de-brief. Rachel noted that the patient's stage of illness would make a significant impact on how they responded to the test situation.

Four participants commented that the assessment process facilitated their ability to cope with and accept their impairments. In two cases however this was qualified by observations that the more personal aspects of adjustment to illness and disability were not adequately addressed during contact with the neuropsychologist.

Lastly, the support structures associated with the assessment were important in the participants' overall experience of care. Participants highlighted the accessibility of the location and the welcome they received on arrival from the psychologist and reception staff. Participants were particularly touched by numerous examples of courteous attention to individual needs (e.g. comfort breaks, walking with the participant to show them the way, checking that they could get home safely) and commented on how this differed from their usual experience of medical care.

These suggestions can be directly applied to service planning and indeed suggest a protocol for neuropsychological assessment that is both evidence based and consumer led.

4.2 Emergent theme: Experience of Illness/Disability

For many participants, reflection on the experience of neuropsychological assessment connected them with more general experiences of medical care. As the story of their “journey” to the neuropsychology assessment unfolded, it was evident that some participants, such as Frances and Alistair, had struggled to access appropriate services in the aftermath of their head injuries (McMillan & Greenwood, 1993). Care seemed haphazard and disorganised and at the early stages of injury, care was focussed almost entirely on physical injuries with no information provided about the cognitive and psychological implications of head injury. Referral to neuropsychology appeared to depend ultimately on making contact with a “good doctor” who set referral pathways in motion and who was, in Alistair’s words:

“...the man with the master plan in all this...” (Alistair, 3.7).

Alistair elaborated on the difficulties in accessing information. He understood that the doctors wished to minimise distress and maintain hope, but from his perspective, he:

“...would have preferred to know the truth.” (Alistair, 9.31)

Julia and Denise both found themselves at the end of the communication chain when they sought to access their test results. In Denise’s case, the test findings were communicated via her manager, who summarised the findings for her, telling her that she had “learning difficulties”. Julia was left to work out who would ultimately explain the implications of the test findings for her everyday life, and it appeared that her GP, the practitioner with least neuropsychological expertise, would be left to take on that role.

These case examples indicate the real difficulties for patients in determining who “owns” the information regarding their care and treatment. Doctors continue to filter information from patients, possibly from a sense of protectiveness (Vernooij-Dassen, 2001). In neuropsychology practice, the sharing of test information has not been subject to any real consideration or debate, but this will soon change in response to government directives on copying letters to patients (Department of Health, 2000).

Power imbalances were particularly evident for patients like Denise and Barbara who felt discredited and disempowered by the experience of testing, and believed that power was tipped in the favour of the professionals:

“ She’s not going to be proved wrong because she’s like, the psychologist, and you’re the one with the brain injury...” (Barbara, 23.25).

A connected theme focussed on the failure of the healthcare system to offer a person-centred rather than, case-centred, approach to care (Heller et al., 2001). Alistair would have preferred to know the reality of his situation so that he could have played an active role in determining his information needs. He concluded however:

“Then obviously I am a case and they have to treat the majority” (Alistair, 9.33).

The data clearly support findings in the medical literature that patients want their doctors to treat them as individuals, consult with them about care plans, take charge of issues within their field of medical expertise when necessary and consider their personal circumstances when evaluating treatment options (Coulter, 2002).

Conversations with the participants about their assessment experiences also led into a broader consideration of the issues of coping and adjustment. A number of participants volunteered their perceptions of how their lives and value systems had changed as a result of their illness experiences.

The strategies adopted seemed to focus on enabling participants to cognitively re-appraise the meaning of their injuries/impairments for their everyday lives (Weinman & Petrie, 1997), either by reformulating their value systems to embrace goals still within their reach (Prigatano, 1991) or by minimising the importance and impact of their impairments:

“ I will forget things and that’s part of life ” (Barbara, 27.25).

Acceptance seemed to play an important role in coping. Rather than being a passive coping strategy, acceptance for participants in this study seemed to facilitate consideration of more realistic goal-setting and a problem solving approach that focussed on using one’s strengths rather than grieving for one’s losses (Godfrey et al., 1996):

“ ... ’cos there’s nothing you can do about it...or there might be something you can do about it, but...there’s no point whinging ‘cos it’s happened... ” (Rachel, 6.18).

Friends, family and health professionals were seen as important coping resources in the rehabilitation journey. The narratives of participants in this study support the buffering hypothesis of social support in adaptation to chronic illness (Cohen & Willis, 1985) and indicate that people draw on a range of social relationships to facilitate both their physical recovery and their acceptance of losses.

4.3 Conclusions

Prigatano (1991), in his sensitive and thought provoking article on the role of psychotherapy after brain injury tells us, that psychotherapy with brain injured patients must focus on their “disordered minds” and “wounded souls”. The participants in this study clearly wished to learn more about the nature of their disordered minds and how they could continue to live meaningful lives with diminished intellectual and functional capacity. They wanted the expert psychologist

to communicate with them in ways that acknowledged their cognitive limitations yet respected their autonomy and humanity. They wanted to take responsibility for choices where they could but they also wanted expert help and guidance.

There was ample evidence that skilled and sensitive clinicians could combine the rigours of testing with therapeutic attention to the needs of the patient's "soul". In some instances, however, the experience of neuropsychological assessment failed to take account of the patient's personal story. When given the opportunity to tell the story of their assessment, participants placed it within the context of the broader context of their illness or injury and it became integrated with the complexity of this experience. They brought their whole selves to the assessment but for some, the rigours of the standardised neuropsychological assessment meant that all but cognition was left outside the office door. As Alistair tells us:

"...If I hadn't done this interview with you, then I wouldn't have actually been asked, at any point, by any doctor, neurosurgeon or psychologist, how the process [of brain injury] affected me at all..." (Alistair, 46.29).

4.4 Methodological evaluation

The "trustworthiness" of the research findings can be evaluated according to the principles of transparency, credibility and transferability (Stiles, 1993). The following section will consider the methodological rigour of the study using the criteria outlined in Section 2.9 (Elliott et al., 1999).

4.4.1 Owing one's perspective

A reflexive review of the position of the clinician as researcher in this study suggests that it facilitated rather than hindered the research process. It was helpful to have an understanding of the cognitive and communication needs of the research participants. Because of fatigue, memory disturbances or attentional difficulties, participants required more summarising, clarification and prompting than might be expected in qualitative interviewing and it was helpful to have had extensive clinical experience with this client group. It was also helpful to have an understanding of contextual issues raised in participant interviews without requiring excessive or intrusive explanations that may have proved difficult for the participants.

However, there were some disadvantages attached to the clinician-researcher role. There was some suggestion that participants associated the researcher with the profession of clinical neuropsychology, and thus, in some part, with the phenomenon under investigation:

“ ...you're in your field, and you know what you're doing...” (Paul, 4.28).

This may have been encouraged by the researcher occasionally slipping into a clinical role by indicating knowledge of or clarifying queries about test procedures. There was evidence too, that participants saw the researcher as a person who would provide consumer feedback to the neuropsychology service and they were eager to provide generally positive information (see Appendix 3.4). This may have biased participant responses, though it must be added that the data were not uniformly uncritical.

4.4.2 Grounding in examples/audit trail

It is possible that the researcher's interpretative stance, made explicit by means of the audit trail (see research diary, 7th April, 2004) and grounded in quotes from participant transcripts, was particularly attuned to psychological processes associated with adjustment to illness and disability as reflected in her theoretical background and clinical training. It would be fruitful to explore how a researcher from a different professional /research perspective (medical, sociological, consumer-led) would both frame the research questions and interpret the data.

4.4.3 Situating the sample

The researcher's position may also have impacted on recruitment issues. Though independent of the clinical setting from which participants were recruited, she was professionally acquainted with the referring psychologists. The researcher was aware that they might have felt at risk of scrutiny due to the personal and intensive nature of the research enquiry. Recruitment to the study seemed slow on occasions and there was a possibility that only "good patients" were being selected (see research diary of June 19th, 2003). Consequently the reader is reminded that the transferability of the findings is limited to clinical groups that closely resemble the sample chosen for this study.

This study opted for a selective recruitment procedure rather than a more open process of invitation to participate. Future studies could consider ways of depersonalising the role of the assessing psychologist in the recruitment procedure, perhaps by sending an invitation to participate letter to patients meeting the research criteria subsequent to their assessment.

4.4.5 Respondent validation

The researcher was conscious of the delay, sometimes up to six months, between conducting the interviews and providing summary feedback to the participants. This may have affected the ability of participants to recall the interview process in sufficient detail to provide critical evaluation of the summary. Three participants provided written feedback (see Appendix 3); another returned her interview summary with some factual amendments and a fifth participant provided telephone feedback. It seems important for future research to ensure a minimal time delay in providing participant feedback and to consider a follow-up telephone call to elicit participants' responses to the summary. This may be particularly important to ensure that people with cognitive impairments can fully contribute to the process of respondent validation.

4.4.6 Suitability of method

This method of investigation was well suited to the specific needs of people with acquired cognitive impairments. The semi-structured interview format allowed the researcher to follow pre-determined areas of enquiry, yet enabled participants with cognitive and communication difficulties to largely determine the pacing and content of the interview (Paterson & Scott-Findlay, 2002). The data proved to be rich and enlightening, not only in its elaboration of existing research findings but also its implications for coping theory and rehabilitation practice.

4.5 Implications for clinical practice

Patients who undergo neuropsychological assessment want and need more information about the nature and process of neuropsychological assessment. Clinical psychology services could improve their practice in this regard by sending patients preparatory information in advance of appointments, with information outlining: the purpose of assessment, what will happen in the assessment, common feelings and reactions to assessment, how the results will be used, how and to whom the results will be communicated, and how and when they will receive feedback. An excellent model of an explanatory leaflet is included in the Bennett- Levy et al. (1994) paper.

In addition, clinical neuropsychology services could include a simple questionnaire asking prospective patients to outline their main problem areas, what they hope to gain from testing and to indicate any concerns they might have about the process. This would not only help orientate the patient to the rigours of the test situation but also provide the psychologist with valuable information about the personal context of the referral.

The findings have implications for clinical psychology training. Clinical experience suggests that trainees and novice psychologists are pre-occupied by the “technology” of clinical neuropsychology (the selection, administration and interpretation of tests), and frequently see the discipline of neuropsychology as separate from mainstream clinical psychology. This pre-occupation is reinforced by a large literature on neuropsychological assessment (Lezak, 1995, Spreen & Strauss, 1998), only a small portion of which concerns itself with the qualitative aspects of the assessment process.

It is important that clinicians learn to maximise the therapeutic opportunities inherent in neuropsychological assessment, and not leave patients as victims of a “hit and run” assessment experience (Lezak, 1995, p.127).

The study also draws our attention to the role of assistant psychologists in the administration of neuropsychological tests. Though there is no evidence to suggest that participants had a poor experience at the hands of assistant psychologists, they did have a limited experience, in terms of information sharing and advice on coping strategies (as indeed is appropriate for the role of assistant psychologists). Services employing assistant psychologists for neuropsychological testing need to ensure that qualified neuropsychologists conduct pre-assessment interviews and feedback meetings in a streamlined manner designed to ensure that the patient experiences an integrated process of care.

4.6 Contributions to the literature

The results of this study have contributed to our understanding of how the process of neuropsychological assessment impacts on the patient. The study has lent empirical support to the professional practice literature that exhorts practitioners to attend to the responsibilities and opportunities available in the testing situation (Gass & Brown, 1992, Pope, 1992). The results elaborate on the initial findings of the Bennett-Levy et al. (1994) study and offer clarification on how the process of assessment can be of benefit to the patient.

Specifically, the results clarify that neuropsychological assessment can change the patient’s view of self and the future by facilitating more accurate self-knowledge.

When this information is transmitted in the context of a supportive relationship and coupled with advice on the use of basic coping strategies, the participant can learn to re-appraise their impairments and disabilities in a manner that facilitates on-going adjustment in the context of a new, legitimised sense of self (Hill, 1999).

These findings contribute to the literature on sharing a diagnosis of dementia and cognitive impairment. They support the growing body of data indicating that patients want to be informed of their diagnosis (Holroyd et al., 2002), and contribute to our understanding of the dimensions of the clinician – patient relationship that will enhance or hinder the quality of the communication process (Van Dulmen et al., 2002). The study also draws our attention to the importance of evaluating the personal and contextual elements of the assessment process. It suggests that in order for feedback to be perceived as meaningful and beneficial to the client, it needs to take account of the patient's unique illness appraisals and most immediate functional needs (Moos & Schafer, 1984).

Finally, the results contribute to our understanding of theoretical models of coping, supporting the stress-appraisal-coping model of Godfrey et al. (1996). It is suggested that the process of neuropsychological assessment impacts on the domain of coping and adjustment through its influence on the patient's primary appraisal of the degree of threat associated with their condition, and their secondary appraisal of their repertoire of coping responses. The strength and quality of the therapeutic alliance acts as a buffer against the degree of perceived threat of the test findings and thus can be perceived as having a significant social support function (Cohen & Willis, 1985).

4.7 Opportunities for further research

These findings suggest a number of interesting avenues for further investigation. Of immediate need perhaps, is a large-scale national survey of the beliefs and practices of clinical neuropsychologists in the conduct of neuropsychological assessment. We are now better informed about the patient's expectations and experiences but have no systematic understanding of how psychologists select and prepare patients for assessment, how they conduct assessments, when, if and how they communicate information (and to whom), and how they use the results of neuropsychological assessment as part of ongoing treatment and case-management.

Interestingly, this suggestion brings the researcher full circle in terms of her original, rather more ambitious research interest that sought to explore the assessment process from the interacting perspectives of both patient and psychologist. The complexities of the issues suggested an initial phenomenological study of the patient's perspective. The rewarding nature of the current investigation suggests that, as an initial step in a large scale national survey of clinical neuropsychology practice, a qualitative investigation of the psychologist's perspective of neuropsychological assessment would elucidate the richness and complexities of the belief systems and decision-making processes that govern clinical practice. IPA methodology is inherently suited to systematically unravelling complex issues and themes (Smith et al., 2002), and could offer clarification on issues to be explored in a large, survey-based investigation.

On a clinical level, the results highlight the key issues of importance to patients undergoing neuropsychological assessment. A model of good practice in the conduct

of neuropsychological assessment is suggested. Clinical neuropsychology services could design consumer feedback questionnaires based on the findings of this study and adapt them to the needs of their particular client groups and service needs. This would make a valuable contribution to clinical governance (BPS, 2000).

Finally, it would be fascinating to explore the research possibilities of a longitudinal phenomenological investigation that tracked development in the perspectives of a group of people with acquired cognitive impairment over an extended period of time. This would provide a fascinating insight into the evolution of the coping process and the patient's journey towards a revised sense of self.

4.8 Closing summary

This study arose from a clinician's curiosity about the thoughts and experiences of the patients who sat across the table from her at neuropsychological assessment. The research exercise has provided valuable insights into their needs and experiences and has given her much to reflect on in terms of her own clinical practice, and indeed, the organisational of clinical psychology services. IPA, as a methodology, has opened doors to a new way of accessing and making sense of the experiences of people with cognitive impairments. It has much to offer the field of scientific enquiry, as a unique methodology in its own right and in collaboration with methodologies from other research traditions. The research journey ends with many more questions to answer.

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The Experience of Neuropsychological Assessment

Interview schedule

Name:

Date of Birth:

Thank you for agreeing to speak to me about your recent experience of neuropsychology tests. I am conducting interviews with a group of people who have taken these tests to find out what you think about the experience, if it was of benefit in any way and if the experience could be improved for you or other people.

We will speak together for about 40 minutes. I will ask you a number of questions and you can say as little or as much as you like in response to my questions. There are no right or wrong answers. I am really interested in your own views and experiences.

When the interview is finished I will type out the details of our conversation and write a summary of the main findings that have been important for you. The findings of your interview will be combined with the findings from the other interviews and written up as a research study that will be shared with other interested professionals who work in neuropsychology.

Your name and personal details will be changed so you cannot be identified in any way. Are you happy with this? Do you have any questions at this stage?

I will ask you if you want to take a break half way through, but you can stop the interview at any time you wish.

Before we start can I check some details with you?

Date of Assessment: one month two months three months

Place of assessment:

1. Expectations and Understanding:**1.1 Why were you sent to have a neuropsychology assessment?**

Prompt: What happened that you were sent to have neuropsychology tests?

1.2 What did you expect would happen (at the assessment)?

Prompts:

What did you think they might ask you about?

What did you think they might ask you to do?

What kind of information did you get beforehand?

1.2 What did you expect to get out of the assessment?

Prompt: In what ways did you think it might be useful/worthwhile?

2. Experience of Assessment:**2.1 Can you describe what happened during the assessment?**

Prompts:

What sorts of things did you do?

What sorts of things did the psychologist do?

2.2 Was this different in any way from what you expected?**3. Feelings and Reactions:****3.1 How did it feel doing the tests?**

Prompts:

How did you react (got stressed, felt embarrassed, enjoyed the challenge, nothing in particular)?

Did you have any particular difficulties with any of the tests?

How did it feel getting some right and others wrong?

3.2 How did you feel after the tests were finished?**Prompts:**

What affect did doing the tests have on you? (Feelings about yourself, mood, self-image, understanding of problems, hopes, worries)

Straight afterwards?

Now?

BREAK IF NEEDED**4. Feedback:****4.1 What were the results of the tests?****Prompts:**

What's your impression of how you got on with the tests?

What information were you given about the test results (who, what, where, when)?

4.2 Did the test results tell you anything useful or help you in any way?**Prompts:**

Help you understand your diagnosis?

Explain your difficulties/cope with your problems?

Reassure you, give you more confidence?

Make decisions, set goals?

4.3 Did the test results match with how you thought you would do?**5. General Evaluation:****5.1: What are the main good things and bad things about the experience that stand out for you?**

Prompt: What was positive about the experience for you?

What was negative about the experience for you?

5.2 Have you any suggestions that might improve the experience of neuropsychological assessment for other people?

Thank you very much for your time and openness. Do you have any further comments to add.....or questions to ask?

Debriefing:

Enquire about how it felt to participate in the study and whether any distress was experienced.

Ask about the participants views on the nature of the questions asked, whether they were clear and could be understood.

Ask if any important topics were not covered and should be included in future interviews.

Enquire if the participant would like a summary of the interview data and the opportunity to comment on my interpretations (enquire whether participant would prefer a written or taped version).

Check if participant requires any issues to be followed up with the clinical team.

Check that the participant is feeling comfortable to conclude the interview and make their way home.

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Information Sheet for Psychologists

A Research Project Investigating the Experience of Patients Undergoing Neuropsychological Assessment

Introduction

Thank you for agreeing to participate in my study investigating the experience of patients undergoing neuropsychological assessment. This information leaflet will tell you everything you need to know about the study and the procedures you will need to follow if you invite some of your patients to participate.

Aims and objectives of project:

This project aims to investigate the patient's experience of undergoing a neuropsychological assessment. Clinicians believe that testing can be used to provide constructive feedback to the patient on their strengths and difficulties, and is a useful aid to rehabilitation planning. Few previous studies, however, have investigated if patients find the assessment process helpful or informative.

This project will investigate:

- Patients' understanding of the purpose of neuropsychological assessment,
- Patients' experience of the process of undergoing testing and
- Explore how the experience affects patients' views of themselves and their ability to cope with the consequences of their impairments.

The project is a small-scale exploratory study that aims to uncover the main issues of importance that depict the patient's experience of neuropsychological assessment. It is anticipated that the results of this study will raise clinicians' awareness of the educational and therapeutic benefits to the patient of neuropsychological assessment. It is also expected that the findings will contribute to the theoretical literature on the meaning and representation of illness and the coping process in the neurologically impaired person. The themes arising from the interview data can potentially be used by the Neuropsychology service in the future to generate further quality improvement projects.

Brief outline of project

A sample of 8-10 patients who have undergone neuropsychological assessment at the hospital/rehabilitation centre will be interviewed in depth about the experience. The aim is to interview patients who have experienced assessment by a variety of psychologists in a variety of assessment settings (assessment for rehabilitation planning, out-patient and in-patient diagnostic assessment), so as to reflect the core themes that arise for patients across a diverse range of assessment experience. They will be selected on the basis of their ability to recall details of their experience and verbally communicate their views.

Suitable patients will be invited to participate in the study when they present to you for assessment. You will provide them with a verbal explanation of the rationale and procedure and give them a written information sheet. If initial interest is expressed, a pre-interview meeting or telephone discussion with the researcher will follow this up and arrangements made to proceed to an interview if consent is granted.

Participants in the study will take part in a semi-structured interview that will be audio taped. The interview will last between thirty to forty-five minutes. The data will be transcribed by the researcher and analysed qualitatively, using a methodology called Interpretative Phenomenological Analysis (Smith, 1996). This methodology identifies the core meaningful themes that arise from a rigorous and systematic analysis of the data.

Participants will be asked about their expectations of the assessment and its relevance to their understanding of their presenting difficulties. Participants will be asked to describe what happened during the assessment and how it felt to undertake memory and intellectual tests. They will be asked what they understand of the test findings and will be asked in what ways the experience was helpful or unhelpful.

Each participant will receive a summary of the data from their transcript and be asked if the conclusions represent their views. Any additional feedback on the veracity and authenticity of the interpretations will be incorporated into the final report.

Inclusion/ Exclusion Criteria

I would like you to invite your patient(s) to consider participating in the study if they fulfil the referral criteria listed below:

- 1) Patients between the ages of 18-65 years,
- 2) Experience of neuropsychological assessment,
- 3) Ability to recall details of the assessment experience,
- 4) A knowledge of English sufficient to give informed consent and participate in the interview without the need for an interpreter,
- 5) An awareness of the nature of their cognitive impairments that is wholly or partially consistent with the results of their cognitive assessment.

Please take note also of the exclusion criteria listed below:

- 1) Evidence of severe amnesic deficit that would preclude adequate recall of the assessment experience,
- 2) Evidence of significant denial of cognitive impairments or unawareness of impairments that would preclude insightful participation in the interview process,
- 3) Evidence of a severe language/communication deficit,
- 4) Significant problems with fatigue, distractibility or emotional inhibition that would be likely to disrupt the interview process,
- 5) Evidence that the patient is likely to suffer significant distress at the content of the interview.

What will I have to do if I take part?

- At the end of the assessment please invite suitable candidates to participate in an interview about their experience of assessment. Please follow the prepared text (attached) and then feel free to answer any additional questions your patient may have.
- If your patient is agreeable to a pre-interview meeting with me, please pass their details on to me. I will arrange to contact them within the next week to have a discussion, in person or over the phone, about the study, which hopefully will enable them to make a decision about their participation.
- If your patient does not want to participate, you can let me know on their behalf, or they can fill in the slip at the end of their information sheet and send it back to me, c/o the Psychology secretary.
- If your patient is undecided, tell them that I will contact them in a week's time to find out if they are agreeable to a meeting with me.
- I would appreciate if you would agree to provide any follow-up support that might be needed by the patient after the interview, if any issues arise that might be worrying or confusing for them. As the sample size is small, I would not anticipate that this commitment would result in a significant clinical burden.

Where will the interviews take place?

I can arrange for the patient to have their interview at the Hospital/ Centre during their period of admission if it is convenient and feels appropriate and useful to the patient. Otherwise I will arrange to interview the patient any time up to eight weeks post assessment at a more convenient time and place.

Confidentiality Arrangements:

The names and personal details of all patients and psychologists will be disguised to ensure confidentiality is maintained. Individual patient feedback will not be linked to individual psychologists, rather the data will be analysed to uncover common themes, and the factors that determine similarities and differences in experience.

Any material will be kept in strictest confidence in locked premises away from the Hospital site. The treating consultant will be informed that their patient has been invited to participate in the study.

What do I do now?

- Please read over the procedural details again and read the explanatory text attached.
- If one or more of your future patients should meet the criteria for the study please invite them to participate when they complete their assessment. Ask if they would be willing to meet with me, and if so pass their details on to me.
- If they do not wish to meet me, let me know.
- If they are undecided, let me know and I will follow them up within a week.
- Please be available to have a follow-up meeting with your patient if they request it after I have completed the interview.

That is all you have to do! Many thanks in advance for your support and co-operation. All contributors will be cited in any subsequent publication and your support gratefully acknowledged.

Many thanks,

Noelle Blake

Chartered Clinical Psychologist

Clinical Research Supervisor: Dr. Martin Van Den Broek, Head of Neuropsychology Services.

A Research Project Investigating the Experience of Patients Undergoing Neuropsychological Assessment

Explanation of Study for Participants

Now that you have completed your assessment I would like to ask you if you would be willing to speak to a researcher about what it was like to take these tests.

Noelle Blake is an experienced clinical psychologist who is interested in finding out how people feel about taking tests like the ones you have done today.

She would like to interview a small group of patients who have recently taken these tests and find out

- 1) what you thought about the experience,
- 2) If it was of help to you in any way and
- 3) In what ways the experience could be improved for you and other people.

Your personal details and comments will be kept strictly confidential. The information gathered will be used to provide a summary to the clinical psychology staff and may be published for other professionals to read. Noelle hopes that this research will improve assessment services to patients and make clinicians more aware of patients' views.

Your participation is entirely voluntary and makes no difference to your treatment here.

If you would like to meet Noelle and find out more about the study, I can arrange for her to get in touch with you. If you definitely do not wish to take part, tell me, that is fine. You can take a week to decide what to do; there is no hurry or pressure to decide quickly.

Please take this information sheet away with you. Read it and discuss it with a relative or someone you trust. Noelle's contact details are on the sheet if you want to get in touch with her.

Is there anything further I can help you with at this stage?

Many thanks (please give information leaflet and invitation to participate letter).

Noelle Blake
Consultant Clinical psychologist
Feb 2003.

A Research Project Investigating the Experience of Undergoing Psychological Tests of Memory and Thinking.

Information Sheet for Participants

Introduction

You have been invited to take part in a study investigating how people feel about undergoing tests of memory and thinking following a brain injury or neurological illness. You have taken these tests as part of your assessment for rehabilitation at the Centre. This information leaflet will tell you everything you need to know in order to make a decision about taking part in the study.

Explanation of the Project

Psychologists use tests of memory and thinking to understand how people have been affected by a brain injury. These tests can help them to plan your treatment. If the results are explained to you, they can help you to understand how your injuries or illness have affected you. The results can also give you ideas on how to cope with difficulties associated with your condition.

The aim of this project is to find out what people think about taking part in these psychological tests and find out if they find them helpful in any way. The results will be used to improve the service provided to patients who undertake psychological tests.

What will I have to do if I take part?

You will take part in an interview with me that will be tape-recorded. The interview will last about 45 minutes. I will ask you about the following topics:

- What happened when you had your psychology tests?
- How did it feel to be tested?
- Did you understand the results?
- What was helpful and unhelpful about the experience?
- Your suggestions for improvement.

If any issues arise that need to be followed up with your doctor or clinical psychologist, then I will arrange for that to happen. After the interview I will listen to the tape and make typed notes of everything that was said. I will read your comments in great detail and summarise the important points you have made. I will then send this written report to you. You can make changes to the report if I have left

any thing out. I can send you the summary on a cassette tape if you prefer, and you can send your reply back to me on tape.

Where will the interviews take place?

We can arrange for you to have your interview at the Centre during your period of assessment if you wish. Otherwise I will arrange to interview you at a more convenient time and place.

What are the possible benefits of taking part?

You may find it interesting to discuss your experiences of testing and have that information used anonymously to inform the clinical staff about patients' views. The information will be used to improve assessment services for patients and find better ways of gathering their views more regularly. The information gathered will also be submitted for publication to a research journal so that it can be shared with other professionals.

What are the possible disadvantages of taking part?

You may not enjoy speaking about your experiences of testing, or speaking about personal feelings with a stranger. You may feel temporarily sad or upset if you have found the tests stressful or difficult. You can stop the interview at any stage if this happens. The interviewer is an experienced clinical psychologist and will ensure that any distress you might feel is kept to a minimum.

Confidentiality Arrangements:

Any material will be kept in strictest confidence in locked premises away from the Centre. Names and personal details will be changed so that participants cannot be identified when the findings are written up

With your permission, I would like to inform your consultant that you are taking part in the study. However I will not disclose the details of your interviews in any form that will allow you to be identified.

Will it affect my treatment?

It will make no difference to the care you receive whether you take part or not.

Do I have to take part?

No. Your decision to take part is voluntary and based on whether you would find it interesting or helpful to do so.

You do not have to take part and you may decide to withdraw from the project at any time, without giving a reason, from the start until the very end of the study. You will be asked to sign a consent form if you do wish to take part in the study, but you can still decide to stop at any stage.

What do I do now?

Read this information carefully and, if you wish, discuss it with a relative, friend or advisor. If you are interested in taking part you can tell the psychologist who has done the psychological tests with you. He/she will contact me and arrange for us to meet and discuss the project further.

If you are not sure about taking part, but would like to speak to me in person about it, I would be very happy to speak with you on the telephone or arrange to meet with you at a convenient time.

If you have any questions at all, you may contact me by telephone on ... If I am not available, please leave your name and telephone number on my answering machine and I will return your call as soon as possible.

If you definitely do not wish to take part either tell the psychologist who has assessed you or fill in the form at the end of this page and return it to me.

Thank you for taking the time to read this information and giving some consideration to taking part in the study.

Noelle Blake

Chartered Clinical Psychologist

Clinical Research Supervisor: Dr. Martin Van Den Broek, Head of Neuropsychology Services.

I, _____, do not wish to take part in the "Experience of Undergoing Psychological Tests of Memory and Thinking" study.

Please return to Noelle Blake, c/o Medical Secretary,

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A Research Project Investigating the Experience of Patients Undergoing Neuropsychological Assessment

Explanation of Study for Consultants

Dear Dr.,

I am writing to let you know that your patient,....., has consented to participate in a study investigating patients' experiences of neuropsychological assessment.

Aims and objectives of project:

Clinicians believe that neuropsychological testing can be used to provide constructive feedback to the patient on their strengths and difficulties, and is a useful aid to rehabilitation planning. Few previous studies, however, have investigated if patients find the assessment process helpful or informative.

This project will investigate:

- Patients' understanding of the purpose of neuropsychological assessment,
- Patients' experience of the process of undergoing testing and
- Explore how the experience affects patients' views of themselves and their ability to cope with the consequences of their impairments.

The project is a small-scale exploratory study that aims to uncover the main issues of importance that depict the patient's experience of neuropsychological assessment. It is anticipated that the results of this study will raise clinicians' awareness of the educational and therapeutic benefits to the patient of neuropsychological assessment. It is also expected that the findings will contribute to the theoretical literature on the meaning and representation of illness and the coping process in the neurologically impaired person. The themes arising from the interview data can potentially be used by the Neuropsychology service in the future to generate further quality improvement projects.

Brief outline of project

A sample of 8-10 patients who have undergone neuropsychological assessment at the Centre or at the Hospital will be interviewed about the experience. They will be selected by the

psychologist administering the neuropsychological tests on the basis of their ability to recall details of their experience and verbally communicate their views. A rigorous process of preparation and discussion will follow before consent to participate is requested.

Participants in the study will take part in a semi-structured interview that will be audio taped. The interview will last between thirty to forty-five minutes. The data will be transcribed by the researcher and analysed qualitatively, using a methodology called Interpretative Phenomenological Analysis (Smith, 1996).

Each participant will receive a summary of the data from their transcript and be asked if the conclusions represent their views. Any additional feedback on the veracity and authenticity of the interpretations will be incorporated into the final report.

The interview will end with a debriefing period. The researcher will ensure that the clinical psychologist follows up any patient questions or concerns that have arisen as a result of the interview.

A summary report will be prepared for the clinical team on completion of the study. I would be happy to provide you with a copy of the study findings at your request.

Confidentiality Arrangements:

The names and personal details of all patients and psychologists will be disguised to ensure confidentiality is maintained. Individual patient feedback will not be linked to individual psychologists, rather the data will be analysed to uncover common themes, and the factors that determine similarities and differences in experience.

Any material will be kept in strictest confidence in locked premises away from the Hospital site.

If you have any concerns about your patient's participation in the study or would like to discuss any aspects of the project with me, please contact me on ...or leave a message for me with the Psychology secretary at the Rehabilitation Centre.

Yours sincerely,

Noelle Blake,

Consultant Clinical Psychologist

Clinical Research Supervisor: Dr. Martin Van Den Broek, Head of Neuropsychology Services.

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Master theme 1: Expectations of Assessment**Fears and Uncertainties:**

Paul (9.3)... *"I didn't really understand what I was actually doing there"*.

Alistair (7.12)... *"To be honest I didn't know what to expect because nobody told me anything about it"*.

Julia (2.23)... *"I had absolutely no idea"*.

Information and Clarification:

Rachel (4.36)... *"At least if I'm struggling with something, then I know why I'm struggling..."*

Frances (1.8)... *"I don't know how many of the areas that I know I have weaknesses in...how many I could strengthen"*.

Julia (5.31)... *"I want to understand... why... I might find doing certain things rather more difficult than others"*.

Advice on coping:

Rachel (8.15)... *"I just think that knowing the bits I'm struggling with will help me in my job"*.

Barbara (22.18)... *"If we do find something, this is how we're going to re-dress it"*.

Julia (3.2)... *"I really want to know what I can do to improve the things that are working well"*

Master theme 2: Context of Assessment**Coerced Assessment:**

Denise (4.30)... *"...if I 'd been doing it under any other circumstances than what I am doing at the moment...it might have been different"*

Barbara (4.2)... *"I didn't want to go"*.

(15.2)... *"I felt sort of obliged to fulfil my programme and that was part of it"*.

Trust in professionals:

Paul (4.19)... *"But, you know, I didn't mind em...because I believe that, you know, they are looking after my best interests"*.

(8.16)... *"I trust em, you know, the doctors and nurses... to look after me"*.

Frances (4.32)... *"I was just so pleased to get there because it was help offered to me"*.

Julia (5.19)... *"I was happy that...Dr.X was very confident that he knew exactly who to contact to do with...the tests and stuff..."*

Master theme 3: Experience of Process**Emotional Engagement**

Rachel (6.38)... *"It was absolutely devastating to be given these simple things to do, like to be asked to name some animals...and I could say...probably one..."*

Frances (7.35)... *"I remember because it was massively, massively important to me to do these tests properly. I was very intense about them"*.

Julia (9.19)... *"I was very cross that I just...thought I'd remembered the first bits and...then I kept forgetting"*.

Relationship with Psychologist:

Rachel (3.42)... “...she told me what we would be doing...as in when each task came up she'd explain what I needed to do”.

Denise (5.19)... “I felt it was being done to me... I felt very distant”.

Rosa (10.14)... “I remember S., she was... really patient...when I was flustered, she was really calm...”

Awareness of Performance:

Danny (9.31)... “I tried to recall listening to the story, and what the hell the story was about...and I had no recollection whatsoever...”

Rosa (11.28)... “I think the difficult ones I remember was...the puzzles...[and] the story was very difficult”.

Paul (12.29)... “I had a clock and I put the hands the wrong way round”.

Alistair (43.28)... “I saw during the tests what it was they were trying to get me to do”.

Feedback Process:

Denise (20.26)... “I'm hoping it will give me some sort of understanding on...call it [my] performance over the years”.

Paul (24.5)... “I can look back on it [written summary of results], read it through and just say, hold on a second, I forgot about that bit, and then bring that bit into practice as well...”

Julia (12.16)... “what was the whole idea...what was it supposed...what was I supposed to demonstrate?”

Master theme 4: Impact on Self**Self-Awareness:**

Rachel (5.45)... “it makes you more aware of the problems you've got”.

Denise (17.39)... “It's a whole...almost paradigm shift for me”.

Alistair (38.1)... “These are things that I hadn't really thought about before”.

Self-Esteem and Validation:

Rosa (10.32)... “It did help me because I thought, well, you know, I'm not stupid, you know I can do it”.

Paul (24.9) “I did feel more positive with myself”.

Barbara (5.35)... “I was getting on all right and you're kind of making me think...ooh, when I get home I won't be able to do all these things”.

Use of Strategies:

Danny (22.33)... “it made me realise that if I were speaking with anybody em...then I could solidly say, I honestly don't remember that”.

Rosa (20.24)... “But now I've learned to be patient, to...look at things twice. You don't always have to look at things just once...”

Julia (16.25)... “I'm thinking I want to get my words in the right order rather than jump straight in the deep”.

Master theme 5: Components of a Good assessment**Providing Information:**

Rachel (8.20)... *“ it’s essential to do the tests and it’s a good thing to do if it...highlights what you struggle with...”*

Denise (18.2)... *“ if this sort of thing was available 40 years ago...would I have taken the career path I took...I would probably have been advised not to go into such a practical field”*.

Alistair (39.20)... *“ ...it might have been quite nice if, if there was a sort of briefing process about the tests...”*

Good Preparation for Testing:

Denise (25.34)... *“ I would have appreciated being given time to calm down...”*

Danny (24.38)... *“ ...encourage the psychologists to be aware of the need to emphasise what ...the series of tests were going to be...to justify it...make it less awkward”*.

Providing Feedback:

Danny (26.30)... *“ ...to ask...somebody... to be able to define and recognise what I would be talking about and to be able to clinically put it in terms or words that would make sense.”*

Frances (23.3)... *“ I’d rather somebody tell me, be with me so I could ask questions...”*

Alistair (40.42)... *“ ...[it would be] nice to come away with some idea as to how they came to these conclusions”*.

Appreciating the Emotional Impact:

Rachel (8.23)... *“ ...the only bad things are when you’re ill...and things...things are all quite shocking to you at the time because you’re struggling with why you’re ill and the reasons why you’re doing the tests...”*

Denise (25.34)... *“ I would have appreciated being given time to calm down...if you’ve got a highly anxious person in front of you and you’re working with them, you can’t really connect”*.

Facilitating Coping and Adjustment:

Rosa (26.34)... *“ ...it helped me to be patient and it helped me to accept things. You might not remember...there’s nothing wrong with that”*.

Paul (22.18)... *“ now when I talk to my sister on the phone, I turn the tele off”*.

Frances (11.18)... *“ there were things I had to come to terms with, and I’d never done things like that [the tests]...”*

Support Structures:

Frances (26.1)... *“ there was a lady there...she was good to me...she walked with me...and said, will you be able to find your way back...they go the extra mile, walked with me to show me...otherwise I would have been confused...”*

Julia (34.1)... *“ you don’t have to walk miles...good to be somewhere quiet...”*

Master theme 6: Experience of Illness/Disability**Accessing Information/Services:**

Denise (17.5)... “...it’s left a lot of questions and quite frankly, something I thought was, if I hadn’t the background I have got, would I have known how to...would I have known what questions to ask?”

Rosa (4.9)... “...you have to find things out for yourself ‘cos the hospitals can only do so much...the rest you have to do for yourself”.

Alistair (19.1)... “ People will give you the most basic down the line information...there’s a hell of a lot I don’t know...”

Feeling heard/Being a person:

Paul (1.23) ... “ ...it was two seconds in this... I went to Dr. X, em, the other week and it was only two seconds in this room, there was something like two students there and this doctor, it wasn’t Dr. Y, it was one of his colleagues who saw me instead. And em, he said, oh, he was quite happy with me and em, you know...he said to make another appointment...that was it and I came out thinking, well, that’s a bit strange because everything doesn’t feel like, you know, right...”

Barbara (31.32)... “ I don’t think they realise that people who are suddenly disabled, who have been working and ringing up a family, it does lower their self-esteem ”.

Power Imbalances:

Paul (4.9)... “ I said I wasn’t really happy about certain things, and he [the neurologist] said, oh well, don’t worry, I’m very pleased with you, and that was the end of it...I don’t remember anything being discussed to say he was going to refer me anywhere”.

Barbara (23.22)... “ ...she’s making out you’ve forgotten a whole issue, when if it’s important to you, you would remember it...she’s not going to be proved wrong because she’s the psychologist and you’re the one with the brain injury...so you can’t really win there , can you...?”

Adjustment/Acceptance:

Rachel (6.18)... “ ...’cos there’s nothing you can do about it, or there might be something you can do about it but...there’s no point whinging ‘cos it’s happened”.

Denise (22.37)... “...and afterwards I’ve thought, no, you know, I’m never going to regain this, I’ve gone on for long enough trying to recapture what was there and let’s move on...”

Rosa (20.13)... “ ...but if you use your energy on the positive things and think, oh well, I might not be able to crochet but I will be able to sew”.

Role of Social Support:

Rachel (8.11)... “ ...in my job, I can be aware of them so that maybe I can get someone else to help me with certain areas...make sure I don’t forget things or stuff like that...”

Rosa (17.22)... “ Mum goes...think of the children, them at Church, on Sunday school, they’re dying to have you back...”

Barbara (33.26)... “... there’s very good camaraderie amongst the patients as well. One of them invited me over on Sunday. She’s been over here so we’re keeping in touch and that...”

Danny (participant 3):

“It was wonderful to receive your letter and I am delighted to have the opportunity to reply, enclosing any of my views arising from your summary of research interview of June 27, 2003...”

I would like to begin by confirming that your interview of research is indeed generally quite accurate. In fact I must admit that as I first read it I became anxious and very confused, as I had no recollection of these events at all. I am now very pleased to say that gradually I was able to recall most memories from referring to my diaries etc. I say this as by no means a criticism of benefits I gained, but rather a *positive benefit*. I recall P’s encouragement to me to continue keeping diaries etc. An important point I would like to highlight is that while I was with P., as a professional he was able to encourage me to realise that I need not be having problems with various people and situations when I would feel obliged to explain any difficulties I would think they were having due to my memory problems etc. Now I feel completely comfortable as I think, in these, like, situations... *“Oh, what a shame they are having problems [understanding me]”, as I proudly walk away.*

The 31/2 hours of assessment did in fact fly by very quickly. This was because I felt so comfortable and without feeling under any pressure at any time. In fact, I am still amazed at how P. made me feel that time was of no importance for him, as he casually made me feel free to talk of issues and times past. I know indeed that I have never done so with anyone in the past.

Generally the experience of the assessment did have a big impact on my self-esteem – I now have more confidence in accepting that I do have problems – that are not a major issue for me generally – unfortunate for others who may choose it to be so for themselves.

Finally, P. did send me copies of a summary of the test results, which I was able to share with partner and family. This was of great benefit. Thank you to P. again.

I hope you are in good form yourself...*I regret that writing this has actually taken me a considerable length of time before I now feel it’s ready to post. I do have difficulties in concentration and do have to make several attempts before getting there – but I enjoy the challenge when I finish.*

...best regards...”

Rosa (participant 4):

“ Thank you for sending me the feed back on the report, which I have read, with my daughter.

I am still finding that I have to be patient and ask for help from family and friends. I am trying to accept that my memory might not be 100% again, but I have come a long way, with the help of the team working with me.

I am pleased with how far I have come and I have also learnt a lot about myself. And accept that life is not always black and white. Have a lovely New Year and keep up the good work.

Thanks again...”

Barbara (participant 7):

“Many thanks for your summary of research interview in 23rd July 2003.

I confirm it to be an accurate summary; bearing in mind my testing was as a wheelchair user, at the time of seeing the psychologist. I was uncertain if and how far I would be able to walk after completing rehab. My physio was fantastic and built-up my self-esteem with continual praise and encouragement.

Since our taped interview in July, although my memory is not quite as sharp, it has not caused any major problems in my day to day activities, whereas my [physical] *disability has, in that although I was offered a place on the “return to work” scheme*, I felt that my previous job would be unsuitable as I can still only use one hand. I felt that too many adjustments would have to be made i.e. more machines etc. I am also *aware that it takes a lot longer to do things; even placing a customer’s purchase in a paper bag is difficult ad the customer usually does it themselves*, which does seem unprofessional.

I therefore wanted the emphasis to be on what I can *do rather than what I can’t do*, therefore I have applied to do a half-day voluntary work at a hospital for profoundly physically and mentally handicapped children, helping out at the school. Altruistic – yes, partly, but I would still like to help too.

Fatigue is still a problem and jobs have to be staggered. I feel my time at rehab was invaluable in making me believe I can do things for myself, albeit taking longer to do so.

Looking back, I feel I have been extremely lucky to have had such a good recovery *and I’m still increasing my walking distance and building up stamina. I hope my input will be of use to others and I look forward to reading your paper when complete.*

Best wishes for 2004 ...”