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Brain Injury and the Experience of Caring: Intrapersonal Aspects from a Personal Construct Perspective

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Contents

Thesis

Written Exercise 1

Critically evaluate the concept of "dual diagnosis" and argue its degree of relevance to treatment planning.

Introduction

To critically evaluate the concept of dual diagnosis, that is two comorbid or simultaneously existing psychiatric disorders (Mueser et al., 2001), the unitary concept of diagnosis must be critically analysed. The concept of diagnosis forms the basis of the contemporary medical model (Kroese and Holmes, 2001), although systems of classification have been in existence since classical times (Gross and McIlveen, 1996). Diagnosis has several explicit purposes including aiding research; summarising information; and guiding treatment (Nurcombe, 2000). To explore the concept of psychiatric diagnosis, the categorical diagnostic framework of the Diagnostic and Statistical Manual (DSM) (American Psychiatric Association, 2000) will be the exemplar analysed. This system of diagnosis is multi-axial, involving assessment on five axes all of which map on to different kinds of information that ought to enable the assessor to plan treatment (ibid.). Attention will be focused on Clinical Disorders on Axis I, and Personality Disorders on Axis II. "Axis I is for reporting all the various disorders or conditions in the Classification except for the Personality Disorders and Mental retardation... "(American Psychiatric Association, 2000: 27). On Axis II, DSM- IV lists 10 separate personality disorders, grouped into three separate clusters based on descriptive similarities: Cluster A (an odd or eccentric pattern); Cluster B (dramatic, emotional or erratic); Cluster C (anxious and fearful) (Parker and Barret, 2000). Personality Disorders comprise, "... an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture and is manifested in at least two of the following areas: cognition, affectivity, interpersonal functioning or impulse control." (American Psychiatric Association, 1994; cited in Parker and Barrett, 2000:1). Furthermore the "enduring pattern" must be "inflexible and pervasive", "stable over time", and have an "onset in adolescence or early adulthood" (ibid.). A client with a dual diagnosis may be diagnosed with two disorders on the same axis or one from Axis I and one from Axis II.

Psychological treatment planning based on a diagnostic system can take the form of a manual-based approach, in which an empirically supported standard treatment programme is developed for a diagnosis from a particular therapeutic standpoint drawing on core elements of the diagnostic criteria. For example, Fairburn (1997) describes the cognitive-behavioural manual-based approach to Bulimia Nervosa (BN) in which a structured twenty session outpatient programme addresses central diagnostic criteria such as behavioural compensation to binge eating, and self-perception as being evaluated in terms of body shape and weight. Thus, treatment planning based on a diagnostic system can be found to have its proponents, but it may not necessarily be appropriate for clients with a dual diagnosis. Moreover, not all forms of therapy accept diagnosis as compatible with their model (Bozarth, 1998), and, from a Person-Centred standpoint, treatment planning would be philosophically incompatible with an approach based on diagnostic criteria (Merry, 1999). An alternative method of psychological treatment planning can be found in a case formulation-based approach. According to Butler (1998: 1), "the process of clinical formulation remains the lynch pin that holds theory and practice together.", and, while formulations can be constructed from disparate psychological theoretical models (Horowitz, 1997), a formulation essentially comprises:

"(1) A hypothesis about the relationship among various problems of the individual; (2) Hypotheses about the aetiology of the aforementioned difficulties; (3) Predictions about the patient's future behaviour." (Turkat, 1990: 17; cited in Bruch, 1998a).

Thus, a formulation is not a treatment procedure, per se, but a means to understanding the client and all his problems, permitting the selection and design of treatment based on each individual case (Adams, 1996; cited in Bruch, 1998a). A formulation is also a dynamic entity that can be altered throughout therapy as the therapist develops a greater understanding of the case (Butler, 1998), and can include aspects of the therapeutic process, such as the therapeutic relationship (Bruch, 1998b).

While the proposed intentions of a diagnostic system appear to be beneficial for the individual's psychological well-being (Nurcombe, 2000), including treatment planning, the reality is that the concept of diagnosis does not always provide the intended benefits and, indeed, can be found to be theoretically flawed. Moreover, while socio-cultural themes have had an impact on the utility of the diagnostic concept, methodological debates and criticisms abound for single and dual diagnoses; all of these factors ultimately affect the relevance of a dual diagnosis for treatment planning.

Unitary Diagnosis & Manual-Based Treatment

Multi-disciplinary teams provide the environment in which many psychologists currently work. In such a setting, a collection of people with disparate professional backgrounds need to find a common language in which to communicate regarding clients. One of the strengths of a diagnostic system of classification is that it provides a shared nomenclature (American Psychiatric Association, 2000) for such communications. Thus, this diagnostic system can provide a "meaningful lexicon" to aid case-formulation (Parker and Barrett, 2000:8) by multiple professionals; this would of course equally apply to clients who have a dual diagnosis. Furthermore, as no one therapeutic model, including cognitive, interpersonal, neurochemical, and psychodynamic, has greater empirical support than another to explain presenting disorders, (Widiger and Clark, 2000), a categorical diagnosis can provide an understanding accessible to all professionals from which treatment can be planned.

However, it must be noted that while no one therapeutic model may have been proved superior to explain disorder, Persons (1989) argues that psychiatric diagnoses are merely descriptions of symptom clusters and are not underlying explanatory aetiological mechanisms. Moreover, while manual-based treatment has been planned for certain unitary diagnoses from a variety of theoretical standpoints (Fairburn, 1997; Ryle et al.,1997), not all diagnoses have had a manual-based approach developed, with manual-based approaches currently dominating only the cognitive-behavioural literature, thus limiting their potential role in treatment planning. Furthermore, clients with "complex disorders and enduring symptoms", such as those with a dual diagnosis, have not tended to be addressed by manual-based approaches as a single therapy is evaluated in a narrowly defined clinical research group (Guthrie, 2000: 132), thus not only denying an empirical understanding of treatment planning for this group, but limiting the external validity of the findings for clinical, rather than research, participants. When randomised clinical trials have been undertaken in clients with a dual diagnosis, such as Linehan et al.'s (1999) study on substance-abusing women with Borderline Personality Disorder (BPD), a standardised manual-based treatment was not utilized and the Axis I disorder was the only diagnosis evaluated at outcome.

Diagnostic Construct Properties

As one of the design aims of the DSM is as an aid to research, it can also provide a structure from which scientist-practitioner psychologists can build their research, ultimately informing their clinical practice and treatment planning. The most recent version of the Diagnostic and Statistical Manual, DSM-IV-TR (American Psychiatric Association, 2000), is the most research-driven and empirically grounded version so far (ibid.) and, thus, ought to provide an empirically robust platform for research. However, Widiger and Clark (2000) have criticised it for inadequate pilot testing, Mullen et al. (1999) have questioned the reliability of personality disorder diagnoses, and Tyrer (2000) has expressed doubts over the validity of the DSM as the diagnostic categories have been founded on clinical judgement. Thus, the diagnostic categories may be insufficiently theory-driven, and, indeed, are merely reflecting behavioural descriptions based on observations (Clark et al., 1997); in the case of a dual diagnosis, this may just result in a large objective symptom profile without an understanding of the problems and goals of the individual. For example, two clients with dual diagnoses of BPD and BN may have very different problems they wish to address in therapy. One of them may be concerned by the frequency of her binge eating and compensatory behaviour (part of the diagnostic criteria for BN), while the other may be concerned that she does not have a high enough self-esteem to progress at work. The second client's main problem may appear to be related to a number of diagnostic criteria but, to understand the problem in it's entirety and plan treatment for this client, hearing her story may permit the development of an individual longitudinal formulation, including the core cognition "I'm not good enough" which drives much of the diagnostic criteria. As such, the utility, and relevance, of a diagnostic-based operationalisation can be limited in treatment planning, merely providing the symptom profile classified as representative of a disorder, or dual disorders, and, not necessarily reflecting the difficulties the client hopes that treatment will address, nor the engine that is driving them.

Operationalisation is perceived as a particular problem in personality assessment, and by extrapolation, in the assessment of personality disorders. Trull (2000) presents several alternative models to quantify personality and personality disorder. He asserts that dimensional models of classification provide more reliable scores, both across raters and time. One dimensional approach to quantifying personality would include measuring each personality disorder construct to generate a score to represent the degree of presence of the symptoms from each disorder. This may solve some of the theoretical problems with the assessment of personality disorders, such as the data that suggest the largest group of personality disorder diagnoses received by a sample of inpatients and outpatients was Personality Disorder Not Otherwise Specified (Grabe et al., 1999). This level of non-specific assessment supports Bateman and Fonagy's (2000) belief that the categorical nature of personality disorder assessment does not provide predictive validity. Certainly, given the assessment process in DSM-IV - TR (American Psychiatric

Association, 2000), in which only five out of nine symptom profiles have to be met for a diagnosis of Borderline Personality Disorder, clients who share only one common feature can be diagnosed with the same disorder. This limited common variance would seem unlikely to predict their difficulties and treatment needs. It is perhaps surprising then that Bateman and Fonagy (2000) even suggest that face validity exists for personality disorders, although they believe it is the only form of validity that does exist. Moreover, as Fryer et al. (1988) (cited in Tyrer, 2000) established that Borderline Personality Disorder was found to exist in a pure form in less than 10% of patients selected with this disorder, it would appear that the categorical system may lead to dual or multiple diagnostic labels being applied to clients. Whether this is an artefact of the structure of diagnostic categories and/or does indeed reflect greater treatment needs will need to be established.

Stigma

The stigma of receiving a diagnosis, whether single or dual, is an aspect of the categorical system that has been explored by researchers such as Tyrer (2000). Moreover, the power of this stigma has been reported by Szasz (1974,1994) (cited in Gross and McIlveen, 1996) in relation to political aims; this has certainly been evident in the former Soviet Union (ibid.). Nowhere is this more of a problem than with personality disorders. DSM-III placed personality disorders on a separate axis (McGlashen et al., 2000). Tyrer (2000) asserts that the advent of a separate axis for personality disorders and mental retardation in the DSM diagnostic design, resulted because psychiatrists and patients alike wish to avoid such stigmatic labels. Given the nature of diagnosis as either present or absent (Carter et al., 1999), the power of slipping over the threshold from a subclinical presentation to a diagnosis cannot be underestimated; however, as we have no data on subclinical rates (Westen and Arkowitz-Westen, 1998), it is impossible to state how usual certain symptom patterns are. Yet this entry into mental illness from "normality", this diagnostic system that lends itself to the assumption that a dichotomous situation exists in which an abnormal psychological state can result from the presence of five out of nine symptom profiles instead of four, is defined merely by statistically significant deviations from the mean (Bruch, 1998a); these deviations are not necessarily clinically significant for the individual, nor more acute in relation to treatment needs, in multiplicity.

Thus, a client diagnosed with BPD and major depressive disorder (MDD) who meets the diagnostic suicidal ideation criterion is likely to be subject to rigorous risk assessments, especially given the research that suggests inpatients and outpatients with this dual diagnosis have the earliest, and greatest number, of suicide attempts (Soloff et al., 2000; Bank and Silk, 2001). In this instance, the diagnostic pattern may be perceived as very relevant for treatment planning, which may include elements such as a "no suicide contract" between the therapist and client. However, a client who meets no full diagnostic category, but is found to harbour suicidal thoughts, may also be a suicide risk, although she may not have the interpersonal difficulties that could influence the therapeutic process. Thus, at the individual level, the fact the client objectively has a subclinical presentation does not mean her subjective despair or suicidal intentions are any less than the client with a dual diagnosis; it is only that she does not sport pejorative labelling.

Szasz, (1961) viewed the concept of diagnostic labelling as counterproductive for therapeutic endeavours (cited in Bruch, 1998a), while Lane (1998) warns us that, "Diagnosis is not neutral." (p 106) and "... has very real consequences." (p 105). Certainly, this has been shown to be the case by Barnham and Hayward's (1991) research on the impact of psychiatric diagnosis: "...you wake up every morning and you think, "Oh, God, I'm a schizophrenic!"" (cited in Wallcraft and Michaelson, 2001:179). As the Mental Health Act white paper now proposes new powers for compulsory assessment, care and treatment of "dangerous people with severe personality disorder" (Cohen, 2001: 118), the rights of the individual, who is seen to present a future risk, to refuse treatment are being eroded. Spitzer et al. (1999) express the view that the DSM diagnostic approach can be seen to medicalise social problems. Given the high degree of overlap, or dual diagnoses, among personality disorders (Widiger and Clark, 2000), and the proposed Mental Health Act, the risks to informed consent by the individual, and the increased power of the therapist, for treatment planning cannot be underestimated; certainly, the psychologist must never lose sight of his ethical responsibility concerning consent (British Psychological Society, 1998). However, clients are to receive some protection from rigidly enforced diagnostic criteria as DSM-IV has added a "clinically significant distress or impairment" clause before an individual can be diagnosed with a number of categories (ibid.:1857). For an unexplained reason, only 46% of Axis I and II disorders are protected by this criterion, and, there are no guidelines regarding how to define the contents of the term (Spitzer et al., 1999). The distress or impairment is to be witnessed in social, occupational or other important areas of functioning (ibid.), permitting at least some latitude for the individual to express his own treatment needs, and for the assessor slavishly not to apply diagnostic labels.

However, even if the client is diagnosed with dual diagnoses/labels, or multiple diagnoses, treatment planned from a diagnostic perspective would customarily address any diagnosis on Axis I first (American Psychiatric Association, 2000); this default approach is also the one advocated by Zanarini et al. (1998) and Tyrer (2000), except in forensic settings where Tyrer suggests any personality disorders take precedence. Alternatively, Steketee et al. (2001) and Chambless et al. (2000) approve a more subjective treatment plan in which the most incapacitating diagnosis takes therapeutic precedence. Utilising the treatment planning based on DSM's prioritising of Axis I disorders may appear to be a paradox, in which a therapeutic process embedded in the therapeutic relationship does not address interpersonal problems inherent in personality disorders. This strategy could lead to difficulties in the therapeutic process not being addressed in terms of relationship issues; missed opportunities to test out hypotheses as to the impact of the Axis II disorder on the other diagnoses; or even a cessation of therapy by the client owing to the fundamental interpersonal difficulties. However, interestingly, and in support of Mullen at al.'s (1999) stance that personality disorders are state dependent, successful treatment of MDD can lead to the individual no longer meeting diagnostic criteria for personality disorders (Carter et al., 1999; Hirschfield, 1999); the stigma can remain, though, as DSM-IV affords the opportunity to record "prior history" even when the client has recovered from the disorder.

Socio-Cultural Aspects

An issue that is related to stigma is the historical mediation of diagnostic entities. Spitzer and Wakefield (1999) proposed the possibility that diagnostic labelling can medicalise normality. However, it is also the case that what is perceived as abnormal can change through time. The development of DSM-III in 1980 (DSM is an American publication) saw a fierce debate over whether the behaviour pattern of homosexuality should be classified as a mental disorder (Widiger and Clark, 2000); to be a practising homosexual had been overturned as illegal by the British Parliament in 1967. Fortunately, homosexuality is no longer perceived as a mental disorder, but the example of it must alert practitioners to the power of diagnoses in marginalising particular groups in society. In this case there was a period when the historical and cultural backdrop defined a certain sexuality as pathological. The relevance of diagnoses in treatment planning becomes ridiculous in this instance as part of an individual's identity was deemed eligible for therapy; a man suffering from MDD who was homosexual, would have been deemed to have a dual diagnosis. Alternatively, a formulation-based approach to therapy would have taken an ideographic perspective in which an individual's sexuality was acknowledged, and only addressed in therapy if he deemed some sex or relationship problem to be in existence.

Paedophilia is illegal in the United Kingdom, and United States of America from where the DSM derives. To diagnose paedophilia according to the DSM-IV, the criterion of clinically significant distress or impairment in social, occupational or other important of functioning is applied to the behaviour, sexual fantasies or urges (Widiger and Clark, 2000). To this end, it is possible to be engaged in illegal sexual acts with children, but for it not to be considered a mental disorder if the individual is not distressed or impaired in areas of role function mg. While the debate concerning child sexual abuse revolves round whether the individual abusing the child is "mad or bad", a patient in a forensic hospital setting could be denied access to treatment services on the basis of not meeting the clinical significance criteria. However, if he had a dual diagnosis, the other part of which was a severe personality disorder seen to make him a potential threat, he could soon be forced to undergo compulsory treatment for it. This situation can, of course, have far-reaching implications for society and, coupled with the above example of homosexuality, highlights the fact that diagnostic nosology is temporally mediated and may not adequately address the treatment needs of the individual or society.

Gender and cultural elements are also implicated in diagnosis. Sue and Sue (1999) report the prevalence of affective disorders as the following: white women twice as high as white men, and the same ratio between African American women and men. DSM-IV estimates that schizoid, schizotypal, and antisocial personality disorders are diagnosed more frequently in males, while borderline and dependent personality disorders are diagnosed more frequently in females in clinical settings (Carter et al., 1999). A possible explanation for this finding involves the role of socialisation. Dohrenwend and Dohrenwend (1976) have suggested that social pressure on males to externalise their distress, may lead to them predominating in externalising personality disorders (cited in Carter et al., 1999). However an alternative explanation is that males need more psychopathology to seek treatment than females. Indeed in Carter et al.'s (1999) study on depressed outpatients, it was discovered that males had an average of 1.5 personality disorders compared to 0.72 for females. Moreover, they were statistically more likely to be diagnosed with shizotypal and paranoid personality disorders from Cluster A, and Narcissistic, Borderline and Antisocial personality disorders from Cluster B.

A number of interesting findings may be considered from this study. First of all there do appear to be gender differences in diagnoses, although the data from DSM-IV and Carter et al.'s (1999) study are not isomorphic. One explanation for this lack of congruence in results could be that the primary reason for referral in Carter et al.'s (1999) study was with an Axis I diagnosis of Major Depressive Disorder; thus there could be inherent sample differences. However, another point of note is the number of diagnoses the participants were assigned in Carter et al.'s (1999) study. From the perspective of treatment planning then, the gender of the client can affect the number of diagnoses he or she receives, and the initial reason for referral may not be the only problem that the client brings. A supplementary issue is that while DSM-IV acknowledges the need for culturally relevant information to aid assessment and the existence of culture-bound syndromes (American Psychiatric Association, 2000), the existence of disparate levels of categorical presentation by gender has not been explained, prompted the need for gender-based information to be included in assessment, nor indeed influenced manual-based treatments. Furthermore, diagnostically-based approaches do not acknowledge the potential cultural differences between client and therapist (D'Ardenne and Mahtani, 1999), which could lead to power imbalances in the therapeutic process.

Kokkevi et al. (1998) states that studies on dual diagnoses in substance abuse, Axis I disorders and personality disorders have found the cultural setting to have an impact on drug use (ibid.). As such, the historical background of drug abuse in the country and the prevalence rates within the general population are associated with the levels of drug abuse. Mueser et al. (2001) report that African Americans are significantly more likely to be diagnosed with schizophrenia than white Americans. Further evidence of the impact of culture on diagnosis comes from Whaley (1997). He undertook a controlled study to explore cultural bias in diagnostic assignment using a representative community sample as the control group, and inpatients and outpatients from the same medical centre in New York as the clinical group. Whaley (1997) discovered that clinicians were more likely to mistakenly diagnose black Americans with schizophrenia when they were depressed. The reason for this error was established to be due to type II errors in the assessment process, in which the clinicians assumed that there were no differences in the cultural expression of symptomatology and, thus, interpreted paranoid symptoms as evidence of schizophrenia instead of depression. Thus, even though DSM-IV acknowledges the need to consider cultural relativity, bias within individual assessors can lead to false positives in diagnosis. In the case of the difference between a diagnosis of schizophrenia and depression, the implications for treatment could be far-reaching. Thus, a nomothetic diagnostic scheme that's approach to individual differences is to assign a few pages of text at the back of its manual to them, as occurs in DSM-IVTR (American Psychiatric Association, 2000), does not appear to prioritise the treatment needs inherent in disparate cultural expressions. Moreover, incorrect diagnoses from biased assessors could result in patterns of dual diagnosis being recorded on client notes as one therapist diagnoses schizophrenia, and another depression.

Methodology and Incidence

The method utilised in assessment can also influence issues in the concepts of diagnosis and dual diagnosis. Zimmerman and Mattia (1999) highlighted a problem of instrumentation in assessment. When structured diagnostic interviews, such as the one produced to use with DSM-IV, are used in the assessment process, more diagnoses are ascribed to clients than when a clinical interview is the mode of assessment. This finding has been supported in many papers (Phillips et al., 2001) and appears to address a wider issue of research versus clinical interview diagnoses. Westen (1997) suggests that when semi structured research interviews are used as the mode of assessment in personality disorder, multiple Axis II diagnoses are forthcoming, while clinicians will assign only one diagnosis (Parker and Barrett, 2000). Certainly this finding is empirically supported by studies such as Tyrer (2000) and Ball (1998) whose paper, on the treatment of substance abuse in outpatients with personality disorder, established that most patients in treatment had two or more Axis II disorders. Moreover, Pepper et al. (1995) found a greater number of multiple diagnoses of personality disorder were recorded when informants, rather than patients, were interviewed (cited in Corruble et al., 1996). Thus, the number of diagnoses, and treatment plan, offered to the same individual could vary depending on whether the assessment used a clinical interview or semi structured interview and who is the interviewee.

However, the number of diagnoses assigned to one individual is not merely a reflection of the assessment method. Exclusion criteria that affected 60% of disorders existed in DSM-

III (Widiger and Clark, 2000). These rules led to less examples of dual diagnoses, as a diagnosis was not made if a disorder was found to occur in conjunction with another disorder that was considered to warrant precedence (ibid.) When it was discovered there was inadequate theoretical and empirical support for such a premise, the exclusion criteria were removed from DSM-III-R; this resulted in widespread examples of dual, or multiple, diagnoses (ibid.). Moreover, criterion changes in Axis II diagnoses, from monothetic (all criteria required for diagnosis) to polythetic (only a subset of criteria required for diagnosis) between DSM-III and DSM-III-R also led to increased rates of diagnostic co-occurrence (Clark et al., 1997). Thus, dual diagnosis may, in part, be an artefact of current diagnostic nosology. If this were the case, it would be difficult to argue that co-occurring disorders had specific treatment needs on the basis of unreliable diagnoses.

However, although a high degree of dual diagnoses exist among personality disorders and between personality disorders and Axis I disorders (Widiger and Clark, . 2000; Steketee et al., 2001), it may be that not all dual diagnoses are as a result of methodological problems. Dulit et al. (1990) (cited in Linehan et al., 1999) discovered that 67% of individuals with BPD met the criteria for a substance abuse disorder, but when substance abuse was not used as a criterion for BPD, the incidence dropped to 57%. Thus there may be a degree of symptom overlap inflating diagnostic levels.

Data from clinical and epidemiological studies (Steketee et al., 2001), Primary Care (Guthrie, 2000), and community samples (Enns et al., 2001; Lewinsohn et al., 2000) have supported the frequent existence of dual diagnoses, sometimes even in the majority of participants. Moreover, a study by Dressen et al. (1997) on clients referred to a community mental health centre with obsessive compulsive disorder found that while 22/43 participants had one or more personality disorders, seven further participants met subthreshold criteria; thus, excluding the clients with a subclinical presentation, more than 50 % had dual diagnoses.

Dual Diagnosis – An Example

When the patterns of diagnostic co-occurrence are explored, the regularity of certain dual diagnoses is noteworthy. Chambless et al.'s (2000) paper on agoraphobia found avoidant personality disorder to be the most frequent co-occurring diagnosis, while several researchers have identified the dual diagnosis presentation of BPD and MDD (Siever, 1999;

Soloff et al., 2000; Corruble et al, 1996). Given the viewpoint that diagnoses merely reflect behavioural descriptions based on clinical observations (Clark et al., 1997), and the finding that the rate of BPD decreases when MDD is treated (Hirschfeld, 1999), using the BPD/MDD exemplar, it could be suggested that apparent affective symptom overlap is leading to inflated "caseness" being identified; add to this the methodological concerns inherent in assessment and any form of validity of dual diagnoses is questionable.

As the treatment plan from a diagnostic perspective would customarily treat the MDD, Axis I diagnosis, first (American Psychiatric Association, 2000), with manual-based treatments being amply empirically supported for unitary diagnoses (Wilson, 1996; Wilson, 1997: cited in Butler, 1998), the point of ascribing a dual diagnosis per se could be called in to question. However, Wilson (1997) admits that there are often no empirically supported protocols for certain disorders (cited in Bond, 1998), while Guthrie (2000) has explained that complex disorders, in which dual diagnoses would feature, are inadequately researched in terms of treatment protocol. However, research has established that of those who recover from MDD, many are still eligible for diagnosis with BPD (Hirschfeld, 1999). Moreover, the chronic cognitive and affective instability of BPD may make treatment gains harder to maintain leading to increased risk of relapse (Wilfley et al., 2000). Thus, not all dual diagnoses would appear to be a diagnostic artefact, but as integrated therapeutic approaches are not readily available for them, the concept's relevance for treatment planning must be questioned. Moreover, a diagnostic system provides no depth of understanding as to why MDD and BPD overlap.

A clinical formulation may help to address treatment planning; this would hypothesise the aetiology for the co-occurrence of these disorders and include predictions about the client's future behaviour. Moreover, the ideographic nature of a case formulation means a problem list is assembled with each client and a hypothesis regarding underlying psychological explanations for these problems is constructed (Persons, 1989); in this way, a multitude of symptoms may be not only reduced, but the client's subjective problems used as a template to prioritise treatment aims and plan goals. For example, the client with BPD and MDD may find maintaining relationships to be the most pressing problem, and her initial goal could be to be on "speaking terms" with her neighbours; not banging on the wall, and escalating relationship problems, when the neighbours' dog barks at the ringing doorbell may be the first step towards this.

Further strengths of the case formulation approach include: tailoring of the . formulation to the individual including her gender, cultural and historical identity; no stigmatic labels need be applied to the client; it is a method of treatment planning philosophically acceptable to all models of psychotherapy, including person-centred therapy; does not rely on methodologically dubious diagnostic constructs; and has the flexibility to test out whether explanatory hypotheses are correct, and to amend them if they are not; in essence, it acknowledges individual differences even if diagnoses are equivalent, but does not suffer from the flawed methodological rigidity of diagnoses. Moreover, a formulation can provide a framework for process aspects of therapy, including the therapeutic relationship (AuBuchon and Malatesta, 1998).

A longitudinal formulation could be used to address aetiological issues, such as heredity, early experience, socio-cultural identity; given the plethora of research that attests MDD in childhood and early adulthood is often the precursor for the development of BPD (Kasen et al, 1999; Klein et al., 1999a; Klein et al., 1999b; Koenigsberg et al., 1999; Lewinsohn et al., 2000; Skodol et al., 1999), information on the developmental nature of the client's problem is essential, and may help to establish the core beliefs of the client, as well as providing an explanation as to why she developed the difficulties from which she suffers. A cross-sectional formulation may also be constructed, for example from a cognitive-behavioural perspective, and explain the cognitive, affective, biological and behavioural elements as they interact to maintain the problem; moreover, by reducing the problem to these elements, points at which to target treatment are apparent. Moreover, although the empirical success of formulation-based treatment plans has been questioned, Butler (1998) explains that formulations are always theory driven, and research-founded.

Thus, for example, a cognitive model of the diagnostic category of social phobia may be utilised to inform the explanatory nature of a formulation, and even when using manual based approaches, individual formulations can be constructed to assist the choice of treatment strategy.

Conclusion

As no one therapeutic model has ultimate empirical support, dual diagnosis can provide a common currency for communication in multidisciplinary working environments.

Moreover, as DSM-IV is the most research-based categorical system to date, dual diagnoses stemming from it should allow confidence in the robust nature of this taxonomical system. Thus, a utilitarian method of reducing large symptom profiles to easily understood labels would appear to exist. However, a cautious approach must be employed before mindlessly endorsing the praxis of a dual diagnosis. The construct properties of DSM's diagnostic system have been questioned, which, combined with cultural and historical mediation of diagnosis and issues of assessment methodology, have resulted in debate over whether dual diagnosis is merely an artefactual entity. Thus, the concept of dual diagnosis may need to be analysed on a case-by-case basis, in light of the aforementioned criticisms, to explore the integrity of the concept.

This conceptual veracity is particularly crucial given that a dual diagnosis can have far-reaching pejorative implications for the individual, and may even include the future potential power of enforced assessment and treatment should dangerous personality disorder be an aspect of the dual diagnosis. Even if dual diagnosis is upheld as notionally robust, the approach to treatment planning ought to acknowledge inherent individual differences and permit the inclusion of more ideographic formulation-based planning. Thus, clients, with identical dual diagnosis labels and isomorphic symptom profiles, may not only have unique problems and treatment needs; this individuality will also influence the therapeutic process.

Currently, manual-based treatment options to address this diagnostic ensemble do not appear to be available and, certainly, the need for empirical exploration into the treatment of clinical populations with dual diagnosis is long overdue given the data on the prevalence of diagnostic co-occurrence. Moreover, longitudinal empirical work to explore the reason for particular diagnostic overlap would also have purpose, ultimately establishing the point at which an individual's risk of developing more disorders increases. In this way, future treatment planning for dual diagnosis may actually be the construction of preventative treatment strategies, thus rendering the concept of dual diagnosis as obsolete.

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Written Exercise 2

Critically discuss the concept of challenging behaviour and the role of the clinical psychologist in assisting with this.

Introduction

Kiernan and Quereshi (1993) report that 10-15% of people with learning disabilities (LD) show behaviours that present a significant challenge to carers and support agencies (cited in Emerson et al., 2000), while Emerson (2001) reports the rate as 7.3% of those administratively defined with a LD. These challenging behaviours (CB) have been found to develop in early childhood (Kiernan et al., 1997; cited in Emerson, 1998) and be resistant to change (Emerson et al., 1989; cited in Rose, 1995). CB in LD has been defined as:

> "... culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or the behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities." (Emerson, 1995;cited in Emerson, 2001: 3).

Objectively, these behaviours have been described as covering a number of forms, or topographies, of behaviour, such as aggression, destructiveness, self-injury, overactivity, inappropriate social or sexual conduct, bizarre mannerisms and the eating of inappropriate objects (ibid.). One half to two thirds of people who showed CB did so in two or more out of four possible areas of aggression, self-injury, property destruction and "other" behaviour (Emerson and Bromley, 1995: cited in Emerson. 2001); while the co-occurrence of CBs within the same category may be as high as 54% (Oliver et al., 1987; cited in Emerson, 2001). However, it appears there is little consensus regarding the operationalisation of the CB construct, and varied stakeholder perspectives exist concerning the expected outcome of therapeutic intervention. The term itself is a social construction and can have powerful implications for those labelled with it. Moreover, a number of factors will influence whether a behaviour is deemed to be challenging.

The belief of the person, or system, which defines the behaviour as challenging is instrumental in the meaning of the label ascribed to it, while the context of the behaviour mediates whether the behaviour is deemed to be challenging. The object of the challenge, be it the environment or service-user, is also instrumental in the concept of CB. Individual factors related to the person with a LD are formative in terms of the definition of CB. Empirical support for the way in which CB has been defined, can provide an understanding of possible points of intervention for the clinical psychologist.

Theoretical models, explain the reason for CB in different ways, and provide a rationale by which the clinical psychologist may assist with the behaviour. The models are not mutually exclusive, thus permitting intervention from differing approaches in unison, or combination, at disparate points in the evolution of the behaviour, and at varying systemic levels. Thus, the psychologist may work directly one-to-one with a service-user; directly, and collectively, with the family; indirectly with staff teams and the service-user's family, including training, and in a consultative role regarding service development. Models based in behavioural, communication, attachment, psychodynamic and systemic theories will all be considered in this paper.

However, of paramount importance in the role of the psychologist is the awareness of the need for the therapeutic approach taken to be person centred (Department of Health, 2001; Iles, 2003); to be constructed under the philosophy of inclusion (Culham and Nind, 2003), where difference is valued; and to plan for socially valid outcomes (Fox and Emerson, 2001). Socially valid interventions should, "(a) address a socially significant problem (b) be undertaken in a manner which is acceptable to the constituents involved and (c) result in socially important outcomes or effects."(Kazdin and Matson, 1981; cited in Emerson, 2001: 10). For example, while a statistically significant reduction in CB may be noteworthy, if the intervention did not ameliorate some of the health and social consequences of the CB, the outcome would not be socially valid. A socially valid intervention is particularly important given the ethical position of working with a service-user who may not be able, personally, to consent to "treatment" (Arscott et al., 1999).

Social Construction

"Social constructionism emphasizes the centrality of language, thought, interaction, and culture in the making of human meaning in lived contexts." (Danforth and Novarro, 1998: 31). The maintenance and furthering of the diagnostic entity mental retardation relies on the words and actions of professionals and nonprofessionals (ibid.). Just as learning disability is the latest term to be used in the UK (Emerson, 2001) to describe mental handicap, the term "challenging behaviour" has replaced previous terms for behaviour used in the UK and North America (ibid.). However, as Emerson (2001) states, "Today's scientific terminology quickly becomes tomorrow's terms of abuse." (p. 2). Thus, although a single term is used, the meaning of that term will evolve, and may take on a pejorative connotation. Care staff in an NHS unit for people with severe LD and CB have defined CB in a variety of ways:

"I think it would be a challenge to....the people who have to deal with the clients or residents."

"A behaviour that doesn't conform to the norm of the group. If everyone starts thumping each other that's the norm, it's not challenging..." (Hastings, 1995: 305).

Elgie and Hastings (2002) have expressed the need for professionals and support staff who work with people with a LD, "... to speak the same language as far as challenging behaviour is concerned - that they are talking about the same construct." (p. 202); from the above staff quotes, it is quite apparent that this is not the case.

Construct Operationalisation

Literature in LD has also utilised a variety of operationalisations for CB. Carr et al's (2003) study with eight participants with moderate to severe LD, used a dichotomous response, three topography question, "Does the person engage in aggression, self-injury or property destruction?" to define CB, while Ross and Oliver's (2002) study on people with severe and profound LD defined CB on the informant-based Challenging Behaviour Interview, which measured five topographies of CB over the past month, and included a question on severity of behaviour. Hollins (2000) included sexually violent behaviour in a group of men with mild or moderate LD who could verbally express their actions themselves. Sequeira et al. (2003) utilised two informant-based scales to cover six topographies of CB, including sexual behaviour as measured by the Adaptive Behaviour Scale - Residential and Community (Nihira et al., 1993), in a study where the participants ranged from mildly to profoundly LD, on cognitive assessment. While diagnostic criteria for LD require concurrent impairments in adaptive functioning (American Psychiatric Association, 2000), very little research on CB (Emerson et al., 2000) has included adaptive functioning as a variable. There is therefore little consensus on the range, time period, severity and frequency of the concept of CB, and there are also empirical flaws in many of the studies where small numbers of poorly matched participants are included.

Given that the purpose of positive behavioural approaches to CB is to produce socially valid outcomes (Emerson, 2001), it is difficult to conceptualise how this is possible without individual assessments of baseline adaptive abilities. However, it may be that the lack of measurement of adaptive functioning is a reflection of the differing perspectives of stakeholders on the outcome of interventions for CB in LD (Fox and Emerson, 2001). LD service-users valued increased friendships and relationships, and being able to stay in the local community, as their preferred outcomes of CB interventions; clinical psychologists prioritised developing alternative ways of service-users getting their needs met, and a reduction in the severity of CB; and managers, psychiatrists and nurses prized a reduction in the severity of CB (ibid.). Thus, individual beliefs are reflected in stakeholder outcomes.

Beliefs Intentions and Influences

Emerson (2001) has identified that beliefs held by "participants in the setting" influence what is defined as CB (p. 7). Moreover, how staff make sense of CB will determine their behaviour (Grey et al., 2000). 74% of NHS care staff in Hastings (1995) study believed CB was "mostly intentional", and staff responded to self-injury, but not to stereotypy. Elgie and Hastings (2002) discovered that staff were more likely to respond to topographies of CB that had an impact on the environment, rather than the service-user. Yet, self-injury has been shown to be the greatest predictor of people with LD showing aggressive behaviour (Davidson et al., 1996; cited in Emerson, 2001). However, the very acts that are perceived as challenging and impacting on the environment, may be highly adaptive for the individual with a LD, for example as a strategy to escape an aversive situation, and a way of controlling the environment (Toogood and Timlin, 1996).

Rule-governed beliefs about what is appropriate behaviour may also influence the concept of CB; these beliefs may be culturally held, at an organisational or individual level, about the person with LD. For example, a belief about the person exhibiting CB as an "eternal child" , may absolve the person of responsibility for their actions (Emerson, 2001). Negative beliefs about the sexual rights of a person with LD (Cambridge et al., 2003) may also be held, and masturbation, for example, be deemed CB; this cultural belief may be particularly pertinent for women (Williams and Nind, 1999). However, as the "secret of sexuality" is often kept from people with LD (Hollins, 2000), "normal" sexual behaviour may merely be expressed in an inappropriate setting due to ignorance of social rules (Oliver et al., 2002).

Attributional studies have found that beliefs about CB that is perceived as being more stable, and less controlled, such as self-injury, mean staff have more positive emotional responses to it and will intervene "to help" (Stanley and Standen, 2000), although, without a functional analysis of the behaviour, "helping" may actually provide a reinforcing contingency that fuels a cycle of mutual reinforcement (Wanless and Jahoda, 2002). Stanley and Standen (2000) discovered the attributional evidence meant that the same description of CB in service-users of mild and severe LD was evaluated differently. Those with a mild LD were evaluated more negatively as they were assumed to be in control of their behaviour.

Certainly, Emerson (2001) has suggested that the ability to give a plausible account of the behaviour is pertinent to the concept of CB. He suggests that CB is found in people with severe and profound LD, and it may be that less developed communication skills mean an account of the rationale for the behaviour of service-users cannot be given. An alternative perspective would be that it is the CB that interferes with the ability to communicate (Nind and Kellett, 2002), or indeed is a form of communication (Thurman, 1977; cited in Macleod, 2002).

Context and Capacity

" .. . context is essential in giving meaning to any behaviour." (Emerson, 2001: 7). As the earlier quote from Hastings (1995) demonstrates, in a setting in which the norm is aggression, the organisational culture ceases to define that behaviour as challenging. Cultural beliefs and developmental expectancies are also implicated in the contextual meaning of CB. Thus, while stereotypy by a person without a LD may be deemed CB, membership of a "deviant group" carries expectations of "abnormal" behaviour, in British society, and so may not be perceived as so challenging (Emerson, 2001). Moreover, while stereotypy can be considered a form of CB in adults with LD, it is part of normal infantile cognitive development (Thelen, 1979; cited in Nind and Kellett, 2002).

Not only do the same behaviours acquire meaning via context, different situations influence the capacity of the people and environment to cope with the behaviour. Staff team influences may determine their capacity to cope with CB. Staff may have extreme negative emotional reactions to CB (Jones and Hastings, 2003), become clinically anxious (Jenkins et al., 1997) and feel stressed (Hill and Dagnan, 2002), resulting in high staff turnover (Rose, 1995), or even abuse of service-users (Brown, 1999a; cited in White et al., 2003). White et al. (2003) suggest that a variety of beliefs may be invoked by staff to justify abuse of service-users. Given the vulnerable nature of this client group (Felce et al., 1995), and the role that abuse may play in causing CB (Cambridge, 1999), the necessity for staff to have the capacity to cope is vital. To this end, an organisational culture of support, with a clear management structure, a culture of accountability, role boundaries, high standard staff training and activities for service-users (White et al., 2003) can all provide an environment in which staff coping capacity is augmented.

However, although CB is constructed dependent on language form, operationalisation, belief and context, there are certain areas of conceptual uniformity. Hastings and Remington (1994) suggest there are three major forms of CB: aggressive/destructive behaviour, self-injury and stereotypy, while Emerson et al. (1988) established aggressive behaviour, destructive behaviour and self-injury typified the greatest types of CB (cited in Emerson et al., 2001). Moreover, there are acknowledged risk factors that increase the probability of showing multiple forms of CB: more severe intellectual disabilities (Janssen et al., 2002), maleness, aged 15-35, specific syndromes, e.g. autism, and additional sensory, communication or mobility impairments (Emerson, 1998).

Approaches to Challenging Behaviour

Various theoretical positions have been taken to explain the reason for CB, although Emerson (1998) states that no one approach will be applicable across all topographies of CB. The explanations proposed include: behavioural, neurobiological, mental illness, attachment, psychodynamic, systemic, and communication theories; neurobiology and mental illness will not be directly considered in this paper. The theoretical positions provide models for the clinical psychologist to work in with CB.

Behavioural Approach

Behavioural models have been much favoured in the role of the clinical psychologist. CB is seen as an example of operant behaviour. It is functional and adaptive, providing the individual with a partial ability to control his environment (Emerson, 1998). Intervening at an indirect level, the clinical psychologist would undertake an informant based clinical interview regarding the CB (ibid.), in which the behaviour would be defined, along with physical and environmental factors that may elicit the behaviour, and potential functions of the behaviour in terms of the maintaining consequences (O'Reilly, 1997). This would be followed by a functional assessment, to establish the eliciting and maintaining variables of the target behaviour, and perhaps a functional analysis to demonstrate causal relationships empirically (ibid.). The functional assessment can take many forms including informant-based rating scales, ABC charts and direct observation (Toogood and Timlin, 1996). Selection of measurement format may depend on issues such as the severity and frequency of the behaviour, and the available human resources. The same behavioural topographies do not necessarily have the same function, and each CB may be controlled by more than one contingency (Emerson, 2001). CB may also be differentially maintained temporally and contextually (ibid.).

Crucial to the role of the clinical psychologist in applied behavioural analysis is the undertaking of a constructional approach (Emerson, 2001), in which new behaviours are developed, rather than merely eradicating CB. This intervention meets the criteria of social validity, as deficits in adaptive skills may be identified and new skills taught to meet the function of the behaviour. These skills may result from Functional Communication Training whereby alternative communication strategies are taught that are reinforced by naturally occurring reinforcers (Durand and Carr, 1991; cited in Whitaker 2002).

An example, would be an incident of verbal aggression, in a severely LD service-user with limited communication abilities, that is motivated by a biological state of pain exacerbated by sitting for too long, and maintained by negative reinforcement of escape from the sitting position. The intervention could involve teaching the service user to signal for aid manually as the pain is developing. A staff member could then reinforce the behaviour by providing assistance. From an ethical perspective, not only is this approach person centred (Department of Health, 2001), but Hanley et al. (1997) suggest that functionally based approaches may be preferred by people with severe LD and CB (cited in Emerson, 2001). Further aspects of the environment could be adjusted (ibid.). For example, the context could be altered such that the service-user was assisted to stretch every 20 minutes, and he could be provided with analgesia to alter the experienced bio-behavioural state thus altering the establishing operation. Moreover, further contextual change in the form of embedding could be used in "high risk" situations (Emerson: 1998). For example, positive reinforcement, desirable to and age-appropriate for the individual, such as staff attention, could be included when sitting for half an hour was necessary to attend a Whole Life

Review meeting.

Behavioural approaches utilising functionally equivalent alternatives to CB have been empirically supported. CB may be rapidly and substantially reduced, and the intervention effects may persist over time and generalise to new settings (Durand and Carr, 1992; cited in Emerson, 1998). However, central to any psychological intervention involving staff, or carers, is the necessary understanding and ability to carry out guidelines and recommendations from the clinical psychologist, be they behavioural or skills based. As staff have been implicated in the initial development of CB (Hall et al., 2001;.cited in Jones and Hastings, 2003), and have been found to maintain it by "benevolent enslavement" (Emerson, 2001), and a process of mutual reinforcement (Wanless and Jahoda, 2002), staff training may be an important aspect of the clinical psychologist's role. All staff in McDonnell et al. (1998) received a three day training in behavioural approaches to CB. This provided a rationale for the approach being taken. In this way the belief that the service-user was able to "do as he pleased", that had led to staff anger, was modified, thus eliciting a greater motivation to implement the approach consistently.

Setting conditions can determine staff as well as service-user behaviour (Allen, 1999). Staff attributions are not only implicated in staffs behaviour when faced with CB, but the aversive affect they may feel (ibid.) and the probability of appropriate implementation of intervention programmes (Watts et al., 1997; cited in Grey et al., 2002). Coping style and stress appraisal have also been identified as predictive of support staffs behaviour response to CB (Hill and Dagnan, 2002). Thus, drawing on knowledge of Lazarus and Folkman's (1984) research on the transactional model of stress, the clinical psychologist could provide staff training. The training should facilitate the development of active problem-solving, which attempts to change stressful situations, rather than wishful thinking which tries to cope with one's feelings, and may result in stress reduction, and more helpful staff behaviour (Hill and Dagnan, 2002).

Communication Approach

While functional assessment tries to establish what is being communicated by the CB, literature about communication difficulties in people with LD and CB has been published. Emerson (1998) has identified the increased probability of CB in people with LD and communication difficulties, while Chamberlain et al. (1993) have maintained that communication deficits have a role in causation of CB (cited in Macleod, 2002). Kevan's (2003) thesis modifies this argument. She maintains that communication difficulties are instrumental in episodes of CB, not just because the service-users lack expressive communication skills to convey their needs, but because there is a mismatch between their receptive communication abilities and the level of expressed communication. being received. Thus, instead of CB acting as a negatively reinforced escape from an aversive situation, such as a task demand, it may be a response to the aversive experience of not understanding the demand (ibid.). Alternatively, the behaviour could be misconstrued as challenging when the service user is merely acting on what he thought he understood (Clarke-Kehoe and Harris, 1992; cited in Kevan, 2003).

The role of the clinical psychologist in the communication model may embrace different theoretical perspectives. Using a behavioural model, it would still be important to carry out a complete functional assessment. However, should the CB be related to expressive communication difficulties, staff and environmental adaptation should contribute to increased comprehension of communication and, hence, not only a reduction in CB, but an increase for the service-user's ability to participate in social and community activities. A referral to speech therapy could provide advice on the individual's functional level of receptive communication, and strategies for professionals to moderate their verbal expressive communication levels. However, a clinical psychologist could provide guidance concerning the appropriate environmental adaptations to facilitate communication. Facing the individual and saying his name, before talking to him, in an environment with minimal auditory distractions would be important. Visual cues may also be developed to compensate for verbal comprehension difficulties. Thus, a simple system of signed communication, such as Makaton, or the utilisation of a system of functionally meaningful cards could be used independently, or in combination with verbal communication.

Grove et al. (1999) posit there are inherent difficulties in interacting with people with severe communication difficulties as meaning may be ascribed to behaviour, without an understanding of their cognitive level of intentionality. Thus, it appears the message understood may merely be a construction of "reality". Developmental psychologists discovered the developmental trajectory of intent is an evolving phenomenon (ibid.). Communication moves through stages from reactive, to anticipatory, to intentional communication, and this knowledge can be usefully applied to communication with people with severe and profound LD (ibid.). Bruner and Vygotsky spoke of the need for "scaffolding", that is, to provide support to develop communication skills (ibid.).

Harris (2002) notes the role of stereotypy in blocking interaction and engagement, while Nind and Kellett (2002) describe it as a "barrier to learning and social acceptance" (p. 266). If it does act as a barrier to learning, from a behavioural perspective the ability to teach functionally equivalent skills will be compromised. However, Nind and Kellett (2002), operating under a philosophy of inclusion, suggest an approach to working with individuals who have a severe LD, and exhibit CB in the form of stereotypy, that responds positively to them and their stereotyped behaviours, sometimes using them to make a connection; this approach is called Intensive Interaction (II).

Multiple functional reasons for stereotypy have been suggested including sensory stimulation (Brusca et al., 1989), communicative function (Durand, 1990), learned behaviours maintained by perceptual reinforcement (Lovaas et al., 1987), neuropathology (Miller et al., 1996) and normal exploratory developmental phenomenon which have been delayed and prolonged in someone with LD (Murdoch, 1997; cited in Nind and Kellett, 2002). Thus, as with all CB, from a behavioural perspective, a functional analysis should be utilised to establish individual meanings for the same topography of CB.

However, II holds an alternative construction of stereotypy by embracing it as a form of difference, rather than trying to eradicate it as a form of CB. Moreover, Nind and Kellett (2002) describe a movement towards a more positive construction of stereotypy by using alternative terms for it, such as "idiosyncratic behaviour". Utilising an approach based on the developmental understanding of caregiver-infant interaction, II focuses on establishing rapport and communication in ways that an individual finds meaningful (ibid.). In practice this may mean, "...joining in with, imitating and weaving interactive games around their stereotyped behaviours." (ibid., p. 271). This interactive concept purports that through the development of a relationship, further development will follow.

A clinical psychologist would have the requisite developmental knowledge which, combined with skills developed working with individuals with LD and young children, would mean that this is an approach that could be used in a one-to-one direct setting, or indeed be part of staff training carried out by the psychologist. Thus, via the interactional relationship, it may be possible for the clinical psychologist to provide Vygotsky's "scaffolding", enabling the individual with LD and stereotypy to develop communication abilities at the next stage of development.

Nind (1993) established that six adults with a LD, and extensive stereotyped behaviours, demonstrated reductions in over half of their nineteen stereotyped behaviours after a year of daily II (Nind and Kellet, 2002). With no control condition, it is not possible to establish whether specific interactional factors, or non-specific attentional aspects, were implicated in this result. Moreover, with no knowledge of the meaning of the stereotypy for the individuals, it is impossible to say whether further development provided new functional skills. Perhaps, development had moved beyond the "early infant" stage of stereotypy, or perhaps stimulation had provided an enriched environment that led to adaptation of the neural architecture. Nonetheless, II provides a potentially fruitful approach for one form of CB to date, in the form of socially valid outcomes, and can be practised by the clinical psychologist.

Attachment Theory, Psychodynamic and Systemic Approaches

Behavioural models encourage the acquisition of new skills, and the II approach to communication aspires to promote developmental maturation, however the clinical psychologist can combine Attachment, Psychodynamic and Systemic evidence and find a role preventing CB. Indeed, Systemic therapy, for example Byng-Hall (1995), now also integrates aspects from other therapeutic schools, such as Attachment, and Psychodynamic models.

"Current definitions of learning disability point to the importance of holistic approaches to understanding individual need which look at several aspects of a person's functioning within the context of their own life and relationships. " (World Health Organisation, 1992; cited in Hollins and Sinason, 2000: 32). Grant and Whittell (2000) found that the manner of diagnostic disclosure of their child's LD, left some parents traumatised and daunted by the thought of years of caregiving. These children are more likely to experience insecure maternal attachment (Hollins and Esterhuyzen, 1997; cited in Hollins and Sinason, 2000), the long-term consequences of which may include CB (Hollins and Esterhuyzen, 1997; cited in Hollins and Sinason, 2000).

People with a LD, particularly severe or profound, may have inadequate coping skills leading to the experience of greater stress, especially concerning interpersonal relationships (Bender et al., cited in Janssen et al., 2002). Van Ijzendoorn et al. (1999) reported the significantly greater number of people with a LD who had disorganised attachment styles (cited in Janssen et al, 2002). Without a secure attachment, anxiety cannot be moderated leading to further stress (ibid.), and heightened anxiety levels have been linked to CB (Ranzon, 2001; Holden and Gitlesen, 2003). Berry (2003) talks about an example of an attachment disorder, in which care staff and parents may become the mediators of the person with LD's activities, resulting in "secure attachment at the cost of true autonomy." (p. 42). Distress in this example may lead to CB such as aggression, self-injury or destructive behaviour. Clegg and Sheard (2002) state that CB born out of, insecure attachments is due to separation protest and cite examples of relationship jealousies, as rated by carers and day service staff, particularly for people who are no longer living in the family home.

For those who do still live in the family home, the Family Lifecycle (McGoldrick and Carter, 2003) may operate differently from the established model. For example, "launching children and moving on may never happen." Transitional points may lead to parental grief for another milestone not met, while enmeshed attachment relationships can maintain CB (Clegg and Lansdall-Welfare, 1995; cited in Rhodes, 2003), and lead to abuse (Janssen et al., 2002). Moreover, transition points may refer to transitions between services (Grant and Ramcharan, 2001), for example, from the Child Development Centre to the Adult Community Team for Learning Disabilities.

As a clinical psychologist, there are many facets of the role that could be utilised in assisting with CB. From the outset, the clinical psychologist at the Child Development Centre could develop a model of diagnostic disclosure to enable the parents to receive the news of their child's disability via a planned and evidence-based process to afford them a less traumatic experience. Relevant information about available support from services and support organisations could be made available at this point. Future contact with the clinical psychologist could provide an opportunity to assess how the family are coping, and whether there are any concerns about attachment or behaviour; this is particularly important given the early age that CB often commences (Emerson, 2001). Should the family not require future appointments, the clinical psychologist could provide consultation to the health visitor involved with the family, if necessary.

If the parents are experiencing a sense of great loss while adjusting to the diagnosis (Rhodes, 2003), it may be necessary to provide individual or Systemic Couple Therapy for them. Alternatively, if the sort of support they require is more related to accessing social support and coping strategies (Grant and Whittell, 2000), it may be that the clinical psychologist could facilitate a group for parents with a child with a LD following diagnosis.

In future years, the family may have difficulty coping with a child with LD, perhaps due to "timelessness" whereby the child is not allowed an appropriate level of independence (Rhodes, 2003), or due to behavioural problems. The clinical psychologist could become involved again and offer behavioural, or second order Systemic Therapy, should that be more appropriate on assessment. Of course, Child Services would have to develop substantial breadth to accommodate the clinical psychology role espoused, but as transitions between services can also be problematic (Grant and Ramcharan, 2001), it is important to consider possible adaptive service developments.

In an insecurely attached adult with LD, demonstrating CB, the clinical psychologist could become involved with the family or staff team to provide a formulation of the CB to assist with understanding and management. Systemic Therapy could be an option for the family, or consultation to the staff team. Individual Psychodynamic Therapy (Berry, 2003; Sinason, 1992) may also be beneficial for the service-user exhibiting CB. However, as anxiety and inadequate coping strategies are implicated in CB due to insecure attachment style, it may be that an intervention should consider how to provide appropriate skill and support in these areas.

Conclusion

Challenging behaviour has not been shown to be a unitary concept. Its construction is continually evolving intrapersonally, mediated by cognitive processes, interpersonally in the shared narratives we construct, and experiences we share, and culturally through the collective beliefs we hold. Whilst core definitions of topographies are recognised as challenging behaviour, each individual with challenging behaviour has a different biography, and possibly different functions for the behaviour. Multiple theoretical models have evolved in attempts to explain and intervene successfully in CB, but some of those who are meant to care may become abusive with their own brand of challenging behaviour; for stakeholders in the process have constructed their own aims.

As a clinical psychologist, influenced by the current policy of inclusion, the need to provide interventions which are socially valid in this vulnerable group is of supreme importance. Recent approaches such as Intensive Interaction, inspire hope in me for the service-users, and in my work in this area, it is important to make the following a guiding principle:

"Staff need to think why they want someone to change, abandon or modify their behaviour. . . ..Have they anything better to offer?" (Royal National Institute for the Blind (1993, p. 14); cited in Nind and Kellett, 2002).

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Small Scale Service Related Project

A Clinical Audit of Referrals to an Adult Mental Health Psychology Service

Abstract

This paper explored referrals received by an adult mental health psychology service over a 3 year period. A clinical audit methodology was used in which key data sources comprised a pre-existing referral data spreadsheet and case notes. Explanations for referral patterns found were explored by the inclusion of a qualitative method expert interview. Audit findings showed a trend of annual increases in the number of referrals. Unequal proportions of referrals were noted in the 3 areas covered by the service. Area 2 showed a relatively constant number of referrals for all 3 years, but was disproportionate in terms of referrals by population base, and area 3 demonstrated annual increases in referrals. Increases in referrals via Community Mental Health Team/Psychiatry pathways were evident. Depression and anxiety disorders dominated reasons for referral. Various explanations for the audit findings, including mental health service organisation and development, were extrapolated from interview data. Methodological concerns about data quality limit the validity of the audit. Recommendations include strategies for improving data quality and service developments.

1.0 Introduction

1.1 Adult Mental Health Services and Publications

Since the Labour government came to power in the UK in 1997, various influential documents concerning the NHS, including mental health, have been published. Mental health was one of four priority areas identified in the White Paper "Saving Lives: Our Healthier Nation" (Department of Health (DOH), 1999a). In 2000, major reforms for the NHS were outlined in "The NHS Plan" (DOH, 2000). Areas highlighted for development included increased funding, targeting geographical inequalities, improving service standards, and extending patient choice. One of the main tools for modernisation of the NHS, including improved patient care, was to be national service frameworks (NSFs). NSFs comprise a series of policy documents on reform of services, procedures and workforce structures and have been developed for a range of conditions and patient groups.

In 1999, "The National Service Framework for Mental Health" (DOH, 1999b) was published. It lists seven standards that set targets for the mental health care of adults aged up to 65. These standards span five areas: health promotion and stigma, primary care and access to specialist services, needs of those with severe and enduring mental illness, carers' needs, and suicide reduction. The second standard states that:

"Any service user who contacts their primary health care team with a common mental health problem should:

- have their mental health needs identified and assessed
- be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it." (DOH, 1999b: 28).

However, as "The NHS Plan" (DOH, 2000) acknowledges, there are geographical inequalities in access to health services.

1.2 Pathways To Care

Goldberg and Huxley developed a framework for understanding the way in which individuals become defined as having mental health problems and reach specialist services (Goldberg and Huxley, 1980; Goldberg and Huxley, 1992; Huxley 1996). The central thesis of this

"Pathways to Care" model is that a filtering process operates between the community and specialist psychiatric services (ibid.). The model comprises four filters with the second filter involving the recognition of a mental health problem by the GP, and the third filter reflecting the decision by the GP that a referral to a secondary service, for example a psychology service, is required (Huxley, 1996).

The model has 5 levels where the client may be located ranging from community (i.e. having had no contact with services) to inpatient status. Data suggest that 88% of clients who are recognised by the GP as having mental health problems are not referred to secondary care (ibid.). However, the decision to refer on to secondary services has been found to be a function of a variety of factors including service availability and the nature of the problem (ibid.).

1.3 Clinical Audit

Clinical governance is a framework via which NHS organisations are accountable for continuously improving the quality of their services and creating an environment in which good quality clinical care will develop; clinical audit is a building block of clinical governance (Swage, 2004). Clinical audit involves an audit cycle frequently, thought not always (Firth-Cozens, 1993). The audit cycle involves setting standards for care, data collection to establish how well the standards are being met, monitoring the data, and using the data to decide what to change about clinical practice (ibid.). Clinical audit utilises a variety of methodologies, including retrospective case notes analysis which may or may not include standard setting (ibid.).

1.4.1 Service Context

The geographical region, which comprises the catchment area for which the service provides psychological input, is in the south-east of England and has a population of 140k (Office for National Statistics, 2003). The service context for this audit is a secondary level, i.e. outpatient, clinical psychology department organised in a hub-and-spoke model of service delivery. It comprises adult mental health (AMH), older adults (OA), and chronic pain (CP) specialities. Sessional input into primary care via GP Practices (GPP) in one sector of the catchment area is also provided.

The service catchment area has 3 community mental health teams (CMHTs), each providing mental health support for areas of approximately 50K people. The health care in two of these areas is governed by a Primary Care Trust (PCT); a PCT being a free-standing body which holds the budget for local healthcare, and is responsible for strategic health care development in the area (DOH, 1999c). CMHTs are multidisciplinary teams providing community mental health care to populations of 10-60k (DOH, 2002a).

Referrals to the psychology service are received from the CMHTs, GPs, Psychiatrists (referring outpatients or inpatients), as well as varied other referrers, such as the Drug and Alcohol team. One clinical psychologist for the service evaluates each referral on receipt to establish whether it is an urgent referral, or can be placed on the waiting list. The following information on the referral is then entered on to an Excel spreadsheet: date, name, address, sex, date of birth, referrer's name, reason for referral.

2001 heralded a number of changes locally within the psychology service. Until then, the service also comprised a learning disability (LD) psychology service which was dissolved; staff left the service and their posts were not filled; and the Acting Head of Department left the service also not to be replaced. This service re-organisation has resulted in AMH being the dominant speciality in the service, but with fewer staff providing psychology input to AMH referrals. The current staffing ratio is 2.6 whole-time equivalent (WTE) clinical psychology posts and a 0.6 WTE counselling psychologist; this staffing ratio is below the minimum recommendation of the Trethowan Report (1977) which advised 1 WTE in clinical psychology adult services for every 30K population (cited in British Psychological Society (BPS), 2001).

1.4.2 Referring Area Context

Strategic changes to mental health services, and research programme changes, have occurred within the past 3 years. In 2001 a Primary Care Counselling Service was set up to provide up to 8 sessions of counselling for clients referred in the area of the PCT that governs health for 70% of the population of the catchment area ([1]XXXX and XXXX PCT Counselling Service, 2001). This service has meant the dissolution of counselling services within individual GP surgeries in the PCT area; the psychology service continues to provide psychology input of up to 8 sessions in 1 GP Practice in the part of the catchment area that is not served by the PCT.

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[1] Anonymised PCT Title

Research trials on Obsessive Compulsive Disorder (OCD) conducted by the consultant psychiatrist, within 1 of the 2 sectors within the area with the PCT counselling service, have been ongoing for 3 years and referrals to the psychology service for OCD seem to be increasing.

1.4.3 Rationale for Audit

DOH Clinical Psychology Summary Information for England (DOH 2001; DOH, 2002b; DOH, 2003) suggests small year to year changes in the number of referrals to clinical psychology services; the number of referrals was similar for 2000 -2001, reduced by 4% for 2001 - 2002, and increased by 2% for 2002 - 2003.

Staff within the AMH sector of the service had noted an apparent increase in referrals, but, owing to the contextual changes and inadequate quality and quantity of referral data held by the service, were unable to state if this was an objective, measurable increase. For example, the client data, entered on the Excel spreadsheet, did not identify referral by speciality, making any comparisons purely for AMH referrals impossible, and had missing and inaccurate data points. Moreover, strategic service developments within the PCT governed part of the catchment area may have an influence on referral numbers, or indeed the pathway, or route, of the AMH referrals, but this impact is unknown. Furthermore, the distribution of referral reasons is unknown thus not permitting strategic service planning for client needs.

The audit therefore aims to address the following:

1. To develop a database of AMH referrals for the psychology service.

2. To answer: What are the AMH referral numbers for the 3 financial years for April 2000 - March 2003?

3. To answer: Have the proportions of AMH referrals coming from different areas changed during April 2000 - March 2003?

4. To answer: Have the proportions of AMH referrals coming via different pathways changed during April 2000 - March 2003?

5. To answer: Have the proportions of AMH referrals coming via different pathways changed during April 2000 - March 2003 in the area with a PCT that now has a Primary Care Counselling Service?

6. To answer: Have the diagnostic reasons for referral changed over the 3 years from April 2001 - March 2003?

7. To explore what explanations can be found for any changes in referral patterns.

2.0 Method

2.1 Design

The design was a clinical audit and ethical approval was not required for it, however the auditor had an honorary contract with the Trust, in which the audit was undertaken, that allowed case notes analysis.

2.2 Data

The data comprised all referrals to the adult mental health speciality of the service received between 01/04/2000 and 31/03/2003.

2.3 Data Source

The data sources comprised the Excel spreadsheet, on which information on each referred client was held, and client case notes. 4 members of the service provided input on data on the Excel spreadsheet.

2.4 Procedure

Referral information held on Excel was the baseline data used. Date of birth was converted to age, at time of referral, and the data was eye-balled by the auditor to remove referrals to the OA service by filtering out those aged more than 65 at the time of referral. Owing to missing data and inadequate data quality, the auditor discussed the referral information with a member of the service from each speciality (OA, AMH, CP) in order to eliminate referrals that were not AMH from the data set; a clinical psychologist who had previously worked in the LD speciality when it was operational, but now worked in the AMH speciality, also reviewed the data. The 4 clinical psychologists were also asked to identify professions for any of the referrers known to them. The auditor then used records of GP Practices, held by the service, in the catchment area to identify further unknown referrers where possible. The remaining AMH data set was then entered on an Excel spreadsheet.

Retrospective case notes analysis was used to reduce the amount of missing data and improve quality of data, such as information on professions of referrers; quality checks on the fidelity of information given by service staff, by comparing information to data in case notes, were carried out at this point. Further clients found not to be AMH referrals were removed at this stage. The "List of Wards and Polling Districts" ([2]XXXX XXXX, 1996) was used to permit referral area to be coded by address (3 codes for the areas within the catchment area that have a CMHT, and a 4th for referrals from outside the catchment area).

Referral data was then entered into SPSS 11.5 using categorical encoding (CE) where appropriate. The data set comprised the following variables: year (CE), month, sex (CE), age, area (CE), referrer (CE), primary diagnosis (CE) and secondary diagnosis (CE) if provided.

2.5 Expert Interview

In order to explore the factors related to change in referral patterns, a brief semi-structured interview was carried out with the co-ordinator of the 3 CMHTs. The questions were:

1. Changes in numbers of referrals made by Psychiatry/CMHTs have occurred overall, and in the PCT governed sector. More referrals appear to be coming from Psychiatry/CMHT and less from GPs. What could explain this?

2. Area 2 refers far more clients to AMH psychology than the other areas. What explanation could there be for this?

3. How do the CMHTs know what makes an appropriate referral to AMH Psychology?

2.6 Data Analysis

Descriptive statistics were used to explore the clinical audit questions 1-5. A non-parametric analysis was also carried out on question 2. Data gathered from the expert interview carried out to answer question 6 was content analysed for themes.

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[2] Anonymised Polling District

3.0 Results

Table 1 depicts the categorical coding system developed for year, area and referrer.

3.1 Coding

Code	Year	Area	Referrer
1	01/04/2000 – 31/03/2001	*45K CMHT 1	General Practitioner
2	01/04/2001 – 31/03/2002	*50K CMHT 2	Psychiatry/CMHT
3	01/04/2002 – 31/03/2003	45K CMHT 3	Other (e.g. Speech and Language Therapist, Drug & Alcohol Nurse, Psychologist in other service, Occupational Therapist)
4		Out Of Catchment	

Table 1. Coding system devised for data recording and analysis

*Areas 1 and 2 comprise the locale governed by the PCT.

3.2 Audit Questions:

The 7 aims of the audit, as identified in the Introduction, are addressed sequentially with tabular presentation of data, textual explanation, and pictorial representation where appropriate.

3.2.1 *Develop a database of AMH referrals for the psychology service.*

Variables	Initial Data (%)	Database Data (%)
Year	0%	0%
Month	0%	0%
Sex	0.4%	0%
Age	3.5%	2.4%
Area	12%	0%
Referrer	86%*	4.4%
Diagnosis	7%	2.7%

Table 2. Percentage (%) of missing or inaccurate information before and after database development

(*The service used to record on Excel the referrer in one column with client's GP in the next one, but this had mainly stopped and only name of referrer was available so category of referrer was not known for the majority of referrals.)

As shown in table 2, complete data sets were originally available for 2 of the variables in the new database and, following the audit, 3 of the data sets had no missing or inaccurate data, and there was a reduction of incomplete or inaccurate data for the other 4 variables.

3.2.2 What are the AMH referral numbers for the 3 financial years for April 2000 - March 2003?

548 referrals were made to AMH over the 3 year period audited. Of these referrals, 221 (40.3%) were male and 327 (59.7%) were female. The age range of referrals was 17 – 65, with a mean age of 35 for both males and females.

	Year 1		Year 2		Year 3		Total	
Sex	Number	%	Number	%	Number	%	Number	%
Male	53	34.0%	84	44.4%	84	41.4%	221	40.3%
Female	103	66.0%	105	56.6%	119	58.6%	327	59.7%
Total	156	100%	189	100%	203	100%	548	100%

Table 3. Referral numbers for the 3 year period from 01/04/2000 – 31/03/2003

With reference to referral numbers over the 3 year period, there was a year-on-year increase (Table 4) with Year 3 receiving 203 referrals (Table 3).

Year 1	Year 2	Year 3
	+ 21%	+ 30%

Table 4. Percentage change in referral numbers compared to year 1 baseline

A chi-square analysis was carried out on the 3 years of referrals:

χ^2 (2, N = 548) = 6.34, p = 0.4, suggesting a significant association between year and number of referrals received.

3.2.4 Have the proportions of AMH referrals coming from different areas changed during April 2000 - March 2003?

	Year 1		Year 2		Year 3		Total	
Area	Number	%	Number	%	Number	%	Number	%
1	30	19.2%	46	24.3%	39	19.2%	115	21.0%
2	88	56.4%	93	49.2%	95	46.8%	276	50.4%
3	32	20.5%	44	23.3%	61	30.0%	137	25.0%
4	6	3.8%	6	3.2%	8	3.9%	20	3.6%
Total	156	100%	189	100%	203	100%	548	100%

Table 5. Number of referrals by area

Data on referral by area for the 3 year period shows there are differences in proportion referred by each area. Area 2 (population 50K) which accounts for 36% of the catchment area has consistently referred approximately half of all the referrals (46.8% – 56.4%) to the AMH service. Areas 1 and 3 have an equivalent population base (45K) yet area 3 has seen a large increase in the number of referrals to the AMH for year 3, referring 30% (n = 61) of AMH referrals in comparison to area 1 who referred 19.2% (n = 39) of the referrals. Referrals from outside the catchment area have remained relatively constant providing 3.6% of total referrals over the 3 year period.

As area 3 data had shown a substantial year-on-year increase in referrals, referral source analysis was carried out (Table 6).

	Year 1		Year 2		Year 3		Total	
Referrer	Number	%	Number	%	Number	%	Number	%
GP	9	28.1%	15	34.1%	25	41%	49	35.8%
Psychiatry/ CMHT	21	65.6%	26	59.1%	29	47.5%	76	55.5%
Other	0	93.8%	3	6.8%	4	6.5%	7	5.1%
(Missing)	2	6.3%	0	0%	3	4.9%	5	3.6%
Total	32	100%	44	100%	61	100	137	100%

Table 6. Area 3 - Number of referrals by referral source over 3 years

In Year 1, Psychiatry/CMHT referrals provided the majority (65.6%) of referrals from area 3. Although Psychiatry/CMHT referrals have increased over the 3 year period studied, GP referrals have increased by 177% from year 1 (n = 9) to year 3 (n = 25).

3.2.4 Have the proportions of AMH referrals coming via different pathways changed during April 2000 - March 2003?

	Year 1		Year 2		Year 3		Total	
Referrer	Number	%	Number	%	Number	%	Number	%
GP	92	59.0%	81	42.9%	88	43.3%	261	47.6%
Psychiatry/ CMHT	44	28.2%	89	47.1%	93	45.8%	226	41.2%
Other	12	7.7%	14	7.4%	11	5.4%	37	7.1%
(Missing)	8	5.1%	5	2.6%	11	5.4%	24	4.4%
Total	156	100%	189	100%	203	100	548	100%

Table 7. Number of referrals by referral source over 3 years

Over all 3 years, GPs (47.6%) and Psychiatry/CMHTs (41.2%) have referred a similar number of clients to the service. However, while the number of referrals received from GPs and "Other" has remained relatively constant over the 3 year period, the number of referrals received from Psychiatry/CMHTs has increased by 111% from year 1 (n= 44) to year 3 (n= 93).

3.2.5 Have the proportions of AMH referrals coming via different pathways changed during April 2000 - March 2003 in the area with a PCT that now has a Primary Care Counselling Service?

Over the three year period GPs have referred the majority (51.6%) of clients to the service. The PCT Counselling Service became operational in 2001 (year 2). Referrals from Psychiatry/CMHT increased by 174% (from 23 to 63) from year 1 to year 2 and have remained approximately at that level. Referrals from GPs reduced by 26% (from 83 to 66) at the same time period, and have remained at a similar level.

	Year 1		Year 2		Year 3		Total	
Referrer	Number	%	Number	%	Number	%	Number	%
GP	83	65.9%	66	45.5%	63	45.0%	212	51.6%
Psychiatry/ CMHT	23	18.3%	63	43.4%	64	45.7%	150	36.5%
Other	12	9.5%	11	7.6%	7	5.0%	30	7.3%
(Missing)	8	6.3%	5	3.4%	6	4.3%	19	4.6%
Total	126	100%	145	100%	140	100	411	100%

Table 8. PCT Counselling Service area - Number of referrals by referral source over 3 years

3.2.6 *Have the diagnostic reasons for referral changed over the 3 years from April 2000 - March 2003?*

Most of the referrals (85%) stated only one reason or diagnosis for referral. Referral reasons were categorized according to diagnostic equivalence (American Psychiatric Association, 2000), or same referral reason when a clear diagnosis did not exist. Not all referrers were clear about the reason for referral and many of those were subsumed under "other", e.g. needle fixation, immaturity, as were diagnoses of which there were very few e.g. chronic fatigue. The reasons for referral are presented in descending order of frequency for the 3 year total in table 9 (also see figure 1). Depression is the most common reason for referral for each of the 3 years, accounting for 34% (187) of the total number referred over 3 years. Anxiety disorders dominate the other main reasons for referral. Trends of increased numbers referred for certain reasons e.g. neuropsychological assessment, or with particular diagnoses, e.g. PTSD, OCD, psychosis, are apparent.

	Year								
	2000-2001		2001-2002		2002-2003		Total		
Reasons for Referral	Number	%	Number	%	Number	%	Number	%	Cum. %
Depression	63	40.4%	63	33.3%	61	30.0%	187	34.1%	34.1%
Panic/agoraphobia	11	7.1%	21	11.1%	13	6.4%	45	8.2%	42.3%
OCD	6	3.8%	16	8.5%	17	8.4%	39	7.1%	49.5%
Anxiety	11	7.1%	11	5.8%	13	6.4%	35	6.4%	55.8%
Anger	12	7.7%	9	4.8%	12	5.9%	33	6.0%	61.9%
Psychosis	4	2.6%	9	4.8%	12	5.9%	25	4.6%	71.9%
Neuro assessment	2	1.3%	7	3.7%	12	5.9%	21	3.8%	75.7%
Eating disorder	5	3.2%	8	4.2%	7	3.4%	20	3.6%	79.4%
Phobia	4	2.6%	8	4.2%	8	3.9%	20	3.6%	83.0%
PTSD	1	0.6%	3	1.6%	13	6.4%	17	3.1%	86.1%
Other	29	18.6%	29	15.3%	33	16.3%	91	16.6%	97.3%
Missing	8	5.1%	5	2.6%	2	1.0%	15	2.7%	100%
Total	156	100%	189	100%	203	100%	548	100%	

Table 9. Reasons for referral to the service for a 3 year period

3.3 *Expert Interview - What explanations can be found for changes in referral patterns?*

The text presented reflects the interviewee's answers, and the tables (10-12) contain themes derived following content analysis of the interview.

3.3.1 Changes in numbers of referrals made by Psychiatry/CMHTs have occurred overall, and in the PCT governed sector. More referrals appear to be coming from Psychiatry/CMHT and less from GPs. What could explain this?

Changes in funding may mean it is less expensive to refer to the CMHT than directly to Psychology. Moreover, waiting lists for psychology may be a deterrent for GPs. With the development of counselling services, particularly in the area with the PCT Counselling Service, it may be that clients are being referred there first, and then on to a CMHT or psychology if required, or to the CMHT and then to psychology, however there are no data available on pathways to care.

Reasons for change in proportion of referrers
Primary Care Funding Changes
Evolution of Counselling Services
Psychology Waiting Lists
Referrals from GPs following more convoluted Care Pathways via Psychiatry/CMHT

Table 10. Reasons for change in proportion of referrals by referral source

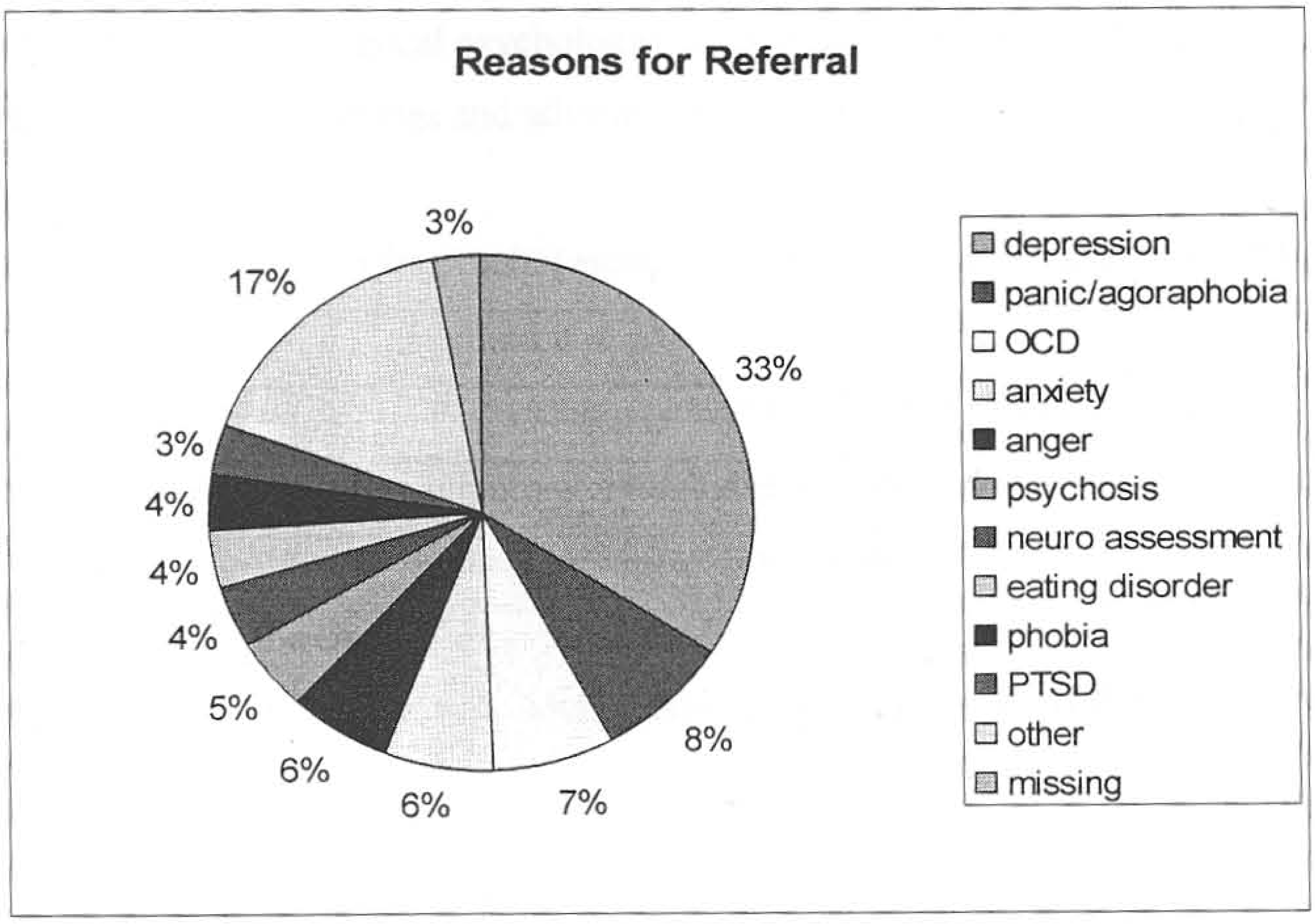

Figure 1. Pie chart of reasons for referral

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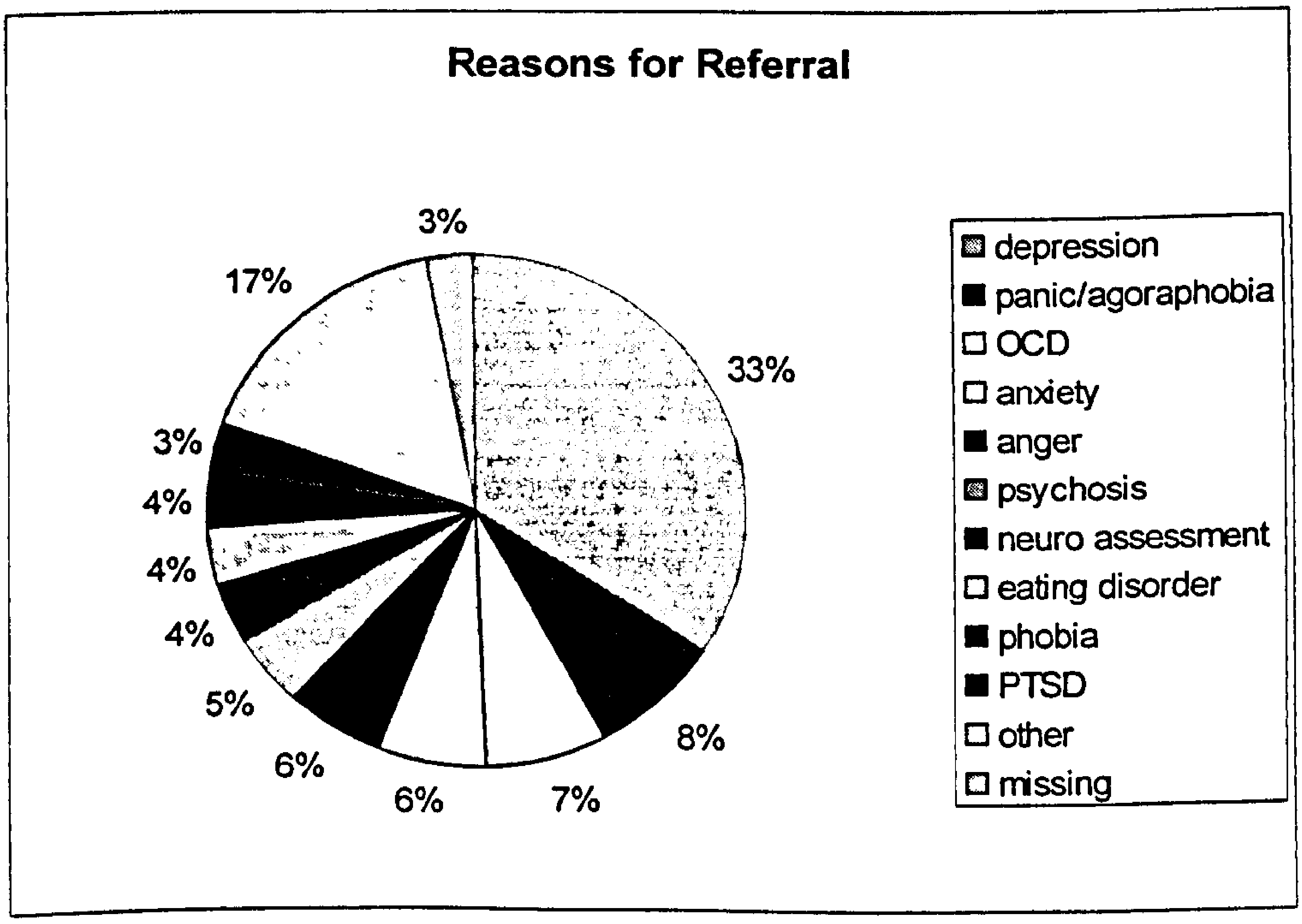

Figure 1. Pie chart of reasons for referral

3.3.2 Area 2 refers far more clients to AMH psychology than the other areas. What explanation could there be for this?

Reasons for greater number of referrals from area 2
Mental Health Team More Established
Management Styles and Operational Policies of CMHTs Differ
Psychologist Recruited only to CMHT in Area 2, Attends all MDT meetings

Table 11. Reasons for greater number of referrals from area 2

The CMHT in area 2 was established in a previous form, a Community Mental Health Centre, in 1991, which provided a free drop-in service with access to mental health services, whereas the other CMHTs were set up in 1996. This raised awareness of mental health issues for other service-providers in area 2, including GPs, as well as a tradition of those with mental health problems not being directly referred to psychiatry. Referral numbers may also be influenced by other team differences. The management style of the CMHT in area 2 means that the majority of referrals to psychiatry are discussed at the team, whereas area 1 operates a 2-tier referral system where referrals are referred either to psychiatry clinics or to the CMHT. Area 3's operational policy is also different as the consultant psychiatrist looks at all the referrals and decides which are referred on to psychology; other professionals in this team, e.g. social workers, also operate independently as they are able to receive direct referrals. Area 2 is the only CMHT that has a clinical psychologist employed as part of the CMHT, including attending all referral meetings and advising on appropriate referrals to AMH psychology.

3.3.3 How do the CMHTs know what makes an appropriate referral to AMH Psychology?

How CMHTs Know Appropriate AMH Psychology Referral
Psychologist Attending CMHT meeting/being part of CMHT
Experience of Outcome of Referrals

Table 12. How CMHTs know what makes an appropriate AMH Psychology Referral

4.0 Discussion

4.1 Summary of Findings

This study was a clinical audit of referrals received by an Adult Mental Health Psychology Service in the south-east of England for a 3 year period from 01/04/2000 to 31/03/2003. A total of 581 referrals were received and referral numbers were found to increase each year. 60% of the referrals were female and 40% male, and the average age of male and female referrals was 35 years. The increase in referrals to this clinical psychology service during this time period is greater then would be expected from national data (DOH 2001; DOH, 2002b; DOH, 2003).

Area 2 of the catchment area has been found consistently to refer a disproportionately greater number of referrals than the other areas. Given the intention to eradicate inequalities in access to health services (DOH, 2000), it is important to understand the reasons for the referral number differences. Interview data suggest a variety of factors may operate to influence the differences including historical development of services, the presence of psychology as part of a team, rather than based purely in the psychology service, and operational policies of CMHTs.

However, pathways into care (Huxley, 1996) may also operate to explain some of the differences in referrals. It was shown that referrals from GPs have been reducing in 2 out of 3 areas in the service catchment areas, while referrals from CMHTs/Psychiatry are increasing. While this may reflect GP referrals going to the PCT Counselling Service, for brief therapy, interview data also suggest the GP referrals may be going to the CMHT/Psychiatry first and are then referred on to the psychology service. This pathway from GP to CMHT may reflect closer working between primary care and CMHTs (Murphy et al., 2002), but this study's aim did not address this hypothesis. Huxley (1996) suggested the nature of the problem determines referral to secondary care as well as service availability. The interviewee commented on psychology service availability being less than the CMHT due to the length of the waiting list, and this may indeed be influencing pathways taken by referrals. However, the need for a mental health problem to be recognized as such also influences referral pathways (Huxley, 1996; DOH, 1999b), as does the identification of appropriate reasons for referral to a psychology service.

Reasons for referral have shown constancies and changes throughout the period audited. Depression is the most common reason for referral, with 34% of all referrals being made for this reason, and anxiety disorders are the next largest category of disorders to be referred to the service; these findings are in line with what would be expected in secondary level clinical psychology services (Hirsch et al., 2000). Marked increases in referrals for OCD, PTSD and psychosis as well as for neuropsychological assessments were found over the period studied. It may be that the active research programme on OCD is attracting referrals to the area, but without data on the number of referrals with OCD following the research programme this is not possible to verify. Nonetheless, changes in reasons for referral will have service implications.

4.2 Methodological Limitations and Proposed Improvements

This audit comprised the first stage of the clinical audit cycle (Riordan and Mockler, 1997). Thus, the baseline stage of evaluating current practice was carried out by analyzing the quality of referral information data. Data quality was then improved and standardized in a new coded format. No standard was set as the referral database had to be developed, however a standard (the 2nd stage of the audit cycle) of, "All new referrals will have a complete, accurate data set of referral information" could now be set and the audit cycle could move on to the next stage of "compare practice with standard" (ibid.) in 6 months time.

Difficulties with data quality remained following database development and so the audit data may not represent a valid picture of referrals to the service. This was largely due to the absence of some clinical notes for case notes analysis. Possible reasons for the absence of case notes included the thin cardboard folders of notes slipping into another file in the over-full filing cabinets, and the files of cases still open to psychologists being stored by them. However, the referral information did not identify which cases were still open to establish how many cases to which this could apply. Moreover, the practice of referrals from the CMHTs and Psychiatry (outpatient clinics and inpatients) being sent by a psychiatrist, mean that a crude coding format was used to represent both sources; detailed case notes analysis of a sample of referrals (e.g. 10%) would have been a useful adjunct to the audit to assist in establishing the pathway to referral to the service for these cases.

Absence of data on ethnic identity of those referred also limits the findings of the audit. It is known that differences exist between ethnic groups on the decision whether to refer beyond primary care, and the pathways decided upon following the decision to refer onwards (Commander et al., 1997a; Commander et al., 1997b). With no data on ethnicity it is not possible to establish whether referral patterns reflect the ethnic composition of the catchment area, or whether pathways into care differ with ethnic diversity. These points are important for service development as standard 2 of the National Service Framework for Mental Health (DOH, 1999b) may not be being met if the mental health needs of all those presenting at Primary Care are not being identified and effective treatment offered.

Referral reasons and diagnoses may also limit the findings of the audit. Referrers appeared to use general terms at times (e.g. anxiety) without clearly specifying which type of anxiety disorder; this led to diagnostic encoding that was not accurate. Moreover, there appeared to be ill-described referral reasons (e.g. needle fixation) but no record was held on whether further information was sought and if referrals were turned back or diverted elsewhere. Other diagnostic reasons may provide inadequate information to evaluate clinical risk and priority. For example, "mood swings" may be related to psychosis, a personality disorder, or low mood due to relationship problems. Information on the outcome of referrals, e.g. did not attend, discharged following 10 sessions, was not held either. This means that the audit data can support the increase in referral numbers, but without more detailed information cannot inform whether the actual increase in workload is equal to that suggested from the augmented numbers.

The use of an expert interview informed the audit findings, however interviewing a representative from only one referral pathway has ethical and methodological implications. Ethically, the knowledge that referrals to the service are increasing and that different areas refer different numbers may influence the likelihood of future referrals from the CMHT/Psychiatry pathway. Methodologically, interviews with the Head of the PCT Counselling Service and GP representatives from each area could have established information about the changing numbers of referrals to the psychology service, and if this is due to a change in pathways into care. These interviews could also have established whether what constitutes an appropriate referral to the service, and the information required by the service, is known.

4.3 Clinical and Service Implications

Two broad areas of implications and recommendations stem from this audit.

4.3.1 Case Notes and Database Development

Storage of existing closed cases needs to be divided into further filing cabinets to allow easier access to the notes. In combination with the use of most robust case files, there would be less chance of files being lost. In relation to the database, due to the methodological criticisms cited, further development of the referral information held is required (Table 13).

By developing the database, reliable data for audit purposes and service-development becomes easily accessible. Moreover, multi-disciplinary communication is facilitated; this is particularly important in a catchment area where only 1 of 3 CMHTs has a psychologist employed by it.

Recommended Additional Fields	Benefits of Additional Fields
If Referral Directed to Other Service	Gives indication of number of appropriate referrals; provides information on ratio of referrals to cases placed on waiting list
Ethnicity of Client/Presence of Disability	Monitoring of access to services; service-planning for diversity of need
Urgent or Waiting List Rating of Referral	Gives information on increase in complexity of referrals and workload
Date of Opt-in Letter	Allows tracking of stage of referral
Date of 1st Appointment	Allows waiting list length to be calculated improving quality of service to client by providing accurate waiting list information
Psychologist Allocated	Allows better multidisciplinary communication if named professional information easily accessible; allows knowledge of where to access notes
Number of Sessions	Allows monitoring of standard treatment times; facilitates planning for staff numbers required to meet referrals
Finer Grained Referral Category	Allows pathways to care to be monitored and audited
Psychologist's Assessment of Reason for Referral	Allows strategic service planning for needs of clients; informs training needs of staff to meet demands of current referrals
Case Open or Closed	Provides easy access to information if query raised about referral e.g. query from psychiatrist to see if client being seen by service or re-referral required

Table 13. Recommended Additional Database Fields and Benefits of them

4.3.2 Staffing and Referral Development Issues

The increase in numbers of referrals to the AMH clinical psychology service suggests a greater workload for a department that was already functioning with below the recommended number of psychologists, according to the Trethowan Report (1977) (cited in BPS, 2001). A summary of findings was fed back to the service in April 2004, and a presentation of the full results is planned.

The data on increase in referrals is currently being used by the service to support an argument for new clinical psychology posts, and the data on percentages referred from different pathways is being used to support a plan for the service to continue to allow direct referrals from GPs, rather than for all AMH psychologists to be employed in CMHTs.

The practise of only the CMHT in area 2 employing a clinical psychologist from the service in their team was cited as a possible reason for knowing which referrals are appropriate for the psychology service. Given the national shortage of clinical psychologists, and varied organisational models of psychology services and CMHTs, many CMHTs do not have a clinical psychologist in post (Department of Health, 2002). However, if there is not a regular clinical psychology presence in the CMHTs it may be useful to have a service leaflet developed to explain what constitutes an appropriate referral to the service, and a proforma of all the referral information required, to be distributed to all referrers. Subsequent clinical audits could focus on how many referrers meet the referral standard, and the impact on referral numbers.

As the service is receiving increasing referrals of certain types, such as PTSD and requests for neuropsychological assessments, staff may need to focus their continued professional development (CPD) on relevant evidence-based training. As such, a training strategy could be developed to meet the needs of the service, and should further staff be recruited an interest in those with expertise in certain types of referral could be expressed. During initial feedback to the service, it emerged that 2 of the clinical psychologists had gone on specialist trauma training owing to a view that referral numbers for PTSD were increasing; a PTSD clinic is currently being planned as part of service development.

In conclusion, this clinical audit has carried out the first stage of the audit cycle on referrals to an AMH psychology service over a 3 year period (01/04/2000 – 31/03/2003). Dissemination of the full results of the audit will be presented on 06/10/2004 to the service, and relevant line managers.

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Literature Review

The Familial Psychosocial Legacy of Traumatic Brain Injury:

Are Informal Carers “the Other Victims?”

1.1 Introduction

Traumatic brain injury (TBI) can have an immense impact on the entire family of the brain injured person. Del Orto and Power (2000) describe the entire family system being changed by the event, while Florian and Katz (1991) write of the consequences for family members who are the "other victims of traumatic brain injury" (p 267). Over time, the responsibility for caring for a person with a TBI lies mainly with informal family caregivers (Harris et al., 2001). Jones (1996) describes family caregivers of traumatically brain injured as being at risk of becoming "hidden patients" (p 9), and Allen (1994) proposes that the mother or spouse of the brain-injured person is most likely to shoulder the responsibility for assisting the person with the brain-injury.

This literature review aims to explore the effect of the TBI on the family. This topic has been researched from several apparently distinct, but overlapping, perspectives. Following a summary of background information, a section focuses on an area of the literature comprising family studies, including the impact on marital sub-systems. Psychological distress that informal carers may experience is addressed under the construct of Carer Burden and a section on Psychological Implications.

1.2 Background

TBI is defined as, "...an external force acting on the skull causing damage to the brain." (Degeneffe, 2001: 258). The most common aetiologies are road traffic accidents (RTA) and falls (Gray et al., 1994; Mitchley et al., 1996), although other aetiologies include accidents, at work or in leisure time, as well as assaults (Jennett and Frankowski, 1990). Physiologically, it is the resultant rotational, accelerative or blunt forces that cause the brain injury (Miller, 1986). Barnes (1998) suggests the UK has an annual incidence of TBI of 300 per 100,000 population; of those 52 suffer a serious brain injury (Wenden et al., 1998). TBI occurs mainly in the age bracket of 17-25 years (Flanagan, 1998) and predominantly affects males (Morton and Wehman, 1995).

Medical technology has made the survival of many TBI patients possible who would have died previously (Miller, 1993). Often TBI survivors have a normal life expectancy, but may have ongoing disabilities that involve economic, social and personal costs for 40 or 50 years (Boyle and Haines, 2002). While the first year following injury may yield major gains in intellectual impairment, the first 6 months is when the most substantial improvement occurs

(Lishman, 1998: cited in Barnes et al., 1998). Few survivors return to work, and those who do often require employment in supported settings (Lezak, 1995).

TBI can be categorised as mild, moderate or severe depending on a variety of neuropsychological and medical markers including Glasgow Coma Scale (GCS) score, Post-Traumatic Amnesia (PTA) duration, and neuroimaging (Degeneffe, 2001). As severity of the brain injury increases, the range and degree of potential long-term physical, cognitive and psychosocial impairments also increases (Cunningham et al., 1999). However, neuropsychiatric symptoms are reported to be responsible for as much disability as physical symptoms (Lishman, 1998: cited in Barnes et al., 1998).

Problems in functioning following TBI cover a range of deficits including cognitive, behavioural, neuropsychological, mobility, physical functioning, and emotional (Minnes et al., 2000). The most frequently cited problems by family carers of the person with the TBI include slowness, fatigability, irritability, memory problems, tension, anxiety, temper outbursts, depressed mood and personality changes (Brooks and McKinlay, 1983: cited in Minnes et al., 2000). However, these are described differently depending on the respondent; the suggestion being that those with a TBI are less aware of their deficits compared to family carers (Ergh et al., 2003), and that mothers are closer to TBI sons' views than spouses (Santos et al., 1998).

As much of the responsibility for supporting someone with a TBI rests upon informal caregivers such as parents or spouses (Knight et al., 1998), the reported effects of providing care can be wide-ranging. Social implications include role changes and financial difficulties (Frosch et al., 1997), as well as social isolation (Marsh et al., 2002). Caring has also been found to have physical impacts such as a high incidence of psychosomatic disorders, and increased consumption of psychotropic medication and alcohol (ibid.). Those who become carers of people with a TBI can also experience psychological sequelae such as anxiety (Livingstone et al, 1985) and depression (Harris et al., 2001). These consequences can remain many years following the injury (Brooks et al., 1986, Brooks, 1991). Moreover, spouses and partners can feel great relationship strain, often leading to separation or divorce (Wood and Yurdakul, 1997; Tate et al., 1989).

1.3 Family Studies

A number of studies have been conducted under the rubric of the family including the family response, family needs, and impact on the family system, including marital subsystem.

1.3.1 Family Response

Initially, following the TBI, the family may just hope for the person to survive the trauma and be overjoyed when he/she does (Williams, 1991). However, a variety of grief reactions can follow (Degeneffe, 2001; MacFarlane, 1999). Indeed, Boss (1999) talks of ambiguous loss in TBI as "...the loved one is present, but his or her mind is not." (p 45). With time and realisation, families may then deny the extent of the changes in the person with a TBI; this may initially provide a form of coping, but may become maladaptive if it impedes planning for the new future of the family (Miller, 1993).

A number of models have been proposed to explain the process of adjustment the family experiences (Lezak, 1986; Romano, 1974: cited in Brown and McCormick, 1988; Spanbock, 1987). Kubler-Ross' (1969) original grief framework was applied to family reaction to disability, but was found not to represent the experience of families (Williams, 1991). Models of Chronic Sorrow (Olshansky, 1962: cited in Williams 1991) and Episodic Loss (Wikler, 1981) have also been proposed (cited in Williams, 1991).

However, these models appear to deny the resilience of many families. Dell Orto and Power (2000) talk of the potential for familial adaptation to the difficult circumstances they experience including caregiving demands, role changes and financial difficulties. McCubbin and McCubbin (1991) have proposed a Resiliency Model of Family Stress, Adjustment and Adaptation which has been found to have utility in understanding the post-TBI family experience (Kosciulek et al., 1993). Of note is the way the family appraises the situation (the immediate sense they make of the TBI family member's behaviour, emotional state etc.) and the family schema (a more enduring world view) they hold will influence the family outcome. Change in the family schema, such as the family's goals, values, expectations, rules and priorities, has been proposed to be necessary for adaptive family functioning (ibid.). This hypothesis has been supported following TBI (Kosciulek, 1997), although methodologically the use of a non-probability sample limits the external validity of these findings. Furthermore, the appraisal of primary caregivers regarding the emotional and behavioural functioning of the family member with a TBI has been found to predict family functioning (Kosciulek and Lustig, 1998).

Sachs (1985) has written of a TBI as, "not merely an event to be painfully endured by families of trauma victims, but one that can be reinterpreted as a growth experience." (p 23). He has also addressed similar concepts to the family schema of the Resiliency Model of Family Stress

(Sachs, 1991). Adams (1996) cites a finding by Perlesz (1994) that the majority of families who undergo brain injury appear to have positive outcomes. However, this does not necessarily imply that families do not suffer. Frankl's (1963) clinical work suggested that suffering became more bearable if a meaning could be found in it (cited in Adams, 1996). Thus the immediate appraisal and subsequent meaning the family, or individuals therein, construe can influence the response and adaptation to TBI.

1.3.2 Family Needs

Family needs following TBI have been researched for over 20 years (Maus-Clum and Ryan, 1981; Mathias, 1984; Campbell, 1988: cited in Stebbins and Leung, 1998). Research using the Family Needs Questionnaire (FNQ) (Kreutzer, 1988) has established family needs post acute injury stage (Serio et al., 1995) and demonstrated that they change over time (Kreutzer et al. 1994; Stebbins and Leung, 1998). The FNQ has 5 scales measuring needs related to medical information, emotional support, instrumental support, professional support and support network. In Serio et al.'s sample, primary carers, comprising spouses, parents and significant others, of 180 USA TBI outpatients who were injured an average of 28 months previously were investigated to establish which of their needs were "met" or "unmet" and what is predictive of "met needs". Of items rated "important" or "very important", the range was from 14% of medical information needs rated as unmet to 30% of emotional needs. However, this data demonstrates that the majority of family needs were rated as met. Behavioural problems, as judged by the family members, were predictive of unmet needs, whereas neuropsychological tests did not predict this finding. Moreover, spouses who spent more time caring had more unmet needs, but this was not the case for parents.

Stebbins and Leung (1998) studied 29 family members, comprising parents, spouses and siblings and adult offspring, in Australia of TBI survivors. Using the FNQ, it was established that family needs in the first 2 years post-injury were for health information, medical and professional support, whereas after 2 years additional needs were identified such as family support, professional support and caregiver support. Moreover, while 25-62.5% of important/very important needs were met at time point 1, by post-two years this ranged between 4.8% and 42.9%. Of particular note is the need "To be shown what to do when my relative is acting strange or upset" was rated as met by 4.8%. These results clearly differ from Serio et al.'s (1995) study. However, differences in study outcome may have several origins:

Stebbins and Leung's sample was small (n=8 in time period 1), recruitment comprised a convenience sample of service-users and attendees at support organisations, and the participants were from a different continent. Moreover, the authors comment on the limited service provision post-rehabilitation.

1.3.3 Family Functioning

A number of authors have researched family functioning following TBI (Glenn et al., 2000; Groom et al., 1998; Kolakowsky-Hayner and Kishore, 1999; Maitz and Sachs, 1995; Moore et al., 1993; Perlesz et al., 1999; Perlesz et al., 2000; Ponsford et al., 2003; Webster et al., 1999), while others have written of interventions for TBI families (Kreutzer et al., 2002; Laroi, 2000; Laroi, 2003; Miller, 1993). Many problems in the family only become evident when the person with a TBI returns home (Webster et al., 1999); part of the problem at this time is the necessary redistribution of family roles that may have been necessary for the family to cope may need to be renegotiated (Maitz and Sachs, 1995). However, the reality of living with the altered TBI person full-time may also impact on family functioning.

Groom et al. (1998) discovered in their USA study of 178 family members (1 per patient) of TBI patients with mainly moderate to severe TBIs, that neurobehavioural symptoms as rated by the family member, particularly inappropriateness and depression, in the TBI patient were strongly positively correlated with poor family functioning as measured by the Family Assessment Device General Functioning subscale (FAD-GF). Of course, what is not possible to determine is how the family functioned before the TBI. Ponsford et al.'s (2003) English sample of 143 family members of TBI outpatients, with a similar proportion of severe and moderate injuries, found family functioning on the FAD-GF to be, on average, in the normal range. However, of those families who did function in the "unhealthy" range the total number of cognitive, behavioural and emotional changes was the greatest discriminator between the healthy and unhealthy groups. Aside from cultural differences, it is not clear the degree of rehabilitation the two samples had experienced. Moreover, Groom et al. (1998) do not report the type of relationship between family member and TBI survivor, and their sample has a much larger range of time since injury. A further salient point is that Groom et al.'s participants were mainly (86%) recruited from support group meetings, and it may be that their greater difficulties were why they participated in this form of support.

Problematic in the above studies is the reliance on one family member, who may be coping with a plethora of difficulties and changes such as social isolation, diminished financial income, and role change, to evaluate how the family is functioning. Perlesz et al. (2000) addressed this methodological flaw by including primary, secondary and tertiary caregivers in his Australian study on family psychosocial outcome. The majority of the 65 TBI outpatients had severe injuries and had been injured 12-24 months previously. One of the outcome measures used was Olson and Wilson's (1982) Family Satisfaction Scale. The data from this demonstrated the following family dissatisfaction: TBI person 10%, primary carer 19.5%, secondary carer 10% and tertiary carer 40%. Thus, the majority of all family members were satisfied. In the case of tertiary carers, the number was small (n=10) and may not be representative, however it may also reflect the differential familial impact as many of the tertiary carers were siblings.

Role changes are often cited as problematic following TBI, and structural family therapists posit the need to strengthen subsystems to restore aspects of roles, such as parental authority (Laroi, 2000; Laroi, 2003). However, the responses to Knight et al.'s (1998) qualitative question included several parents who described caring for their adult offspring with TBI as offering a sense of family unity. Thus the return to the role of carer, albeit for an adult child, was not perceived negatively by some. However, it may be that for parents the role change to carer is less difficult as it may be resuming a former role, and come at a time in life when career and family commitments are not so pressing, whereas for a spouse it adds to familial responsibilities, and is an entirely alien role. Moore et al.'s (1993) study of 65 TBI men, and their wives, in which 43% were unemployed, and the majority of them had moderate to severe head injuries, established financial strain, particularly when there were young children caused poorer patient adjustment as measured by both the TBI patient and spouse. Thus particular points in the family life cycle may be more difficult for TBI families.

1.3.4. Marital Studies

"The man I brought home from the hospital is not the man I married 3 years previously." (Knight, 1998: 476). This quote demonstrates the negative experience of marriage to someone with a TBI, yet other respondents to Knight's study commented on the improvement in the relationship with their husband following TBI, although the lack of data breakdown on injury severity in the study may mean the husbands compared with TBI are not an equivalent sample.

Marital relationships have been studied since Panting and Merry (1972) (cited in Wood and Yurdakul, 1997) and Rosenbaum and Najenson (1976) (cited in Kolakowsky-Hayner and Kishore, 1999). In Panting and Merry's study, by 7 years after injury 3 of the 10 married couples had separated and a further 3 had divorced.

Webster et al. (1999) suggest it is particularly difficult caring for a spouse with a TBI owing to the mainly negative changes in them, changes in the role of the uninjured spouse, lifestyle, and changes in the couple's relationship. Social support to the couple may diminish, leading to isolation, owing to the difficulty inherent in forming and maintaining relationships when one has a TBI, and people's avoidance of disability (ibid.). In combination with financial pressures of the spouse providing for the family or being unable to work as the TBI person requiring full-time care (ibid.), pressures within the marital relationship can mount. Moreover, behavioural and personality changes can alter the way the spouse feels for the TBI spouse and changes in sexual behaviour on the part of the injured spouse, such as disinhibition and lack of affection, can lead to sexual difficulties in the partnership (ibid.).

Wood and Yurdakul's (1997) study on relationship change comprised 131 participants who were married, engaged and living together or in common-law partnerships prior to the injury, which for the majority of the sample had been a severe or very severe TBI. On average, 8 years later, 49% of relationships had ended in separation or divorce. However, this study with severely brain-injured participants suggests that at least half of partnerships continued. Longer relationships were less likely to end and the optimum time for end of relationship was at, or after, 5 years post injury. Wood and Yurdakul suggest that by 5 years or so in the relationship, "...the burden of stress experienced by the partner and family has exceeded tolerance levels..." (p 499).

1.4.1 Carer Burden

Carer Burden is a dichotomous construct that was operationalised from the mental health literature (Grad and Sainsbury, 1963: cited in Montgomery et al., 1985). In TBI, Carer Burden has been defined as stress directly associated with changes resulting from the injury, with objective burden describing impairments or changes that the carer observed in the person with the brain injury, and subjective burden being the distress experienced as a result of the observed changes (Brooks and Aughton, 1979). Subjective Carer Burden (SCB), in particular, has been extensively studied in the TBI literature.

1.4.2 Subjective Carer Burden

A number of published empirical studies exist on SCB, or perceived distress, in TBI (Allen et al., 1984; Brooks, 1986; Brooks; 1991; Harris, et al., 2001; Jones, 1996; Knight et al., 1998; Livingston et al., 1985; McPherson et al., 2000; Machamer et al., 2002; Marsh et al., 2002; Nabors et al., 2002; Sander et al., 1997; Struchen et al., 2002). Early studies on Subjective Carer Burden (SCB) come from two groups of researchers in Glasgow (Brooks et al., 1986; Brooks et al., 1987; Brooks, 1991; Livingston et al., 1985 a, b; McKinlay et al., 1981). Brooks and colleagues studies of SCB in relatives in TBI followed up a significant relative of 42 outpatients with a TBI for 5 years. Using a 7-point rating scale of the "degree of strain experienced in caring for a family member with TBI", it was found that degree of strain increased from 69% experiencing medium to high burden at 3 months post-injury to 89% at 5 years. Brooks (1991) suggests that by one year following injury family members are becoming aware of post-injury changes and the impact they are having on family life. Although injury severity was not predictive of SCB, degree of personality change as rated by the relative was highly predictive of SCB (Brooks et al., 1986) The research results are strengthened by the minimal sample attrition (39/42 participants included at 5 years). However, the method by which SCB was rated meant a "medium" was as low as 3/7; it would be interesting to have data on how much strain other carers experience, or indeed how much of a strain family life, without caring, is perceived to be. Moreover, of those in the high burden category at 1 year, 20% reduced their rating of strain by 5 years (Brooks, 1991), and those who rated a high degree of SCB were less likely to rate their needs as being met (Brooks et al., 1987).

The Livingston group (Livingston et al., 1985a, b) researched 57 relatives of someone with a TBI and found that SCB as measured by the Perceived Burden Scale, a 25 point dichotomous checklist, was high at 3 months post injury and remained so at one year. However, sample attrition (65% assessed at all 3 time-points) limits the findings of the study. In this study more severe injuries were predictive of burden. However, it is of note that Brooks' and Livingston's samples did not have access to rehabilitation (Perlesz et al., 1999).

In Marsh et al.'s (2002) New Zealand longitudinal study of 52 primary carers, degree of SCB, as measured by two questions, decreased from 6 to 12 months post-injury. This was in spite of an increase of endorsement of behavioural problems on the Head Injury Behavioural Rating Scale from 50% agreement of the occurrence of 5 behaviours at 6 months to 12 behaviours at one year. However, the behavioural and cognitive problems and social isolation in the person with the TBI, as rated by the carer, were found to be predictive of SCB. Thus SCB did not increase in spite of apparent increased stressors.

Further evidence of the perceived, and more objective measures, in relation to the person with the TBI, have been found to be related to SCB. Machamer et al.'s (2002) study in the USA of 180 relatives, described as confidants or informal carers by the person with the TBI, undertaken at 6 months post injury utilized a 30 item multidimensional modified version of the Caregiver Burden Scale (Zarit et al., 1980). The TBI patients were moderately to severely injured. SCB was found to be related to caring for someone with a more severe injury, poorer neuropsychological functioning and greater dependence. However, the carers with most SCB were also found to be more likely to be caring for someone with a previous history of drug use and being arrested. Thus, it cannot be suggested that SCB is necessarily a result of TBI.

Factors connected to the carer have also been implicated in research on carer burden. Machamer et al. (2002) found that carers who had to give up more activities, including making financial sacrifices, to care for the person with a brain injury, were more likely to be in the group with the greatest negative burden. Moreover, the greater the degree of depression the carer reported, the more likely he/she was to fall in the group who felt most subjective burden (ibid.). Knight et al. (1998) replicated Allen et al.'s (1994) finding that parents expressed more pessimism and concern for the future than spouses of those with a brain injury. However, Minnes et al. (2000) discovered that spouses experienced greater SCB than parents in their study of carers of those with a brain injury sustained an average of 32 months earlier. Knight et al.'s sample comprised members of a head injury support group and had sustained injuries an average of 6 years previously whereas the source of Minnes et al.'s sample is not reported. The severity of injury is reported for neither study but the parents in Knight and colleagues' study were caring for someone who had been hospitalized, on average, twice as long as the person the spouses were caring for. These study factors may explain the findings.

1.4.3 Methodological Issues

Research in SCB has been limited by methodological weaknesses. Some of the above studies used ratings of 1 or 2 items, or, when they did use a scale, used a rating scale with forced choice dichotomous responses. Thus, there is no equivalence in measurement and the complexity of the SCB concept is not being reflected. When more complex scales are used for research in SCB in TBI (Allen et al., 1994; Knight et al., 1998; McPherson et al., 2000;

Machamer et al., 2002) they have often been developed for other groups of carers and have not been validated for this group, and may even have been truncated and used in a way not validated on any group (Allen et al., 1994). Moreover, lack of consistency in scale construction means there is conceptual blurring between objective and subjective burden (Robinson, 1983) which is then utilized in TBI research (McPherson et al., 2000).

The way in which the term SCB is used empirically has also been varied, being used to describe family unmet needs (Nabors et al., 2002), perceived stress measured by items of self-efficacy and self-mastery (Cohen et al., 1983), and amount of distress experienced by TBI and/or changes in the family carer's life (Marsh et al., 2002). Thus there appears to be a conceptual morass in relation to the SCB construct. In connection to this issue, Chwalisz (1992) has reviewed the need for theory to drive SCB scale development. Furthermore, scales used have, mainly, focused on negative aspects of caring, with a few exceptions (Machamer et al., 2002; Struchen et al., 2002), whereas this review of the literature suggests family carers do not perceive the situation as wholly negative. This continuance on seeing caring for a family member with a TBI as essentially negative perpetuates the views of certain authors (Florian and Katz, 1991; Jones, 1996) and constrains research theoretically. Moreover, the focus of TBI services becomes about pathology rather than progress.

1.4.4 Developments in Carer Burden Research

Research in TBI (Kosciulek and Lustig, 1998; Serio et al., 1995) has demonstrated it is the appraisal of the situation that is predictive of family outcome in TBI. Recent developments in research on SCB in TBI has utilised the concept of appraisal in its studies (Harris et al., 2001; Struchen et al., 2002), where cognitive appraisal (Lazarus and Folkman, 1984) is defined as "...an evaluative process that reflects the person's subjective interpretation of the event." (Pakenham, 2001: 14). Thus, research has moved to a more theoretically-based model, of Carer Appraisal rather than Burden, founded on the Transactional Theory of Stress (Lazarus and Folkman, 1984). Moreover, qualitative methods, or quantitative questions, have been employed in research with carers in brain injury to measure perceptions of positive aspects of the caregiving experience (Knight et al., 1998; Machamer et al., 2002; Struchen et al., 2002).

In Knight et al.'s (1998) study, 2/3 of the sample endorsed "always" or "nearly always" enjoying the work on the Care Burden Scale, while qualitative responses included positive comments such as, "It's made me appreciate and love my daughter more..." (p 476). Data from the modified Burden Questionnaire as reported by Machamer et al. (2002) show that 93% of the sample was happy to have had the opportunity to care for the subject, and 92% felt good about their ability as a caregiver at least some of the time. With Struchen et al.'s (2002) validation of the Modified Caregiver Appraisal Scale on a USA sample, it appears quantitative research can now move forward into the exploration of both positive and negative appraising of caring, utilizing a theoretically-underpinned instrument.

1.5 Psychological Implications

Family carers in TBI have been found to experience a variety of psychological difficulties or maladaptive behaviours. Depression and anxiety have been reported in a number of studies (Blankfeld and Holahan, 1999; Brooks, 1991; Livingston et al., 1985a, b; Marsh et al., 2002; Perlesz, 2000; Ponsford et al., 2003), depression in others (Gillen et al., 1998; Knight et al., 1998), and elevated psychological distress on the General Health Questionnaire by Sander et al. (1997). Details of many of these studies have already been reported, but of note in relation to psychological distress is that in all the studies, irrespective of time post injury, the majority of family carers are not psychologically distressed. Livingston and colleagues and Gillen et al. (1998) did not find a reliable difference between spouses and parents on measures of anxiety or depression, although wives were reported to be more depressed than mothers by Gervasio and Kreutzer (1997).

Hall et al. (1994) found an increase in alcohol dependence and non-prescription drugs in family carers in the first two years following injury, but also reported that the majority of carers with psychosocial issues had them before the TBI occurred. This finding has been supported by Gillen et al. (1998) who discovered the best predictor of carer depression is a history of depression before the TBI. Moreover, Gillen et al. (1998) state the rates of depression in their sample are in accord with lifetime major depression data from community studies. Explanations for levels of maladaptive coping and psychological distress have been proposed including the thesis that some people with a TBI have, or have had, alcohol and drug problems (Perlesz, 2000), and in this cohort there is an increased likelihood of developing a partnership with someone who is depressed (Merikangas, 1994: cited in Gillen et al., 1998).

1.6 Conclusion

Research on the psychosocial implications of having a family member with a TBI has been largely quantitative in nature often omitting perspectives from more than one family member.

Many of the studies have been poorly controlled, not acknowledging time since the injury, the origin of the sample, or the degree of neuropsychological impairment. Theoretically underpinned research on caring has been largely absent, as has a focus on positive aspects of caring. Perhaps one of the most glaring omissions in the literature is the absence of research on intrapersonal aspects of family members, and the implications this may have for family functioning, carer appraisal and psychological distress.

As family members continue to be the main support for those with a TBI, it is essential to begin to recognise the largely non-pathological position they maintain, that enables them to continue caring in very difficult circumstances. Moreover, understanding the meanings that are constructed by them, individually or as a family, to enable this role to be fulfilled could provide a burgeoning understanding of carers' needs and how they cope. In this way, services could be developed to provide the appropriate support necessary for family carers to continue in their role. Utilising a Personal Construct methodology (Kelly, 1955; Winter, 1992) could provide the opportunity to explore individual positive and negative meanings in caring.

Thus, it is recommended to:

1. Undertake better controlled quantitative family studies which are expanded to include the whole family
2. Undertake research in Carer Appraisal utilising theoretically driven questionnaires validated for this sample
3. Undertake research on intrapersonal aspects of family carers to establish what it is about their Personal Construct System that enables them to care for a relative

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Brain Injury and the Experience of Caring: Intrapersonal Aspects from a Personal Construct Perspective

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For Finlay, who puts everything into perspective.

Abstract

Significant proportions of carers for those with a brain injury have been found to be clinically anxious and depressed. Subjective carer burden (SCB) has been defined as the distress experienced as a result of the observed changes in the person with the brain injury. No research has looked at the individual psychological characteristics, or intrapersonal aspects, of the carer in brain injury in relation to SCB and psychological distress. Very few studies have addressed apparent methodological problems regarding the measurement of SCB; no study in brain injury has explored the meanings carers have found in their role; and very few studies have included positive elements of caring in their research.

This study used a non-experimental, non-randomised, cross-sectional design. A theoretically based measure of SCB was used, in combination with a Personal Construct Psychology methodology, to investigate the relationship between the intrapersonal aspects of carers and their relationship to SCB and psychological distress. Positive appraisals of caring and meanings the carers derived from their role were also investigated.

Few predicted study hypotheses were supported. Results showed that a significant proportion of carers were anxious and or depressed and that the majority of carers were shown to have very tight construct systems reflective of having limited flexibility in thinking. Novel findings included the previously unreported relationship between perceived burden, a measure of SCB, and anxiety. The manner in which carers construed the brain injured person was found to be related to the appraisals they form, thus adding to the evidence of the importance of the role of construing of the brain injured person by family members. Meanings derived from caring emerged in a number of themes. 60% of carers' meanings could be categorised in the following three themes: life circumstances, emotional states and health and illness. Carers generated positive as well as negative meanings.

Findings were considered in relation to previous SCB and Personal Construct Psychology research. Clinical implications of the structure of construct systems in this population were considered. Suggestions for future research with an emphasis on the development of clinical practice were included.

1.0 Introduction

1.1 Research Overview

It has been reported that a brain injury can have a wide-ranging impact not only on the affected individual, but on the family aswell. The brain injured person does not acquire neurobiological damage in isolation, but experiences neuropsychological and psychosocial changes too leading to altered functional abilities and role changes (Cunningham et al., 1999). Often a family member may become an informal carer to a much changed loved one, and need to make many adjustments. This situation has been found to be related to multiple family and individual difficulties, including family response and adjustment problems (Boss, 1999; Lexak, 1986), subjective carer burden (Brooks, 1991) and carer psychological distress (Blankfield and Holahan, 1999). Increasing politicisation of the role of the carer, in combination with greater awareness of the impact of caring in brain injury, makes this a timely research area.

Developments in the study of subjective carer burden in brain injury have led to testing more theoretically-driven models and the inclusion of a broader research focus, including positive elements, in caring (Struchen, Atchison, Roebuck, Caroselli and Sander, 2002). However, not all carers experience the same degree of subjective burden and psychological distress. Thus, the consideration of intrapersonal idiographic elements in brain injury carers has been a research omission, while developments from other carer research areas have not been adopted in brain injury. This introduction aims to provide a contextual understanding of the research area; review the relevant family and carer literature; and address the identified empirical gaps to be tested.

1.2 Context

To contextualise this research it will be anchored empirically and politically.

1.2.1 Research Quotations about Carers in Brain Injury

Various research publications have tried to express the plight of carers of those with a brain injury:

"Unlike a death, there are no social supports or institutionalised rituals for this mourning. It is an isolated and often secretive sorrowing that may be unduly prolonged by the frustrating or pathetic presence of the patient and the lack of opportunity to form new relationships" (Lezak, 1986: 247).

"Family caregivers of traumatically brain injured are at risk of becoming 'hidden patients'" (Jones, 1996: 9).

"Family members are the "other victims of traumatic brain injury" (Florian and Katz, 1991: 267).

"The patient is doing well now; the care provider is still struggling." - Quote from mother of head-injured son, 7 months post injury. (Blankfeld and Holahan, 1999: 619).

1.2.2 Political Context

There has been increased interest and acknowledgement of carers' needs generally by legislative and other bodies but, also, specifically carers in brain injury. Thus, over a fifteen year period, the needs of carers have firmly been placed on the political agenda (NHS and Community Care Act, 1990; The Carers (Recognition and Services) Act, 1995; The Carers Strategy, 1999; The Carers and Disabled Children Act, 2000; The Carers Equal Opportunities Act, 2004). Carers' rights, independent of the person for whom they care, have been acknowledged. Consequently, a carer is entitled to an assessment that not only identifies and addresses his/her needs to enable him/her to continue caring, but that also identifies ways in which the carer's plans to work, study and engage in leisure interests can be supported. Thus, the acknowledgement, and impact, of caring on multiple areas of the carer's life including health, relationships and social life are all now considered.

The relevance of the needs of carers has recently been emphasised in Department of Health policy aswell. Since the publication of the National Service Framework for Long Term Conditions, (Department of Health, 2005), the specific needs of carers for those with acquired brain injuries have been highlighted. In particular, "Quality requirement 10: Supporting family and carers" addresses the need to reduce carer stress and improve carer quality of life. Thus, the legislative and policy changes of the past 15 years that enshrine the rights and needs of carers have most recently acknowledged the requirements of carers in brain injury.

1.3 Definitions

Contextualising this research area further by defining the key terms in caregiving and brain injury provides an understanding of the complexity of the area.

1.3.1 Carer

There is no one operational definition of informal carer. The UK government defines carers as people who look after a relative or friend who requires support because of age, physical or learning disability or illness (Wooff, Schneider, Carpenter and Brandon, 2003). As previously reported legislation has recently recognised the rights and needs of carers. However, people undertook caring roles before social policy identified them as carers. Moreover, the application of the label "carer" may not reflect the identity the carer perceives he/she has. For example, supporting a brain-injured spouse may be perceived as fulfilling a personal and social expectation of marital vows, "in sickness and in health", rather than having a role as a carer. This is particularly significant as the majority of research in brain injury does not define carer (Ergh, Hanks, Rapport, and Coleman 2003; Machamer, Temkin and Dikmen, 2002; Marsh, Kersel, Havill and Sleigh, 2002; Perlesz, et al., 2000; Sander et al., 1997), and relies on subjective interpretations of whether the individual perceives he/she is fulfilling a caring role. As "caring" in brain injury does not require as much of the typical physical aspects of caring as does caring for people with other types of injury (Oddy and Herbert, 2003), this adds further complexity to the definition of this term. Thus, the definition of carer is contextually mediated.

1.3.2 Brain Injury

The definition of brain injury is also complex. In the research community, there does not appear to be a unified definition of brain injury (Kraus and Sorenson, 1994). In the USA "traumatic brain injury" (TBI) tends to be used to refer to brain injury (Richardson, 2000) that includes causes such as falls, assault, road traffic accidents and sports injuries (O'Brien, Nicholson, Johnson and Gravell, 2002). From an aetiological perspective, these events can cause insults to the brain including the following: shearing injuries, intra-cerebral haemorrhages and cerebral contusion (ibid.). In Europe, "brain injury" can include other types of neurological damage (Richardson, 2000), and the term "acquired brain injury" (ABI) is a term used in UK brain injury services to reflect this. An acquired brain injury includes traumatic brain injuries as well as non-traumatic brain injuries (United Kingdom Acquired Injury Forum, 2006). Non-traumatic brain injuries include aetiologies such as strokes and other vascular accidents, tumours, infectious diseases, hypoxia, metabolic disorders (e.g. liver and kidney diseases or diabetic coma) and toxic products taken into the body through inhalation or ingestion (ibid.). In this study, the majority of research participants were carers for people who had experienced TBIs. However, some of the people cared for had acquired brain injuries by non-traumatic modes. This mixed sample reflects the referral criteria of the convenience sample sources, exemplifying a difficulty in researching this clinical area.

1.4 Brain Injury Epidemiology and Demographics

Each year over one million people will attend hospital in the UK as a result of an ABI, of whom 100,000 are left with a significant disability (Rehab UK, 2005). It is the foremost cause of death and disability in young people and children and is the largest cause of acquired disability in the UK today in the working age population (ibid.). Exact statistics for all causes of ABI are difficult to establish as episodes of care may be recorded as the primary diagnosis, for example insulin overdose; specific data on TBIs is more readily available. Barnes (1998) states that the UK has an annual incidence of TBI of 300 per 100,000 population; of those, 52 are reported to suffer a serious brain injury (Wenden, Crawford and Wade, 1998).

External causes of TBI have been found to vary cross culturally (Jennett, 1996) and by the age, sex and social class of the affected person (Richardson, 2000). Demographically, TBI occurs mainly in the age bracket of 17-25 years (Flanagan, 1998) and predominantly affects males (Morton and Wehman, 1995) of lower socio-economic status (Kraus and Sorenson, 1994). However, the following are cited in varying proportions as the main external causes of TBI, irrespective of which cohort is studied: traffic accidents, falls, physical assault, and accidents at home, work, outdoors, or while playing sports. Statistically, the external causes of traumatic brain injury in English-speaking industrialised societies are quoted as: road traffic accidents (45%), falls (30%), occupational accidents (10%), recreational accidents (10%) and assaults (5%) (Jennett & Frankowski, 1990).

1.5 Impact of Brain injury

Brain injury can be seen to have an impact at a variety levels from neurobiological, in the affected person, to psychosocial functioning in both the person with the brain injury and his/her family.

1.5.1 Neurobiology

The traumatic brain injury can be "closed", "open" or "crushed" in its typology (Gronwall, Wrightson and Waddell, 1990). Resulting injuries to the brain can be divided into primary and secondary categories (Cassidy, 1994; Richardson, 2000; Miller, Pentland and Berrol, 1990), while secondary brain injuries can be further subdivided into intracranial and systemic effects (Cassidy, 1994). TBI is categorised as mild, moderate or severe depending on a variety of neuropsychological and medical markers including Glasgow Coma Scale (GCS) score, Post-Traumatic Amnesia (PTA) duration, and neuroimaging (Degeneffe, 2001). However, in virtually all forms of brain injury, whether mild, moderate or severe, cerebral neurons and axons are irreversibly damaged (Miller et al., 1990). As severity of the brain injury increases, the range and degree of potential long-term physical, cognitive and psychosocial impairments also increase (Cunningham et al., 1999) with the consequent need for support from others. However, the majority of brain injured people are independent in activities of daily living (Jacobs, 1988), and neuropsychiatric symptoms are reported to be responsible for as much disability as physical symptoms (Lishman, 1998). Thus, the reported impact on functioning is not purely correlated with organic impairment.

1.5.2 Impact on Brain Injured Person

Following developments in medical technology, the survival of many TBI patients who would have died previously has been possible (Miller, 1993). While the first year following injury may yield major gains in intellectual impairment, the first six months is when the most substantial improvement occurs (Lishman, 1998). Those who survive TBI can often have a normal life expectancy, but may have ongoing disabilities that result in economic, social and personal costs for 40 or 50 years (Boyle and Haines, 2002). Problems in functioning following TBI cover a range of areas including cognitive, behavioural, neuropsychological, mobility, physical and emotional functioning (Minnes, Graffi, Nolte, Carlson and Harrick, 2000). Neuropsychological changes can affect memory, visual perception, attention and concentration, problem-solving, abstract reasoning, planning, information processing and organization (NIH, 1999). Few TBI survivors return to work, and those who do often require employment in supported settings (Lezak, 1995). In fact, research suggests that more than 60% of survivors are unable to maintain employment during the first two years after injury (Dikmen et al., 1994). Perhaps not surprisingly, emotional problems including depression, anxiety and apathy are some of the most commonly reported states of psychopathology recorded in those with a brain injury (Groom, Shaw, O'Connor, Howard and Pickens, 1998).

Given that the cohort most likely to be affected by brain injury is young males, in the early stages of establishing independence in friendships, relationships, employment and accommodation (Morton and Wehman, 1995), this potentially leaves a group of people unable to fulfill the expected social and relationship roles for their developmental stage. Moreover, the range of difficulties that can be experienced may require support of varying degrees from family members for significant, if not long-term, periods of time.

1.5.3 Family Perspective of Impact on Brain Injured Person

While the impact on those with a brain injury has been reported as above in the research literature, informal carers have also presented their perspective on the brain-injured person. The problems most frequently cited by family carers of the person with the TBI include slowness, fatiguability, irritability, memory problems, tension, anxiety, temper outbursts, depressed mood and personality changes (Brooks and McKinlay, 1983). Indeed, it has been suggested that those with a TBI are less aware of their deficits compared to family members (Ergh et al., 2003). However, the relationship between reported impact by family carer and brain-injured person is not that clear as mothers have been found to be closer to TBI sons' views of their difficulties than spouses (Santos, Caldas and De Sousa, 1998). Thus, it appears that the perception of injury impact and functional changes is dependent on the person asked, and the role he or she plays in the life of the person with a TBI. Given the perceived changes in the brain injured person that the carer may have to live with, and adapt to, it is not surprising that carers too may experience psychosocial problems.

1.5.4 Psychosocial Functioning in Family Carers in Brain Injury

Psychosocial problems in family carers in brain injury have been reported in a body of research published over the past 30 years. Depression and anxiety have been reported in a number of studies in proportions ranging from 25% to 35% of the sample (Blankfeld and Holahan, 1999; Brooks, 1991; Livingston, Brooks and Bond, 1985a, b; Marsh, Kersel, Havill and Sleigh 2002; Perlesz, Kinsella and Crowe, 2000; Ponsford, Olver, Ponsford and Nelms, 2003). Depression alone has been reported in other studies on carers in TBI (Gillen, Tennen, Affleck and Steinpreis, 1998; Knight, Devereux and Godfrey, 1998), and elevated psychological distress on the General Health Questionnaire was reported by Sander, High, Hannay and Sherer (1997).

In relation to the roles within the family, partners who were TBI carers were reported to be more depressed than parents who were TBI carers (Gervasio and Kreutzer, 1997; Kreutzer, Gervasio and Camplair, 1994a). This finding may be understandable, given research into the impact on relationships of caring in brain injury, as it has been found that spouses and partners who become carers can experience great relationship strain, which can lead to separation or divorce (Tate, Lulham, Broe, Strettles and Pfaff, 1989; Tyson, 2003; Wood and Yurdakul, 1997). Thus, while psychological distress has been widely reported, relationship to the brain injured person may be related to depression.

Informal caring in TBI has also been found to be associated with a high incidence of psychosomatic disorders, and increased consumption of psychotropic medication and alcohol (Marsh et al., 2002). Hall, Karzmark, Stevens, Englander, O'Hare and Wright (1994) found an increase in alcohol dependence and non-prescription drugs in family carers in the first two years following injury. It is thus apparent that the experience of caring for someone with a brain injury can be related to psychological, systemic, and substance-related problems, although causality has not been established.

1.6 Family Impact

Much of the responsibility for supporting someone with a TBI rests upon informal caregivers such as parents or partners (Knight et al., 1998; Oddy and Herbert, 2003), and, as reported above, the psychosocial difficulties reported by family carers can be wide-ranging. A number of studies has been conducted on other aspects of the family in brain injury including family response (Lezak, 1986; Romano, 1974; Williams, 1991), family needs (Kreutzer et al., 1994; Serio et al., 1995; Stebbins and Leung, 1998), family functioning (Glenn, Klemz, and Vanderploeg, 2000; Maitz and Sachs, 1995; Perlesz, Kinsella and Crowe, 1999) and impact on the family system (Webster, Daisley and King, 1999), including the marital subsystem (Panting and Merry, 1972; Rosenbaum and Najenson, 1976; Wood and Yurdakul, 1997). Crawford (2004) undertook a review of the literature relating to family impact of brain injury, pertinent findings of which will be summarised in this section.

1.6.1 Family Response and Adaptation to Brain Injury

Boss (1999) talks of ambiguous loss following TBI as "...the loved one is present, but his or her mind is not." (p 45), while Del Orto and Power (2000) state the entire family system is changed by a TBI. A number of models have been proposed to explain family responses and adaptation to brain injury. Many of these could be considered stage models (Lezak, 1986; Romano, 1974), although other perspectives have been taken (Spanbock, 1987) including a model of Chronic Sorrow (Olshansky, 1962) and one of Episodic Loss (Wikler, Wasow and Hartfield, 1981). Kubler-Ross' (1969) grief model has also been applied to family adjustment to disability (Williams, 1991). In essence, all the models portray the family response to the event of a brain injury as largely negative, with grief responses as part of the process (MacFarlane, 1999), following the potential initial joy at the brain injured person's survival.

These somewhat pessimistic paradigms ignore the resilience of some families in their responses to brain injury. Dell Orto and Power (2000) report possible successful familial adaptation to difficult family circumstances including caregiving demands, role changes and financial difficulties. Moreover, the concept of resiliency in relation to family adjustment to TBI has been developed in the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin and McCubbin, 1991). This model was based on the transactional model of coping (Lazarus and Folkman, 1984) in which a tripartite process of cognitive appraisals, emotional responses, and efforts to cope with the stressor operate. Kosciulek, McCubbin, and McCubbin's (1993) research has found this model to have explanatory power in relation to the family's response and adaptation to TBI. Of note is the way the family appraises the situation (the immediate sense they make of the TBI family member's behaviour, emotional state etc.), and the family schema (a more enduring world view) they hold will influence the family outcome. The ability to make changes to the family schema, such as the family's goals, values, expectations, rules and priorities, has been proposed to be necessary for adaptive family functioning (ibid.). This hypothesis has been supported following TBI (Kosciulek, 1997). Moreover, research focusing on individual primary caregivers has found the appraisal of emotional and behavioural functioning of the family member with a TBI can predict family functioning (Kosciulek and Lustig, 1998).

Conceptually, appraisal is the individual's unique perception of the situation. It is therefore neither inherently negative or positive (Lazarus, 1991; Lazarus and Folkman, 1984), thus affording diverse idiographic perceptions of families affected by brain injury. This theoretical perspective gives meaning to the work of Sachs (1985), who suggested that TBI is, "not merely an event to be painfully endured by families of trauma victims, but one that can be reinterpreted as a growth experience" (p 29). Indeed Sachs (1991) elaborated his views to include similar concepts to the family schema of the Resiliency Model of Family Stress

(Sachs, 1991). Perlesz et al., (1999) added to this new perspective when they discovered that the majority of families who undergo brain injury appear to report positive outcomes. However, this does not necessarily imply that families do not suffer. Frankl's (1963) clinical work suggested that suffering can be present but becomes more bearable if a meaning could be found in it. Thus the immediate appraisal and subsequent meaning the family, or individuals therein, construe can influence the response and adaptation to TBI.

1.7 Carer Burden

Carer burden is a topic widely investigated, and developed to include appraisal, in the informal family carer literature. Carer burden has been in the caring research arena for more than 40 years. It is a dichotomous construct, comprising objective and subjective burden, derived from the mental health literature (Grad and Sainsbury, 1963). In TBI, carer burden has been defined as stress directly associated with changes resulting from the injury. Objective burden describes impairments or changes that the carer has observed in the person with the brain injury, and subjective burden is described as the distress experienced as a result of the observed changes (Brooks and Aughton, 1979). An example of objective burden is the item, "X (the brain injured person) has problems remembering things" (Robinson, 1983). Subjective burden can be exemplified by items such as, "Caregiving gives me a trapped feeling" and "Caregiving makes me feel depressed" (Knight et al., 1998). Subjective Carer Burden (SCB), in particular, has been extensively studied in the TBI literature.

1.7.1 Subjective Carer Burden

In TBI, a number of studies on SCB has been published (Allen, Linn, Gutierrez and Willer 1984; Brooks, Campsie, Symington, Beattie, and McKinlay, 1986; Brooks; 1991; Harris, Godfrey, Partridge and Knight, 2001; Jones, 1996; Knight et al., 1998; Livingston et al., 1985a,b; McPherson, Pentland and McNaughton, 2000; Machamer et al., 2002; Marsh et al., 2002; Nabors, Seacat and Rosenthal, 2002; Sander et al., 1997; Struchen, Atchison, Roebuck, Caroselli and Sander, 2002). Early studies on SCB come from two groups of researchers in Glasgow (Brooks, Campsie, Symington, Beattie and McKinlay, 1986; Brooks, Campsie, Symington, Beattie and McKinlay, 1987; Brooks, 1991; Livingston et al., 1985 a, b; McKinlay, Brooks, Bond, Martinage and Marshall, 1981). In Brooks and colleagues' longitudinal studies it was found that medium to high SCB increased from 69% at three months post-injury to 89% at five years post-injury. Although injury severity was not predictive of SCB, degree of personality change in the injured person, as rated by the carer, was shown to be highly predictive of SCB (Brooks et al., 1986). As an explanation for these findings, Brooks (1991) suggests that by one year following TBI family members are becoming aware of post-injury changes and the impact they can have on family life; this perspective is very much in line with models of adaptation to brain injury, as previously reviewed. However, not all carers continue to experience high levels of burden over time. In Brooks (1991), 20% of carers in the high burden category at one year post injury reduced their reported rating of strain by five years post injury. Moreover, Brooks et al. (1987) found that carers who were rated as high on SCB were found to be less likely to rate their needs as being met.

Thus it is apparent that while the majority of TBI carers researched perceive a significant degree of SCB, burden appears to change over time. Moreover, objective measures of injury severity as well as subjective carer perceptions of change in the injured person may predict burden, though there is not a clear relationship between injury severity and perceived changes in the injured person. Furthermore, these early studies took place prior to the advent of carer assessments and may, in part, reflect unmet carer needs. It is also of note that Brooks' and Livingston's samples did not have access to rehabilitation services (Perlesz et al., 1999).

More recent non-UK studies have provided added dimensions to the research debate. Findings from Marsh et al. (1998a; 1998b) linked behavioural problems in those with a TBI to SCB. However, findings from Marsh et al.'s (2002) later New Zealand longitudinal study suggest SCB decreases between six and twelve months post-injury. In this study behavioural and cognitive problems in the person with the TBI, as rated by the carer, were found to be predictive of SCB. In Machamer et al.'s (2002) cross-sectional USA study of "confidants or informal carers" of someone with a TBI, SCB was found to be related to caring for someone with a more severe injury, poorer neuropsychological functioning and greater dependence. Thus, further evidence suggests that SCB is not purely related to time since injury, nor necessarily to severity of injury. However, it seems that problematic changes in the person with the TBI, as perceived by their carer, are implicated.

1.7.2 Carer Variables Related to Subjective Carer Burden

Factors connected to the carer have also been investigated in research on carer burden. For example, carers' self-perceptions of life changes from pre to post injury have also been reported in the TBI literature (Machamer et al., 2002). In this study, Machamer et al., (2002) found that carers who reported they had to give up more activities, including making financial sacrifices, to become a carer, were more likely to be in the group with the greatest burden. Moreover, the greater the degree of depression the carer reported, the more likely he/she was to be in the group who felt most SCB (ibid.). Thus, the degree of self reported change in carers' lives has been found to be related to SCB, and SCB has also been found to be related to psychological difficulties.

Other carer factors have been found to be related to SCB in carers in TBI. Minnes et al. (2000) discovered that spouses experienced greater SCB than parents. Thus, research findings have established the relationship to the brain injured individual is related to both SCB and depression (Gervasio and Kreutzer, 1997). It therefore appears that factors related to the brain injured person, and the carer's relationship to him/her, have been found to be predictive of, or related to, SCB. However, no research has focused on the individual psychology of carers and the possible relationship of this to subjective carer burden.

1.7.3 Methodological Issues In Subjective Carer Burden Research

Research findings[1] regarding SCB have also been limited by methodological weaknesses, including the measures used. Some of the studies used ratings of one or two items, or, when they did use a scale, used a rating scale with forced choice dichotomous responses. Thus, there is no equivalence in measurement and the complexity of the SCB concept is not being reflected. When more complex scales are used for research in SCB in TBI (Allen et al., 1994; Knight et al., 1998; McPherson et al., 2000; Machamer et al., 2002) they have often been developed for other groups of carers and have not been validated for this group, and may even have been truncated and used in a way not validated on any group (Allen et al., 1994). Moreover, lack of consistency in scale construction means there can be conceptual blurring between objective and subjective burden (Robinson, 1983), which is then utilised in TBI research (McPherson et al., 2000).

The way in which the term SCB is used empirically has also been varied, being used to describe family unmet needs (Nabors et al., 2002), perceived stress measured by items of self-efficacy and self-mastery (Cohen, Kamarck and Marmelstein, 1983), and amount of distress

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[1] All studies in 1.7.3 relate to TBI-only samples

experienced by TBI and/or changes in the family carer's life (Marsh et al., 2002). Thus there appears to be lack of conceptual clarity in relation to the SCB construct. In connection to this issue, Chwalisz (1992) has reviewed the need for theory to drive SCB scale development and proposed the use of transactional stress theory (Lazarus and Folkman, 1984, 1987) as a framework.

In the transactional theory, stress is purported to occur when the environmental demands are appraised and perceived to exceed the available personal and social resources (ibid.). Thus, it is the individual's thoughts about the situation, rather than the situation per se, that determine whether stress is experienced. Lazarus and Folkman (1984, 1987) describe the idea of primary and secondary appraisals. The primary appraisal is the assessment of the apparent threat in the situation and the secondary appraisal is the perception of the individual's ability to cope with it. Secondary appraisals include feelings of not being able to deal with the problem. To reduce stress it may be necessary to change the perception of the situation and of the available coping abilities.

With few exceptions (Knight et al., 1998; Machamer et al., 2002; Struchen et al., 2002), scales used have, predominantly, focused on negative aspects of caring, in spite of this literature suggesting family carers do not perceive, or appraise, the situation as wholly negative. While this continuance on seeing caring for a family member with a TBI as essentially negative may reflect the views of certain authors (Florian and Katz, 1991; Jones, 1996), it could also impede broadening research in this area.

1.7.4 Developments in Subjective Carer Burden Research

Research in TBI (Kosciulek and Lustig, 1998; Serio, Kreutzer and Gervasio, 1995) has demonstrated it is the appraisal of the situation that is predictive of family outcome in TBI. As previously stated, appraisal is not inherently positive or negative but an individual perception of the situation. The concept of appraisal has also recently been utilised in research in SCB in TBI (Chwalisz, 1996; Knight et al., 1998; Harris et al., 2001; Struchen et al., 2002). Chwalisz's (1996) study of spousal carers of those with a TBI amalgamated the fields of SCB and transactional stress theory and generated results supportive of transactional stress theory. However, the instrument used to measure appraisal was a generic scale validated to measure stress in the previous month. Harris et al.'s (2001) study of carers of those with a TBI was also broadly supportive of transactional stress theory, though the measure of stress appraisal involved the investigator's interpretation of the carer's level of stress. Knight and colleagues tested a multidimensional measure of caregiving that included positive appraisals as well as perceived stress. However, the scale used has not been subject to validation in the sample of carers in brain injury.

Struchen et al. (2002) adapted the Caregiver Appraisal Scale, CAS, (Lawton, Kleban, Moss, Rovine and Glicksman, 1989; Lawton, Moss, Kleban, Glicksman and Rovine, 1991), originally developed for use with carers of elderly people, for carers in brain injury. The CAS was founded on the transactional theory of stress (Lazarus and Folkman, 1984; Lazarus and Folkman, 1987). The adapted CAS, titled the Modified Caregiver Appraisal Scale, MCAS, was validated in a North American sample of carers in TBI (Struchen et al., 2002). It includes scales measuring negative appraisal, perceived burden scale (PBS); positive appraisal, caregiving relationship satisfaction (CRSS); neutral views or beliefs about caregiving, caregiving ideology scale (CIS); and coping in the form of mastery, caregiving mastery scale (CMS). Examples, of an item from each of the subscales of the MCAS, are as follows:

- "I feel isolated and alone as a result of caring for this individual." (Perceived Burden Scale)
- "I really enjoy being with this individual" (Caregiver Relationship Satisfaction Scale)
- "A strong reason to take care of this individual is to be true to family traditions" (Caregiver Ideology Scale)
- "I can take care of this individual with no help – or I could do if I had to" (Caregiver Mastery Scale)

Three of the four subscales were found to have good internal consistency, caregiving mastery being the exception (Struchen et al., 2002). Perceived burden was found to be positively related to the General Health Questionnaire (Goldberg and Hillier, 1979), a measure of psychological pathology (Struchen et al., 2002).

Thus, research has moved to a more theoretically-based model of carer appraisal rather than burden, founded on the transactional theory of stress (Lazarus and Folkman, 1984; Lazarus and Folkman, 1987). Following Struchen et al.'s (2002) validation of the Modified Caregiver Appraisal Scale on a USA sample, it appears quantitative research can now move forward into the exploration of both positive and negative appraising of caring, utilising a theoretically-underpinned instrument.

1.8 Developments of Positive Aspects in Carer Research

Both qualitative and quantitative methods have been employed in other research with carers in TBI to measure perceptions of positive aspects of the caregiving experience (Knight et al., 1998; Machamer et al., 2002). In Knight et al.'s (1998) study, 2/3 of the sample endorsed "always" or "nearly always" enjoying the work of caring on the Care Burden Scale, while qualitative responses included positive comments such as, "It's made me appreciate and love my daughter more..." (p 476). Data from the modified Burden Questionnaire, as reported by Machamer et al. (2002), show that 93% of their sample was happy to have had the opportunity to care for the subject, and 92% felt good about their ability as a caregiver at least some of the time. Moreover, previous research has suggested that existential and stress and appraisal paradigms complement the understanding of the way more difficult aspects of caregiving can co-exist with more positive aspects, including finding meaning (Farran, 1997).

1.9 Meaning in Caregiving

Psychological research has recently begun to focus on the positive side of human nature (Berg-Weger, Rubio and Tebb, 2001; Sheldon and King, 2001). Positive psychology (Seligman and Csikszentmihalyi, 2000; Seligman, 2002; Snyder and Lopez, 2002) is a relatively new movement in psychology. It investigates what makes life worth living by focusing on such things as positive emotions, strengths-based character, and healthy institutions. Seligman has demonstrated that it is possible to be happier, to feel more satisfied, to be more engaged with life, find more meaning, have higher hopes, and probably even laugh and smile more, regardless of one's circumstances (Seligman and Csikszentmihalyi, 2000; Seligman, 2002). More recently, positive psychology has presented a more balanced psychological perspective and has suggested that the focus of research should be on, "...understanding the entire breadth of human experience, from loss, suffering, illness, and distress through connection, fulfillment, health and well-being." (Linley, Joseph, Harrington and Wood, 2006: 6).

Perspectives supportive of the newer meaning of positive psychology have been previously reported. It has been suggested that "difficulties and traumas" of living can facilitate finding deeper meanings in life (Lazarus, 2003; Stroebe, Hansson, Stroebe and Schut, 2001), and may lead to posttraumatic growth (Tedeschi and Calhoun, 2004). Finding meaning in life is particularly adaptive as, "...meaning in life is consistently related to positive mental health outcomes, while meaningless is associated with pathological outcomes." (Zika and Chamberlain, 1992: 135). Indeed, Cohen, Colantonio and Vernich (2002) found that carers of older adults who could not identify positive aspects of caring may be at particular risk for depression and poor health.

Some theorists define meaning in caregiving as, "...positive beliefs one holds about one's self and one's caregiving experience such that some benefits or gainful outcomes are construed from it." (Giuliano, Mitchell, Clark, Harlow and Rosenbloom, 1990: 2). However, Cohen, Pushkar Gold, Shulman and Zucchero (1994) reported that individuals may experience positive and negative reactions in caregiving situations. The meanings found in caregiving have been researched from various perspectives (Noonan and Tennstedt, 1997) using a range of methodologies (Kramer, 1997). Noonan and Tennstedt's (1997) quantitative study of informal carers, of frail elderly people, discovered that meaning was negatively associated with depressive symptoms and positively associated with self esteem. Other theorists developed a questionnaire to measure meaning in carers of people with Alzheimer's Disease which included difficult, loss/powerless, as well as meaningful aspects, provisional meaning, and ultimate meaning of caring (Farran, Miller, Kaufman, Donner and Fogg, 1999). However, it has been suggested that qualitative methods afford more positive responses to the experience of the caregiving process (Reinardy, Kane, Huck, Call and Shen, 1999). Cohen's (1994) study provides support for Reinardy et al.'s (1999) view as 55% of carers in their study could report positive aspects of caring, which were subsequently categorised. Meaningful categories analysed included company, keeping the cared for person at home, duty and love.

No published research has been discovered that analyses meanings, positive or negative, generated by carers in brain injury.

1.10 Personal Construct Psychology

One psychological theory that is very well-equipped to explore idiographic meanings, and to investigate intrapersonal aspects of caring in brain injury, is Personal Construct Psychology (PCP) (Kelly, 1955). PCP was developed as a complete psychology of how people make sense of the world, called construing, in which they live, and allows the discovery of explanations for all behaviours, motivations, learning and experiences within each person (Fransella and Dalton, 2000). The building blocks of PCP are constructs and elements. A construct is a dimension of meaning (Raskin, Weihs and Morano, 2005), but is not the same as thinking (Dalton and Dunnett, 2005). Constructs are bipolar mental structures, as it is only through the knowledge of contrast that experience can be understood (Raskin et al., 2005). Aspects of experience in the form of people, situations and events, that is, what we construe, are known as elements (Dalton and Dunnett, 2005).

Each individual develops a unique construct system, or intrapersonal psychology, and, using the metaphor of "person-as-scientist", experiences are used to predict the future and revise the construct system if it does not explain the experiences (Dalton and Dunnett, 1992). Thus, even if two people seem to have certain similar experiences, such as being a carer, each person's construct system will differ. Furthermore, the construct system is organised in different levels. Thus, constructs that are at a lower level, or are subordinate, in the construct system are more concrete, while constructs at the top of the system can be said to be superordinate and are more abstract (Dalton and Dunnett, 2005). Superordinate constructs are more central to an individual's value system. Personally meaningful constructs which we apply to ourselves (Butler and Green, 1998), and which are most central to our survival, are termed core constructs (Walker and Winter, 2005).

There are also different levels of awareness in a personal construct system (Fransella and Dalton, 2000). As such, an individual is not aware of all constructs in his system, and may act in a certain way without understanding the reason for it (Dalton and Dunnett, 1992). For example, a carer may find a particular aspect of her brain-injured husband's behaviour off-putting without understanding why, or may feel fulfilled without being aware that she is construing a sense of spiritual meaning in the process.

1.10.1 Psychological Difficulties and Relevant Research

The theory postulates that psychological difficulties may develop due to the structure and content of an individual's construct system (Winter, 2003). For example, people who become depressed have been found to construe tightly (Winter, 1992). It may be that carers in brain injury who become depressed also construe tightly, or, perhaps, having a tightly organised construct system is mediated by appraisal of caring that is negative, and leads to depression. Winter (2003) states that individuals with tight unidimensional construct systems may feel threatened by re-construing their system as it would involve change in their core constructs; core constructs holding particular importance for individuals (Jankowicz, 2004). Indeed, Winter (1992) suggested depression or anxiety could result from a failure to revise constructions in response to invalidation. Following this thesis, an example could be that a carer who construes tightly may feel threatened and unable to change if a core construct, such as being the partner who is cared for, is challenged by becoming a carer in brain injury.

Content of the construct system is also crucial. Drysdale's (1989) work on people experiencing acute and chronic pain discovered that people with chronic pain generated fewer emotional constructs than those with acute pain. The content of the construct system can be utilised in other ways. For example, a measure of self-esteem can be derived from the content of the construct system and has been found to be associated with psychological well-being; low self-esteem having been shown to be related to depression (Button, 1994). Research that looked at the content of the construct system of significant others in acquired brain injury was undertaken by Winter, Metcalfe and Shoeb (1997). They established that the way in which significant others of someone with a brain injury construed them was implicated in their rehabilitation outcome. A key finding was that if the person with a brain injury were perceived favourably before the injury, and positive expectations were held for him/her post-rehabilitation, he/she had better rehabilitation outcomes.

According to Personal Construct Psychology, dilemmas can occur in the construct system (Feixas and Angel Saul, 2005). For example, if in an individual's construct system, the symptomatic pole on one construct is related to the preferred pole on one or more constructs, movement away from construing oneself as symptomatic could lead to construing oneself in negative ways on other constructs (ibid.). For example, if in a carer's construct system "depressed" and "compassionate" were related, re-construing oneself at the carer's opposite pole of depressed could also lead to construing oneself in a way that could be negative, for example “unfeeling”, and contrary to the individual’s core constructs. Thus, various psychological difficulties can be discovered from the exploration of construct systems.

1.10.2 Repertory Grid Methodology

Kelly devised the Repertory Grid Technique as a method for exploring personal construct systems (Fransella, Bell and Bannister, 2004). It is a form of structured interview which arrives at a precise description uncontaminated by the interviewer’s own viewpoint (Jankowicz, 2004), and is used to elicit a person’s construct system around a particular area of interest.

Repertory Grids have been used in research on topics including stroke (Skelley, 2002), paid carers of elderly people (Cooper and Coleman, 2001), chronic pain (Drysdale, 1989), amputation (Fisher, 1985), psychiatric disorders (Winter, Goggins, Baker and Metcalfe, 1996) and learning disability (Hare, 1997). In research on brain injury, this method has been used to look at the relationship between the construct systems of significant others and the outcome of rehabilitation for the people with acquired brain injuries (Winter et al., 1997), and the relationship between the construct systems of partners of those with an acquired brain injury and marital satisfaction (Tyson, 2003). Tyson’s (2003) primary findings were that marital satisfaction was higher where the “partner now” was construed as being more similar to a “healthy person” (in spite of their head injury), and that marital satisfaction was higher where the partner as perceived “in three years” time was construed as being similar to an “ideal partner”.

Repertory grids, as other methods of measuring constructs, can be analysed to generate subjective meanings (Jancowicz, 2004; Marsden and Littler, 2000). Tyson’s (2003) study generated meaningful categories of the constructs of partners of people with brain injury. However, none of the categories developed appeared to reflect positive meanings.

No published research has used repertory grid technique in research on caring in brain injury.

1.11 Summary

Lack of clarity exists around the definitions of carer and brain injury which may make research findings hard to interpret. However, it is apparent that multiple neurobiological, cognitive and psychosocial changes can take place once someone has acquired a brain injury, and, if a carer is required, family members usually take on the informal caring role. Some research has described carers of those with a TBI as being at risk of becoming "hidden patients" (Jones, 1996), and many TBI carers have been shown to experience negative effects while in a caring role, including anxiety (Livingstone et al., 1985a,b) and depression (Harris et al., 2001).

Various theoretical models have been proposed to account for the process of family adjustment to TBI (Lezak, 1986; McCubbin and McCubbin, 1991). More recently the concepts of appraisal and meaning have been considered with regard to this process (Kosciulek, McCubbin and McCubbin, 1993). The topic of carer burden is an area of research that has also been conducted in the area of family carers in TBI (Allen et al., 1984; Knight et al., 1998; Machamer et al., 2002). Subjective carer burden (SCB) has been found to be related to many factors in carers in TBI, including behavioural problems in the brain injured person (Marsh et al. (1998a; 1998b). SCB has also been found to be related to depression in carers in TBI (Machamer et al., 2002). Moreover, research looking at the relationship of the carer to the traumatically brain injured person has found that partners who are carers may experience more subjective burden and be more depressed than carers who are parents (Gervasio and Kreutzer, 1997; Minnes et al., 2000).

However, not all families or carers experience psychosocial adversity. It therefore seems an empirical omission has been research exploring intrapersonal factors related to subjective carer burden and psychological distress in carers in brain injury. Moreover, measures used to assess subjective carer burden in TBI have been largely atheoretical (Chwalisz, 1992), and have failed to acknowledge the finding that many carers perceive positive aspects in their experience (Knight et al., 1998). Developments in the area of subjective carer burden have included researching transtheoretical models of stress with carers in TBI (Harris et al., 2001; Struchen et al., 2002). However, only Struchen et al. (2002) have utilised a measure of carer appraisal, MCAS, developed and validated for carers in brain injury. The MCAS has not, however, been tested on a UK sample.

Kramer (1997) stated that a "Lack of attention to the positive dimension of caregiving seriously skews perceptions of the caregiving experience and limits our ability to enhance theory of caregiver adaptation." (p 218). Research on this topic has focused on the meanings carers, primarily of those with dementia, have generated in relation to their experience (Cohen et al., 2002; Hollis-Sawyer, 1998; Noonan and Tennstedt, 1997). This research has focused on positive and negative meanings generated in caring, reflecting the newer focus of positive psychology (Linley at al., 2006). However, the search for meaning in caregiving has not extended into caring in brain injury.

Personal construct psychology affords an understanding of the unique, intrapersonal, construct systems through which the world is construed and meaning is made by individuals (Fransella and Dalton, 2000). Structure of the construct system has been linked to depression and anxiety (Winter, 2003), and construct system content has been found to be related to relationship satisfaction (Tyson, 2003) and rehabilitation outcomes (Winter et al., 1997) in acquired brain injury. The idiographic meanings in an individual's construct system can be derived by analysis of repertory grid data (Jancowicz, 2004; Marsden and Littler, 2000). No published research has been discovered that has used the repertory grid technique in research on caring in brain injury.

1.12 Research Plan and Aims

This research will utilise a theoretically based questionnaire, previously untested in a UK population, of the experience of caring, positive and negative, and relate it to psychological distress and how carers in acquired brain injury can make sense of the experience of caring. It is hoped the inclusion of Personal Construct Psychology will provide an idiographic, intrapersonal understanding of the role of carers in brain injury and establish the kind of personal meaning that can be found in the role of a carer.

Thus, the research aims are:

1. To test the Modified Caregiver Appraisal Scale (MCAS) on a UK population of carers in acquired brain injury to:

(i) establish whether the Modified Caregiver Appraisal Scale has the same scale properties in a UK sample of carers as were found in the TBI USA sample.

(ii) establish whether the MCAS can be used clinically to evaluate how UK carers in brain injury appraise their situation, and which of them are at risk of experiencing psychological distress.

2. To utilise Personal Construct Psychology to explore the relationship between the intrapersonal construct systems of people who care for someone with a brain injury, and how they experience, or appraise, caring.
3. To explore how personal construct systems, and the appraisal of caring, relate to psychological distress, in the form of depression and anxiety.
4. To explore the meanings that carers attribute to caring for someone with a brain injury via the analysis of their construct systems.
Specific quantitative hypotheses to be tested are:

1. There will be positive associations between:

    - Severity of cognitive problems in the brain injured person
    - Severity of behavioural problems in the brain injured person
    - Perceived burden

2. There will be positive associations between:

    - Tightness of construing
    - Perceived Burden
    - Depression
    - Anxiety

3. Carers who are partners will:

    - Perceive more burden than parental carers
    - Be more depressed than parental carers
    - Be more anxious than parental carers

4. Carers who construe:

    - they have changed more from pre to post injury will be more burdened
    - the brain injured person has changed more from pre to post injury will be more burdened

- the brain injured person has changed more from pre to post injury will score higher on caregiving ideology
- a greater difference between themselves now and the brain injured person now will be more burdened
- a greater difference between the brain injured person now and how the carer would ideally like them to be will be more burdened
- a greater difference between the brain injured person in 5 years time and how the carer would ideally like them to be will be more burdened
- a greater difference between the brain injured person and a healthy person will be more burdened
- a smaller difference between the brain injured person in 5 years time and how the carer would ideally like them to be will have greater caregiving relationship satisfaction
- a smaller difference between the brain injured person and a healthy person will have greater caregiving relationship satisfaction
- themselves now as more similar to their ideal self will have a higher level of mastery

Qualitative aspects of the study are:

5. Content analyses of core constructs generated. From this process, themes reflecting meaning given to the role of caring now will be established.

6. Individual case studies to elaborate meaning further will also be undertaken.

2.0 Method

2.1 Design

The study has a non-experimental, non-randomised, cross-sectional design. The cross-sectional design permitted participants who had been primary carers, for those with an acquired brain injury, for different periods of time to be included in the study.

2.2 Participants

2.2.1 Target Population

The target population comprised those who defined themselves as the primary unpaid carers of someone with an acquired brain injury. It was decided that the sample populations should be drawn from:

- National Health Service Specialist Brain Injury Services
- Headway, the national UK charitable organization for people with an acquired brain injury and their families.

Given problems encountered recruiting adequate participants for studies involving families of those with acquired brain injuries, hosted by the local Regional Brain Injury Rehabilitation Unit, it was hoped that expanding the target population would maximize the sample size.

2.2.2 Sample Population

The sample population comprised carers of outpatients of an NHS Regional Brain Injury Rehabilitation Unit between October 2004 and October 2005. The unit comprises a 15-bedded inpatient unit, and an outpatient service. It has a multi-disciplinary staff team composed of clinical and research psychologists, neuropsychiatrists, occupational therapists, physiotherapists, speech therapists and mental health nurses.

The sample population also comprised carers recruited from Headway. "Headway: the brain injury association" helps people understand about brain injury and provides information, support and services to people with a brain injury, their family and carers (Headway website, 2005). A registered charity, Headway has a network of 110 branches across the UK.

Headway Centres, which provide rehabilitation for brain injured people and respite for families and carers, operate in 60 of the 110 branches. The two Headway branches which participated in the research were Headway Centres. One of the Headway branches was staffed by paid staff including a social worker, two support workers, a manager and a family support worker. The other Headway branch was voluntarily staffed by carers of those with a brain injury, with one paid part-time administration assistant.

2.2.3 Inclusion and Exclusion Criteria

Inclusion Criteria

Carers aged 18 years or older were included as the evidence base reviewed (Harris et al., 2001; Knight et al., 1998; Struchen et al., 2002.) focused on adult carers. Based on published research (Ergh et al., 2003; Machamer et al., 2002; Perlesz, 2000; Sander et al., 1997), primary unpaid carers do not necessarily have to live with the brain-injured person, nor be related to him/her. The primary inclusion criterion was that the carer identified him or her self as taking the most responsibility for being "active" in the brain injured person's life, providing care and support. Moreover, participants were required to have known the brain-injured person since before the injury due to the requirements of the repertory grid interview.

Exclusion Criteria

Carers from families who were known to be coping with an acute crisis were not contacted. As the researcher met with the majority of participants in their own homes, families in which there was a potential known risk to others were also excluded from the study. Carers who were not fluent in English were also excluded as the Modified Caregiver Appraisal Scale (Struchen et al., 2002) questionnaire had not been validated on people who speak other languages. Moreover, there was no funding available for translators for this study.

2.3 Recruitment Process

2.3.1 Brain Injury Rehabilitation Unit

Liaison took place with the Consultant Clinical Psychologist and Associate Clinical Scientist, field supervisor for the study, throughout the duration of the study between April 2003 and December 2005. The researcher reviewed current inpatient files between October 2004 and October 2005. Information regarding whether the patient had an unpaid primary carer was gathered. A list of potential participants was compiled and reviewed by the Consultant

Clinical Psychologist, Associate Clinical Scientist and, where appropriate, the multidisciplinary team. Participants who should not be contacted, such as those currently experiencing a crisis or relationship problems, were removed from the list. Those carers who lived too far from the Brain Injury Rehabilitation Unit (BIRU) to be visited at home were excluded from the list at this point also. This process was undertaken three times between December 2004 and October 2005. In total, a list of 37 carers who could be approached was compiled. In September and October 2005, the researcher also attended five outpatient clinics at the BIRU and approached four carers of new patients to see if they wished to participate in the study.

Invitation letters (appendix 1), information sheets (appendix 2) and consent forms (appendix 3) were posted to the 37 selected carers, and handed out to carers approached at the outpatient clinics. Carers who did not wish to be contacted about the study were asked to contact the BIRU within a given a three-week opt-out period.

2.3.2 Headway 1 – Voluntarily Staffed by Carers

A representative of voluntary staff at Headway was the person with whom liaison took place during the study. The researcher met with the staff member to explain the study. Subsequent to this meeting the staff member presented the study to the Headway Centre committee to seek approval for the researcher to approach carers at Headway. Following committee approval, the researcher attended three carer support meetings, between October 2004 and April 2005, to hand out information sheets (appendix 2) and consent forms (appendix 3) and answer any questions carers had about the study. The researcher also gave a presentation about the research study at a Headway meeting, for those with a brain injury and their families, in November 2004. At this meeting, the researcher also handed out information sheets and consent forms and answered any questions attendees had about the research. In total, 40 carers were approached.

Carers who wished to participate in the study contacted the researcher directly, or via the liaison member of staff, and provided contact details for the researcher to phone them to arrange participation. The researcher maintained phone and e-mail contact with the liaison staff member throughout the study.

2.3.3 Headway 2 – Staffed by Employees

The researcher undertook three meetings with the family support worker and manager between October 2004 and December 2004 to discuss the study and potential carer participation. A meeting in December 2004 took place that also included two support workers. The process was very thorough owing to previous negative experiences the Centre had with research undertaken by a psychology service, and experiences of supporting carers who were at risk due to mental health problems. In particular, concerns that carers were emotionally very burdened, and therefore had to be selected carefully and to be well supported, were considered of paramount importance. In January 2005, at a convenient point for this Headway branch, 20 carers who had been selected by the staff team were given information sheets (appendix 2), consent forms (appendix 3) and invitation letters (appendix 4) by a member of staff. Carers who were interested in participating contacted the family support worker or manager, and provided contact details for the researcher to phone them to arrange participation. The researcher maintained phone and e-mail contact with the manager in January and February 2005. The family support worker left her role in January and was not replaced. The Headway Centre thought it was necessary to have a family support worker in post if further recruitment was to take place. Given the absence of a family support worker, recruitment at this centre ceased.

2.4 Measures

2.4.1 Demographic and Injury-Related Information

Demographic information, including age, sex, ethnicity and occupation, was collected for the participants. Details of the age and sex of the brain-injured person were collected. Information about time since injury; length of time the participant had been the primary carer; relationship to the person with the brain injury; whether the participant lived with the person with a brain injury; and how long they spent each week caring for the person were also collected. Severity and aetiology of the injury were also included.

2.4.2 Health of the Nation Outcome Scales for Acquired Brain Injury (Fleminger and Powell, 1999)

The Health of the Nation Outcome Scales for Acquired Brain Injury (HoNOS-ABI) is a 12-item outcome measure for acquired brain injury, adapted by Fleminger and Powell (1999) but not published (Coetzer and Du Toit, 2001). Information can be gathered from medical notes or carers. Items are measured on a 5-point scale from 0 (no problem) to 4 (severe to very severe problem). Two of the items from the HoNOS-ABI were used to measure cognitive and behavioural problems in the brain injured person. Demographic information and the two items from HoNOS-ABI were collated into a questionnaire (appendix 5).

The strength of using the two HoNOS-ABI items is that they had been developed specifically for this population to be rated by carers. Moreover, they are brief to complete. The limitations are that the scale has not been validated and is not being used in its entirety in this study.

2.4.3 Modified Caregiver Appraisal Scale (Struchen et al., 2002)

The Modified Caregiver Appraisal Scale, MCAS, (appendix 6) is a 41-item self-report questionnaire measuring appraisal of caregiving in brain injury. It is measured on a 5-point likert rating scale from "strongly disagree" to "strongly agree". Scores range from 4 to 20 on the smallest subscale (caregiving mastery scale), and 15 to 75 on the largest (perceived burden scale). Higher scores denote more positive caregiving appraisals. The questionnaire is an augmented version of the 35-item Caregiver Appraisal Scale (Struchen et al., 2002) which was found to comprise four factors, or subscales.

The strength this scale is that it has been validated on a sample of carers in brain injury and is theoretically based in a Stress and Coping (Lazarus and Folkman, 1984) model. It has also been found to have good internal consistency on three of the subscales (0.7-0.91), and has been increased to provide better internal consistency on the caregiving mastery scale (CMS) (0.52) (Struchen et al., 2002). The limitations of the scale are that it has not been widely tested, and has poor internal consistency on the CMS subscale.

2.4.4 Beck Depression Inventory – II (Beck, Steer and Brown, 1996)

The Beck Depression Inventory-II, BDI-II, (appendix 7) is a 21-item self-report questionnaire used to measure severity of depression in adults and adolescents aged 13 years and older. Respondents endorse one statement out of four for each item. Scores range from 0-63, with higher scores denoting greater levels of depression.

The BDI-II's strengths are that it has been found to have good psychometric properties (Beck et al., 1996) and it has also been validated on a non-clinical sample (Osman et al., 1997). However, the BDI-II has limitations as self-report questionnaires are not diagnostic measures.

2.4.5 Beck Anxiety Inventory (Beck and Steer, 1993)

The Beck Anxiety Inventory, BAI, (appendix 8) is a 21-item self-report questionnaire used to measure severity of anxiety in adults aged 17 or older. Items are measured on a 4-point rating scale from "not at all" to "severely". Scores range from 0-63, with higher scores denoting greater levels of anxiety.

The BAI has been found to have good psychometric properties (Hewitt and Norton, 1993). It has also been validated on a non-clinical sample (Creamer, Foran and Bell, 1995). However, the BDI-II has limitations as self-report questionnaires are not diagnostic measures.

2.4.6 Repertory Grid Technique (Kelly, 1955)

The repertory grid technique (RGT) is a structured interview. The grid is used to elicit an individual's personal construct system around a specific topic (Jancowicz, 2004), in this case the experience of caring as perceived by carers in brain injury. Twelve elements, or examples of a particular topic (ibid.), are provided:

- carer before brain injury
- carer now
- carer in 5 years' time
- carer as ideal self
- typical person with a brain injury
- typical healthy person
- typical person with a mental health problem
- typical person with a physical disability
- brain-injured person before the injury
- brain-injured person now
- brain-injured person in 5 years' time
- how carer would ideally like brain-injured person to be

Constructs are then elicited by using the triadic method where three elements are presented to the participant on cards and the participant construes a way in which two of them are the alike and different from the third (Fransella et al., 2004). The opposite method (Epting, Suchman and Nickeson, 1971) is then used to elicit the contrast pole, or opposite, of the construct; all constructs being bipolar (Kelly, 1955). Thus, participants are asked for the opposite of the alikeness they have construed. In this study ten constructs were elicited in total.

These two poles of the construct become the endpoints for a 7-point rating scale, for example, **thoughtful** (1)......(2)......(3)......(4)......(5)......(6)......(7) **selfish**, and the participant then states which value each element accords on the scale. An example of a completed repertory grid can be found in appendix 9.

Once the RGT has been completed, the structure and content of the repertory grid can be examined. The structure of an individual's construct system can be derived from the percentage of variance accounted for by the first principal component. The higher the amount of variance accounted for by the first component, the less flexible the construct system. Ryle and Breen (1972) state that tight construct systems are ones in which the principal component accounts for more than 40% of variance.

Content of the construct system can be investigated using several methods, including looking at distances between elements. Distances between elements range from 0 to 2. A score of 0 denotes that the participant considers the elements to be identical to each other, while the larger the distance between elements, the more dissimilar they are construed to be. Makhlouf-Norris and Norris (1973) state that distances below 0.8 are considered to indicate elements that are construed as being similar, while distances above 1.2 denote elements that are construed as dissimilar. Inter-element distances of between 0.8 and 1.2 show the elements are being construed as neither particularly similar, nor dissimilar.

The RGT has several strengths. It is a reliable and valid research instrument (Winter, 2003), despite its idiographic nature (Feixas, Proctor and Neimeyer, 1993). Reliability and validity can also be increased by standardising administration procedures (Button, 1985), as was done in this study (appendix 10). The RGT is also a flexible method providing quantitative and qualitative data. Moreover, it affords the opportunity to discover participants' own meanings and perspectives by eliciting their own constructs and rating them on a 7-point scale rather than being asked predetermined questions with a forced choice format (e.g. Beail, 1985). Limitations of the RGT include the time required for administration and interpretation, and the idiosyncratic nature of it which may make it difficult initially for participants to comprehend (Tyson, 2003).

2.5 Power Calculation for Required Sample Size

As research combining repertory grids and caregiver appraisal has not been undertaken previously, it was not possible to do a power calculation for this part of the study. However, prior research (Struchen et al., 2002) suggests that measures of negative appraisal of caregiving in brain injury are positively correlated with measures of depression in the order of $r = 0.50$. Following a power calculation, it was established that a sample of 24 would be required to detect a correlation of this size with an alpha error of 5% (one-tailed) and a power of 0.8 (Cohen, 1992).

2.6 Procedure

2.6.1 Brain Injury Rehabilitation Unit

Following the opt-out period, those carers who had not opted out were contacted by the researcher by phone and asked if they had received the invitation letter, information sheet and consent form. Any questions the carer had about the study were answered and the decision whether to participate was made.

For all the BIRU participants recruited, a convenient time and location for the carer to participate in the research interview was arranged during the phone call. The three research questionnaires (MCAS, BDI-II, BAI) were posted to the participant's home approximately six days before this meeting with a covering letter (appendix 11). The questionnaires were coded to ensure anonymity and confidentiality. Contained within the letter was a contact number for the carer to make contact with the researcher should he/she have any queries about the research materials before the meeting.

All carers chose to have the research interview conducted in their homes. The interviews took place between February and November 2005. During the interview with the participant, the demographic and injury-related information was gathered and the repertory grid completed. Interviews took between one and three hours. Any questions or issues that had arisen from questionnaire completion were also addressed at this time. The questionnaires were checked to ensure all questions had been answered and to ascertain that current risk, for example suicidal intentions, had not been endorsed.

Two carers said they wanted to participate in the main study, but could not do so due to various reasons such as being unable to take time off work. One participant could no longer complete the main study owing to a change in personal circumstances. These carers completed the Modified Caregiver Appraisal Questionnaire (Struchen et al., 2002) and demographic and injury-related information only. They are described throughout the thesis as the "questionnaire participants" to distinguish them from the "main grid study" participants.

2.6.2 Headway 1

The researcher phoned the carers who had agreed to participate in the study. Any questions the carer had about the study were answered. Time and location to meet with the participant were arranged as per section 2.6.1 for the BIRU. Preparation and posting of research materials were also as section 2.6.1.

The majority of research interviews took place in the Headway Centre, though one carer chose to have the research interview conducted in her home. The interviews took place between November 2004 and April 2005. Interviews took between one and a quarter and three hours. Any questions or issues that had arisen from questionnaire completion were addressed at this time. The questionnaires were checked to ensure all questions had been answered and to ascertain that current risk, for example suicidal intentions, had not been endorsed.

2.6.3 Headway 2

As Headway 2 did not think it advisable for the full research study to continue without a family support worker in post, the three carers who had offered to participate in the study were asked to complete the Modified Caregiver Questionnaire (Struchen et al, 2002) and the demographic and injury-related information only.

2.7 Participant Numbers

2.7.1 Brain Injury Rehabilitation Unit

Eight participants completed the main grid study and a further three completed the Modified Caregiver Questionnaire (Struchen et al, 2002) and the demographic and injury-related information.

2.7.2 Headway 1

Five participants completed the main grid study.

2.7.3 Headway 2

No participants completed the main grid study. Three participants completed the Modified Caregiver Questionnaire (Struchen et al, 2002) and the demographic and injury-related information.

2.8 Ethical Considerations

The choice of an opt-out procedure for recruitment from the BIRU could be seen as ethically contentious. However, it had been successfully used within two previous studies hosted by the BIRU with no apparent problems for participants. An application for ethical approval for this study using the COREC process was given a favourable opinion in September 2004 by Camden and Islington Ethics Committee (appendix 12).

It was important for trusting relationships to be built with the recruitment centres involved and, in particular, the Headway Centres which had no other connection to the study. From an ethical perspective it was of paramount importance that the recruitment centres were aware the role of the researcher was not a clinical one. As such, should any participants be found to require psychological support or intervention, the researcher would support access to appropriate services, but would not be providing therapeutic input herself.

It was recognised that some of the participants might be clinically depressed and/or clinically anxious. Moreover, the experience of reflecting on their appraisals of caring and emotions might prove distressing. Furthermore, given the nature of the repertory grid interview, in which aspects of construing out of awareness might become apparent (Kelly, 1955), it was important to design the study in such a way as to minimise the risk of carer distress and provide suitable support as required.

The ethical issues were addressed via the following steps:

- The invitation letter from the BIRU provided the opportunity to opt-out and not be contacted by the researcher
- As participants from Headway opted in, they were not contacted unless they had opted in
- The information sheet was clearly and comprehensively written to enable participants to decide whether they wished to take part in the study and be able to provide informed consent
- If participants from the BIRU did not opt-out, it was possible to opt-out at the initial contact phone call by the researcher
- The information sheet and consent form clearly stated that discontinuing at any point in the research process was possible without prejudicing the carer's or brain-injured person's NHS care or legal rights
- Questionnaires were posted to participants in the same week as the meeting with the researcher to allow any concerns to be discussed promptly
- The available counselling and mental health services in the localities were identified to allow prompt contact if required
- A contact number for the researcher was included on the information sheet and letter sent out with the questionnaires to enable the participant to leave a message for the researcher should he/she be distressed by the study at any point in the process
- The needs of carers recruited via the BIRU who were thought to be in need of psychological intervention could, with their consent, be discussed with the BIRU Consultant Clinical Psychologist
- Carers recruited via Headway 1 were interviewed in the Headway centre in order for there to be support available and to minimise risk for the researcher, who had little knowledge of the participants and the brain-injured people for whom they cared
- Carers recruited via Headway who were thought to be in need of psychological intervention could, with their consent, be discussed with the researcher's principal supervisor, a head of a clinical psychology service

Confidentiality is an essential aspect of the research process and integral part of informed consent. To enable confidentiality, various steps were implemented:

- The identity of research participants in the BIRU was known only to the researcher and her field supervisor based in the BIRU
- The identity of the participants recruited via Headway was only known to the researcher
- All data were anonymised on data entry and thesis write-up, with only the researcher having access to the data

Personal safety for the researcher was also a concern as she would be going on her own to participants' homes. In line with the host Trust's "lone-worker policy", the researcher's location was known by one of her supervisors with an approximate time of interview completion. The researcher then contacted the supervisor to inform him/her that the meeting was complete.

2.9 Data Handling and Analysis

2.9.1 Data Handling

A numerical coding system was developed by the main researcher in anticipation of data entry. All research materials were kept in a locked filing cabinet to which only the researcher had access.

2.9.2 Data Analysis

Data analysis was carried out using SPSS (version 11.5 for windows) and Flexigrid 6 (Tschudi, 1998) computer programmes. An initial SPSS database was constructed to include demographic and injury related information as well as all questionnaire data and measures extracted from Flexigrid analysis of the repertory grids.

2.9.2.1 SPSS Analyses

SPSS was used to undertake initial descriptive data analyses. Subsequent non-parametric bivariate correlational analyses and independent-groups analyses were used to test research hypotheses.

2.9.2.2 Flexigrid Analyses

Relationships between constructs and elements were analysed to ascertain the content and structure of participants' construct systems. This was done via Flexigrid, which performs a variety of different analyses. The following analyses will be considered in this thesis:

- Percentage variance accounted for by first component of principal component analysis

- Element distances between:

i. Carer before brain injury – Carer now
ii. Brain injured person before brain injury – Brain injured person now
iii. Carer now – Brain injured person now
iv. Brain injured person now – Brain injured person as Ideal
v. Brain injured person in 5 yrs – Brain injured person as Ideal
vi. BI person now – Healthy person
vii. Carer now - Carer as Ideal Self

- Dilemmas

Principal Components Analysis

Principal components analysis (PCA) is a mathematical procedure which provides a way of identifying patterns in data. In repertory grid data, PCA is purported to give a representation of the structure of the grid. Thus, correlated constructs are reduced to a smaller number of uncorrelated variables called principal components. The first principal component accounts for as much of the variability in the grid data as possible, and each succeeding component accounts for as much of the remaining variability as possible. The variance accounted for by the first principal component is assumed to measure the tightness (or rigidity) of the construct system.

Flexigrid provides a pictorial representation of the grid by plotting the loading of elements and constructs on the first component against those on the second component. Additionally, loadings on the first or second component can be plotted against those on the third, and so on. The number of components to extract is determined from inspection of the scree plot, although Tschudi (1998) has suggested that no satisfactory solution to this problem exists. However, it is generally found that the vast majority of the variance is accounted for by the first two components, and it has been suggested that examining the components that, between them, account for 80% of the variance is an adequate solution (Jankowicz, 2004).

Inter-elements Distances

Distances between elements, known as inter-element distances are calculated by a Euclidean formula, higher distances indicating that the elements concerned are construed as less similar to each other.

Dilemmas

Statistical correlations between constructs are assumed to reflect the psychological relationships between them. When a positively evaluated pole of one construct is found to be related to the negatively evaluated pole of another construct, this is known as a dilemma.

2.9.2.3 Qualitative Analysis

Content analysis was used to identify meanings and themes inherent in participants' construct systems to gain a more elaborate understanding of the experiences of carers.

2.9.2.4 Individual Case Examples

Individual case examples focusing on grid plots were developed to explore carer meanings and to identify carers' experiences such as dilemmas (Feixas and Angel Saul, 2005).

2.10 Feedback to Participants

As indicated in the information sheet (appendix 2), an anonymised summary of the study findings will be sent to all participants on successful completion of the study.

3.0 Results

3.1 Results Overview

This chapter comprises four sections. The first section, 3.2, focuses on sample description, including characteristics of the brain injured cohort. The second section, 3.3, addresses descriptive statistics of the research measures, and the third section, 3.4, tests the research hypotheses utilising non-parametric data analysis. As certain hypotheses were tested with the complete sample (N = 19) and repertory grid hypotheses were tested in a smaller sample (N = 13), sections 3.2 to 3.4 report data for separate samples where appropriate. In the final section, 3.5, the qualitative component of repertory grids will be explored via content analyses, and individual case examples presented which include grid plot exploration.

3.2 Sample Description

As described in Table 1, 13 participants completed the main grid study, 10 of whom were female and three of whom were male. A further six participants, two male and four female, completed the questionnaire part of the study, totalling 19 participants in the complete sample. The average age of participants was 52 years for both the main study participants (range 34 – 61) and for the complete sample (range 34 – 63).

In terms of ethnicity, all of the participants in the main grid study (100%), and the majority of the complete sample (89.47%), were classified as white European. One participant who completed the questionnaire part only was "Black/Black British" and another one was of "Mixed Heritage". Approximately half of the participants for the main grid study were parents (46.15%) and approximately half were partners (53.85%). In the complete study, the proportion of partners (63.16%) to parents (36.84%) was approximately 2:1. More participants were recruited from the NHS brain injury rehabilitation unit for both the main grid study (61.54%) and the complete study (57.89%) than from Headway (38.46% main grid study; 42.11% complete study).

Table 2 describes the sample characteristics of the brain injured cohort as reported by carers. Participants were interviewed, on average, 41 months (3 years 5 months) after the brain injury had occurred in the main grid study, and 51 months (4 years 3 months) after the injury in the complete sample. However, there is a large range both in the main grid study (5 – 162 months) and the complete sample (5 – 199 months). The majority of the brain injured cohort is male in both the main grid study (76.92%) and the complete sample (68.42%). The mean age of the cohort is younger than for the carers at 40 years for the main grid study (range 20 – 66 years) and 42 years for the complete sample (range 19 – 69). In relation to ethnic origin, the brain injured cohort for the main grid study is all white European (100%), while the majority of the complete sample is also white European (94.74%). Cause of injury in the main grid study was predominantly traumatic brain injury (76.92%), with road traffic accidents accounting for nearly 2/3 of all brain injuries (61.54%) and 80.00% of traumatic brain injuries. In the complete sample the majority (68.42%) of brain injuries were also traumatic brain injuries. Based on length of time unconscious, the majority of brain injuries in the main grid study were very severe (76.92%), and the majority of brain injuries in the complete sample were severe – very severe (68.42%); missing data from two questionnaire only participants means 10.53% of data is missing for this variable. Carers reported the majority of the brain injured cohort to experience minor or mild cognitive problems in both the main grid study (76.93%) and the complete sample (73.68%). Behavioural problems ranging from minor to moderate were reported as 76.92% in the main grid study and 63.15% in the complete sample.

Table 1. Demographic Variables of Carers Divided by Degree of Participation

	Main Grid Study	**Questionnaire Participants**	**Complete Sample**
Gender			
Male	3 (23.08%)	2 (33.33%)	5 (26.32%)
Female	10 (76.92%)	4 (66.67%)	14 (73.68%)
Age			
Mean (SD)	51.62 (8.14)	54.33 (7.15)	52.47 (7.75)
Min – Max	34 - 61	42 - 63	34 - 63
Ethnicity			
White European	13 (100.00%)	4 (66.67%)	17 (89.47%)
Other Ethnicity	0 (0.00 %)	2 (33.33%)	2 (10.53%)
Relationship			
Parent	6 (46.15%)	1 (16.67%)	7 (36.84%)
Partner	7 (53.85%)	5 (83.33%)	12 (63.16%)
Sample Source			
NHS BIRU	8 (61.54%)	3 (50.00%)	11 (57.89%)
Headway	5 (38.46%)	3 (50.00%)	8 (42.11%)
Total Sample	N = 13 (68.42%)	N = 6 (31.58%)	N = 19 (100%)

Table 2. Demographic and Injury Related Variables of Brain Injured Sample

	Main Grid Study	**Questionnaire Participants**	**Complete Sample**
Time Since Injury (Months)			
Mean (SD)	55.92 (40.89)	109.17 (55.14)	72.74 (51.05)
Min – Max	5 - 162	44 - 199	5 - 199
Gender			
Male	10 (76.92%)	3 (50.00%)	13 (68.42%)
Female	3 (23.08%)	3 (50.00%)	6 (31.58%)
Age			
Mean (SD)	40.23 (18.02)	47.80 (19.36) (n = 5)	42.33 (18.15) (n = 18)
Min – Max	20 - 66	19 - 69	19 - 69
Ethnicity			
White European	13 (100.00%)	5 (83.33%)	18 (94.74%)
Other Ethnicity	0 (0.00%)	1 (16.67%)	1 (5.26%)
Cause of Injury			
Road Traffic Accident (TBI)	8 (61.54%)	0 (0.00%)	8 (42.10%)
Fall/Assault (TBI)	1 (7.69%)	2 (33.33%)	3 (15.79%)
Anoxia (cardiac arrest/surgery) (ABI)	1 (7.69%)	2 (33.33%)	3 (15.79%)
Leisure Activity (TBI)	1 (7.69%)	1 (16.67%)	2 (10.53%)
Aneurysm/Haemorrhage (ABI)	0 (0.00%)	1 (16.67%)	1 (5.26%)
Other (ABI)	2 (15.39%)	0 (0.00%)	2 (10.53%)
Injury Severity			
Minor	3 (23.08%)	1 (16.67%)	4 (21.05%)
Moderate	0 (0.00%)	0 (0.00%)	0 (0.00%)
Severe	0 (0.00%)	1 (16.67%)	1 (5.26%)
Very Severe	10 (76.92%)	2 (33.33%)	12 (63.16%)
Unknown or Missing	0 (0.00%)	2 (33.33%)	2 (10.53%)
Cognitive Problems			
None	1 (7.69%)	1 (16.66%)	2 (10.53%)
Minor	6 (46.16%)	3 (50.00%)	9 (47.37%)
Mild	4 (30.77%)	1 (16.67%)	5 (26.31%)
Moderate	1 (7.69%)	1 (16.67%)	2 (10.53%)
Severe	1 (7.69%)	0 (0.00%)	1 (5.26%)
Behavioural Problems			
None	3 (23.08%)	4 (66.66%)	7 (36.85%)
Minor	4 (30.77%)	1 (16.67%)	5 (26.31%)
Mild	4 (30.77%)	1 (16.67%)	5 (26.31%)
Moderate	2 (15.38%)	0 (0.00%)	2 (10.53%)
Severe	0 (0.00%)	0 (0.00%)	0 (0.00%)
Total Sample	N = 13	n = 6	N = 19

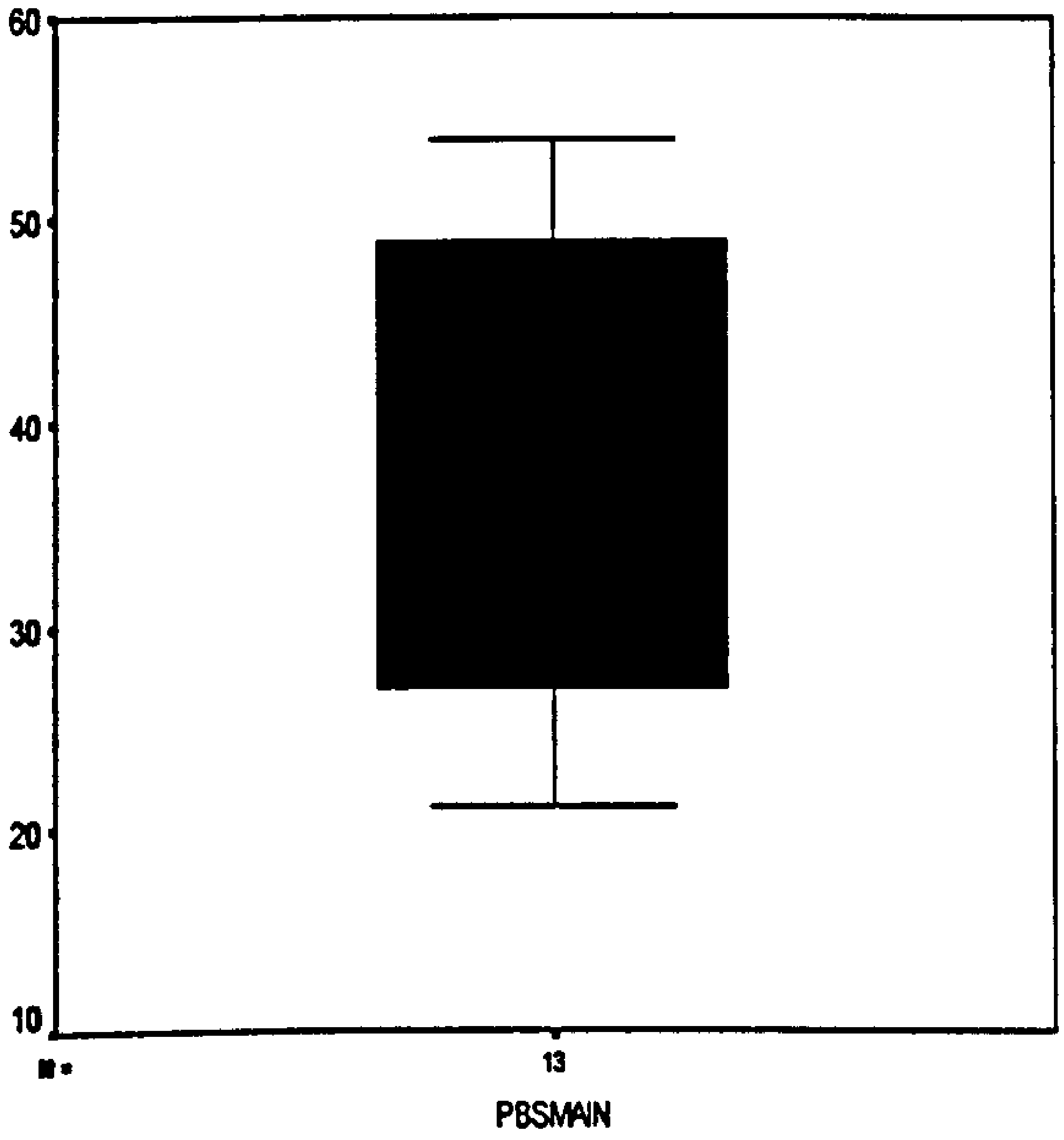
3.3 Instrument Description

Table 3 contains the scores for the main grid study sample and the complete sample on the perceived burden scale (PBS) of the Modified Caregiver Appraisal Scale (MCAS). All scores on the subscales of the MCAS are constructed with higher scores meaning greater positivity. Thus, somewhat counter-intuitively, high scores on the PBS reflect low levels of appraised burden and low scores reflect higher burden. Available data from Struchen et al. (2002) have been included for comparison purposes.

Table 3. MCAS - Perceived Burden Scale Descriptive Statistics

	Main Grid Study	**Questionnaire Participants**	**Complete Sample**	**Struchen et al. (2002) Data**
Minimum Score	21.00	29.00	21.00	
Maximum Score	54.00	56.00	56.00	
Mean	36.38	41.50	38.00	52.70
Median	36.00	40.50	36.00	
Standard Deviation	11.74	12.21	11.80	12.90
Skewness	0.12	0.13	0.10	
Standard Error	0.62	0.85	0.52	
Kurtosis	-1.42	-2.77	- 1.43	
Standard Error	1.19	1.74	1.01	
Total Sample	N = 13	n = 6	N = 19	N = 241

Table 3 shows the range of PBS scores to be 21 – 54 for the main grid study participants with a mean score of 36.38 (SD 11.74). The complete sample scores range from 21 – 56 with a mean score of 41.50 (SD 12.21). In comparison to Struchen et al.'s (2002) data, with a mean score of 52.70 (SD 12.90), the participants in this study appraised higher burden. The degree of negative kurtosis in both the samples shows that the scale scores extend into the tails of the distributions and might not meet the criteria for normal distributions (Breakwell, Hammond and Fife-Shaw, 1995). The boxplots in Figures 1 and 2 provide graphic demonstration of the two study distributions for the PBS: the main grid study and the complete sample. The boxplots for the PBS show there are no outliers or extreme values on this scale.



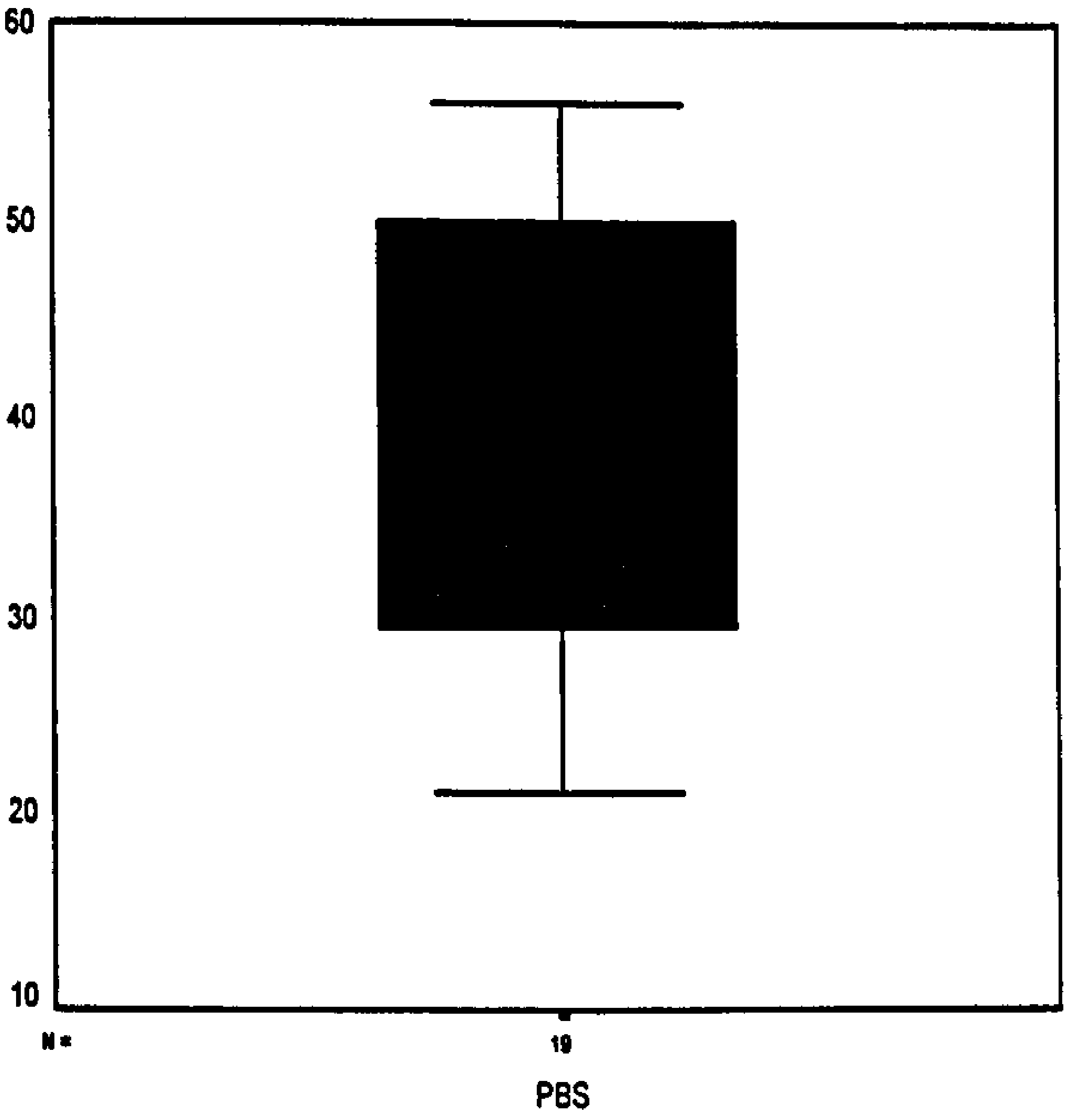


Figure 1. PBS for main study sample (N = 13) Figure 2. PBS for complete sample (N = 19)

Boxplot Interpretation

Boxplots show the distribution of scores obtained on selected measures. The horizontal line through the box indicates the central tendency of the box, that is, the median or middle score. The lower boundary of the box represents the 25th percentile and the upper boundary the 75th percentile. The lines from the top and bottom of the box (called "whiskers") represent the smallest and largest values that are not outliers or extreme scores. Values more than 1.5 times the box-length are known as outliers and are designated with a circle. Extreme values/scores fall 3 box-lengths from the 75th and 25th percentile and are represented by an asterix.

Table 4. Modified Caregiver Appraisal Scale – Descriptive Statistics for Residual Subscales Including Caregiving Mastery Experimental Scale

	Min	**Max**	**Mean**	**Median**	**SD**	**Skew-Ness**	**SE**	**Kurtosis**	**SE**
CRSS Main (N= 13)	32	48	39.77	38	5.40	0.24	0.62	-0.98	1.19
CRSS Complete (N = 19)	32	55	40.84	39	5.75	0.67	0.52	0.66	1.01
CIS Main (N = 13)	5	18	10.38	11	3.45	0.49	0.62	0.85	1.19
CIS Complete (N = 19)	5	18	10.89	11	3.59	-0.02	0.52	-0.40	1.01
CMS Main (N = 13)	5	18	10.38	11	3.45	0.49	0.62	0.85	1.19
CMS Complete (N = 19)	8	16	12.26	12	2.02	-0.36	0.52	0.03	1.01
CMES Main (N = 13)	23	41	32.15	32	4.98	-0.07	0.62	-0.30	1.19
CMES Complete (N = 19)	23	46	33.42	33	5.40	0.36	0.52	0.62	1.01

Key:

CRSS – Caregiving Relationship Satisfaction Scale
CIS – Caregiving Ideology Scale
CMS – Original Caregiving Mastery Scale
CMES – Caregiving Mastery Scale with Experimental Items

Table 4 contains the scores for the main grid study sample and the complete sample on the CRSS, CIS, CMS and CMES of the Modified Caregiver Appraisal Scale (MCAS). Data for the main grid study only will be commented on as they are the ones tested in the hypotheses.

On the CRSS, the scores range from 32 to 48, with a mean score of 39.77 (SD 5.40). The CIS scale scores range from 5 to 18, and the scale mean is 10.38 (SD 3.45). The CMS range is from 5 to 18, and the mean score is 3.45 (SD 3.45). Scores on the untested experimental scale to measure caregiver mastery, the CMES, range from 23 to 41, and the mean score is 32.15 (SD 4.98). Figure 3 shows the CRSS, CIS and CMS distributions are asymmetrical, suggesting levels of skewness that may violate the assumptions of normality of distribution.

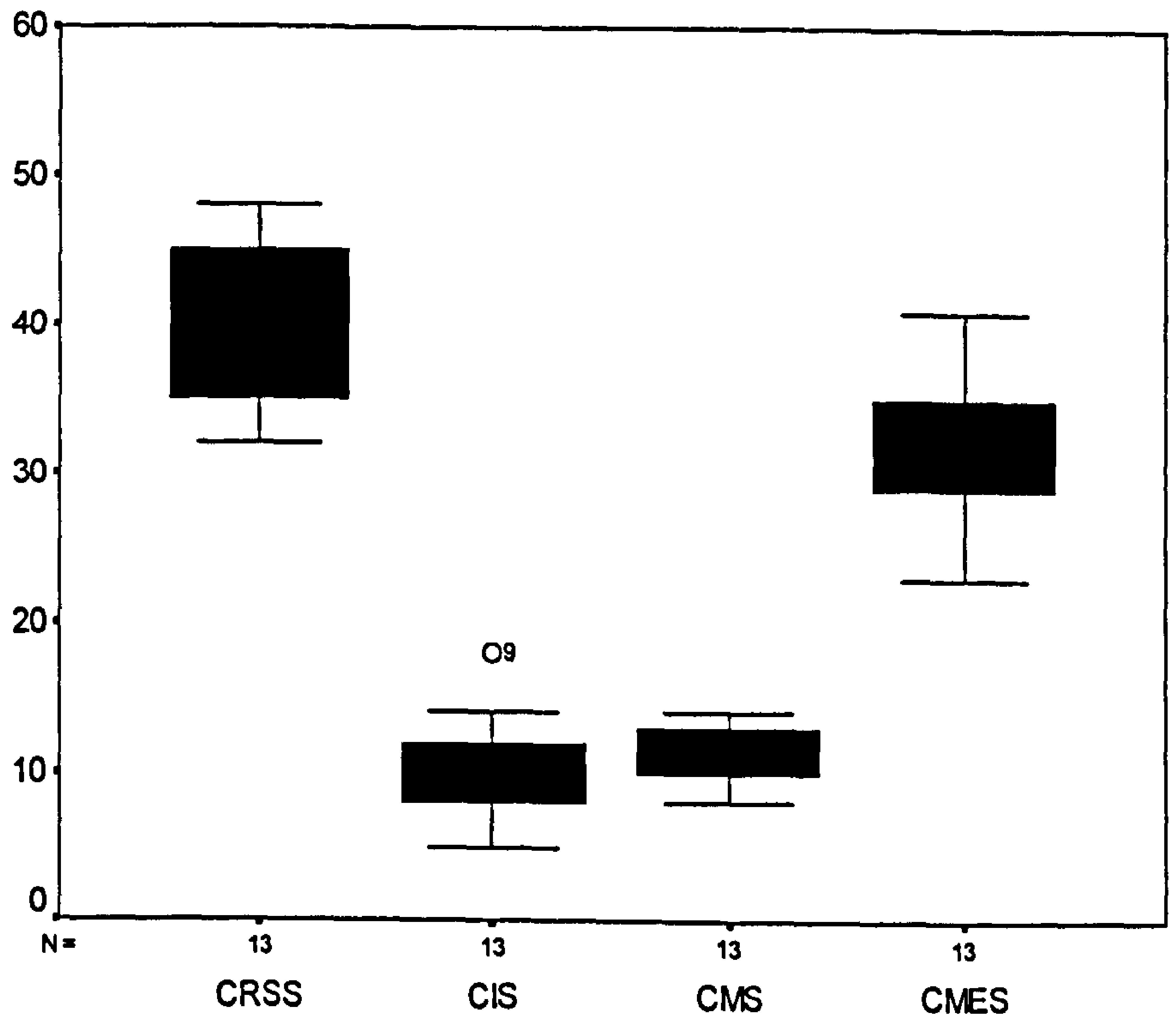


Figure 3. Boxplots of CRSS, CIS, CMS and CMES for Main Grid Study

Table 5. Means and Standard Deviations for Residual MCAS Subscales for Struchen et al. (2002), Main Grid Sample and Complete Sample

	Struchen et al. (2002) (N = 241)	**Grid Sample (N = 13)**	**Complete Sample (N = 19)**
Subscale	Mean (SD)	Mean (SD)	Mean (SD)
CRSS	44.7 (5.50)	39.77 (5.40)	40.84 (5.75)
CIS	12.8 (3.90)	10.38 (3.45)	10.89 (3.59)
CMS	13.9 (3.00)	10.38 (3.45)	12.26 (2.02)

Table 5 compares Struchen et al.'s (2002) sample with the current study. As can be seen, the participants in Struchen et al.'s study experienced greater caregiving relationship satisfaction, stronger caregiving ideology and greater caregiving mastery than the grid sample or complete sample.

Table 6. Cronbach's Alpha Values for Modified Caregiver Appraisal Scale

	PBS (15 items)	CRSS (11 items)	CIS (5 items)	CMS (4 items)	CMES (10 items)
Complete Study (N = 19)	0.88	0.76	0.75	0.54	0.61
Struchen et al. (2002) (N = 241)	0.91	0.77	0.70	0.52	

Table 6 reports the Cronbach's Alpha (α) for subscales of the MCAS as tested by Struchen et al. (2002) and in the current study for the complete sample. Cronbach's Alpha for the experimental scale of caregiver mastery, CMES, is reported for this study also. In spite of the different sample sizes, the α-values for the subscales in both studies are very similar and all, bar measures of caregiving mastery (CMS, CMES), following convention, attain a good level of internal consistency (α = 0.70) (Bland and Altman, 1997). The perceived burden scale, PBS, reached a level of internal consistency that was close to excellent. Revising the scale for caregiver mastery, CMS, to the experimental scale, CMES, has increased internal consistency though not to a statistically acceptable level.

Table 7. Beck Depression Scale-II and Beck Anxiety Scale Descriptive Statistics

N = 13	Min	Max	Mean	SD	Median	Skewness	SE	Kurtosis	SE
BDI-II	0	35	15.23	10.90	14	0.34	0.62	-0.90	1.19
BAI	0	37	16.54	11.27	14	0.60	0.62	-0.22	1.19

As shown in Table 7, the scores on the BDI-II range from 0 to 35, and the mean score is 15.23 (SD 10.90). Scores on the BAI range from 0 to 37, and the mean score is 16.54 (SD 11.27).

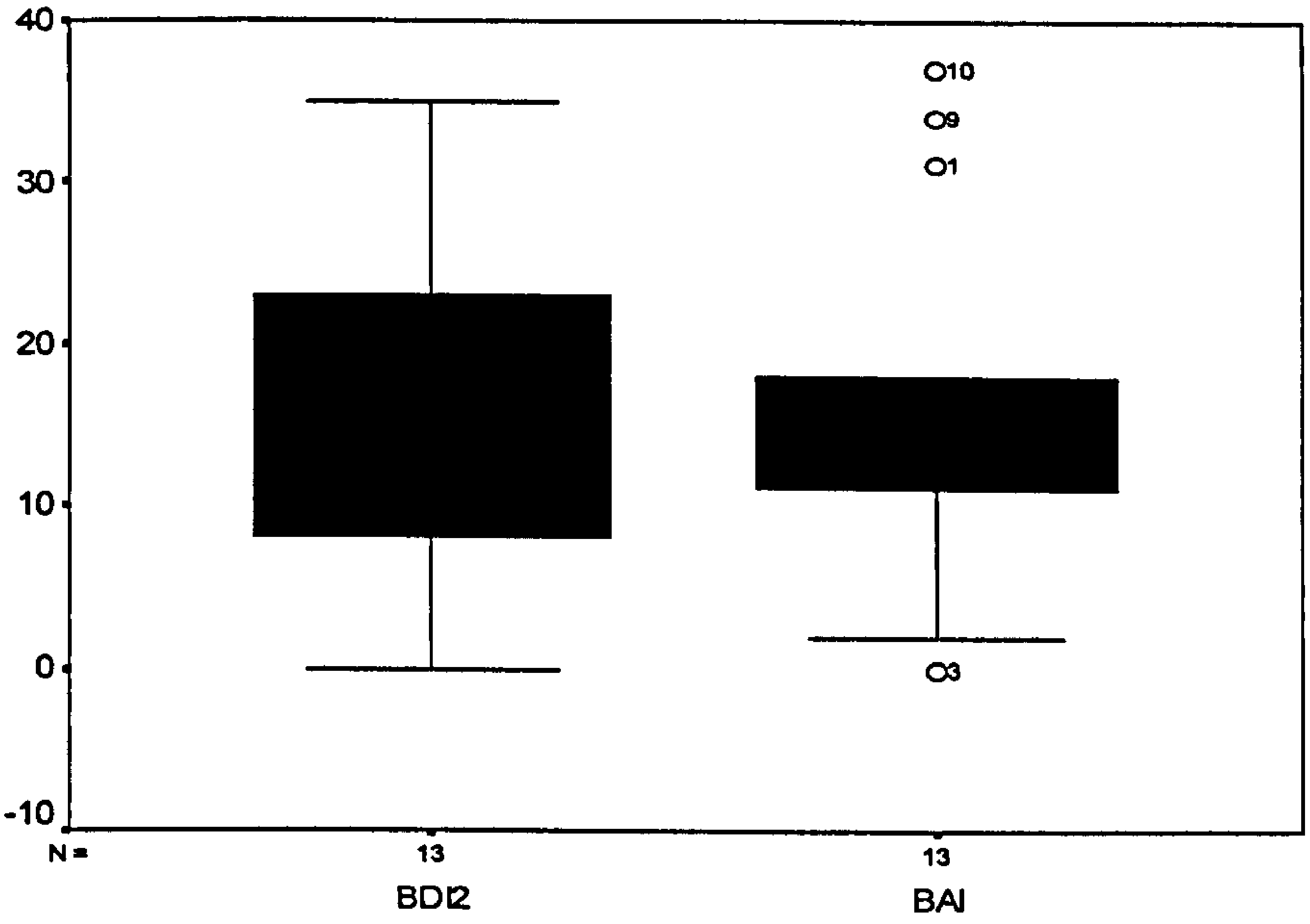


Figure 4. Boxplots of BDI – II and BAI Scores

As Figure 4 shows, the BDI-II appears normally distributed. However, the BAI appears skewed and contains outliers that fall in the severe anxiety range (see Table 8).

Table 8. Clinical Severity Ranges for BDI-II and BAI

	BDI-II	BAI
Minimal	0 – 13	0 – 7
Mild	14 – 19	8 – 15
Moderate	20 – 28	16 – 25
Severe	29 – 63	26 – 63

Table 9. BDI-II and BAI Clinical Severity Ratings

	(N = 13)	Minimal	Mild	Moderate	Severe	Total
BDI – II	Number	6	2	4	1	13
	Percentage	46.16%	15.38%	30.77%	7.69%	100%
BAI	Number	2	6	2	3	13
	Percentage	15.38%	46.16%	15.38%	23.08%	100%

Table 8 provides the key for the clinical severity ratings on screening measures of depression (BDI-II) and anxiety (BAI). The BDI-II and BAI were completed by the main grid study participants only. As shown in Table 9, 38.46% of the sample had scores that were categorised as moderately to severely depressed. The same proportion of participants was moderately to severely anxious.

Table 10 describes the distribution of the percentage variance accounted for by the first principal component of the Repertory Grid. The scores range from 57 – 93%, the mean score being 75.23% (SD 8.64). Ryle and Breen (1972) state that tight construct systems are ones in which the principal component accounts for more than 40% of variance. The sample therefore appears to be construing tightly. Figure 5 shows the boxplot for the percentage variance accounted for by the first principal component of the Repertory Grid. The distribution appears normally distributed though there are two outliers in the distribution, one of whom construes extremely tightly and one of whom construes more loosely than the other participants.

Table 10. Repertory Grid Principal Component Descriptive Statistics

N = 13	**Min**	**Max**	**Mean**	**SD**	**Median**	**Skewness**	**Skewness SE**	**Kurtosis**	**Kurtosis SE**
Principal Component % Variance	57	93	75.23	8.64	75	-0.01	0.62	1.56	1.19

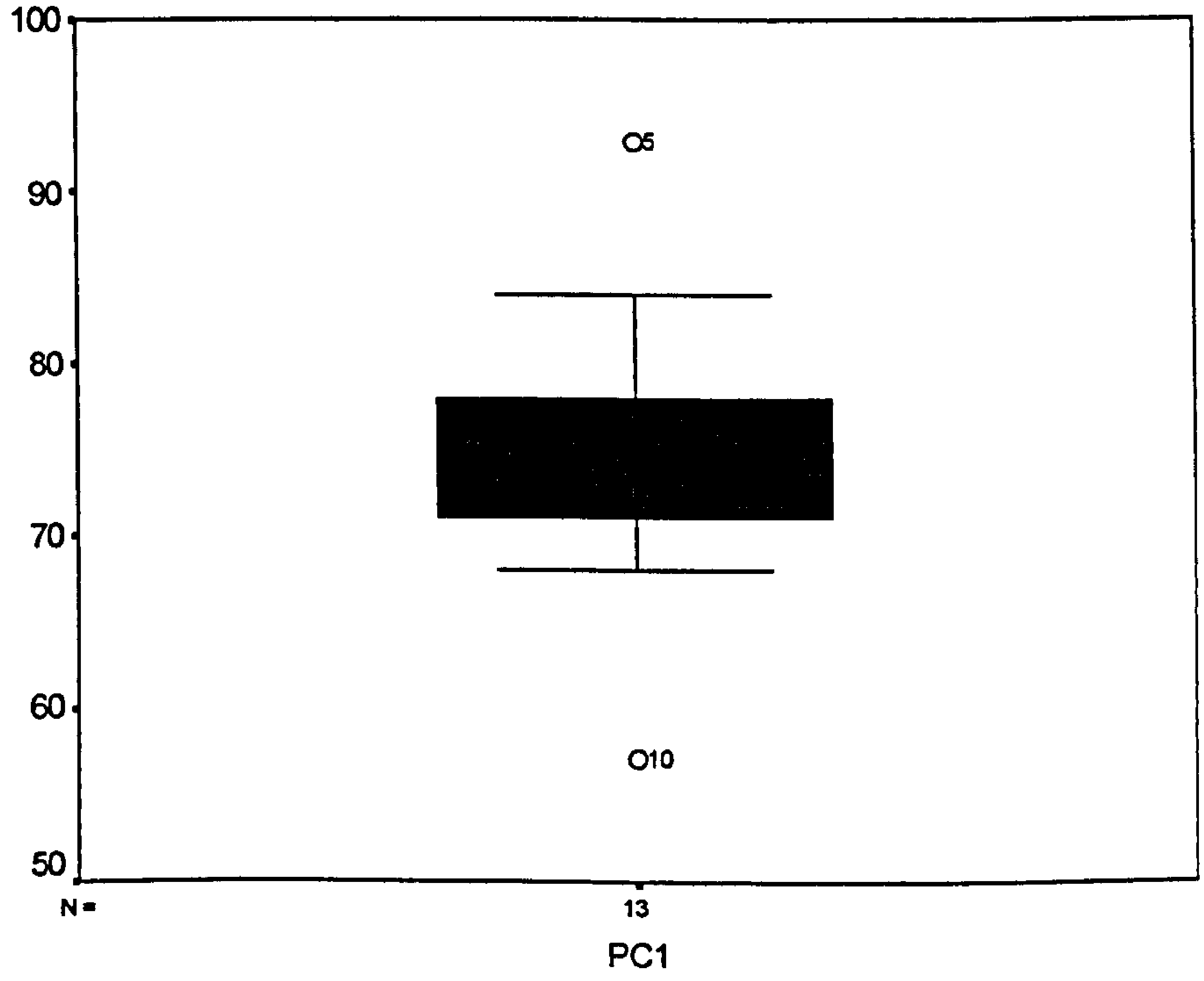


Figure 5. Boxplot of Percentage Variance accounted for by First Principal Component of the Repertory Grid

Table 11 describes the repertory grid inter-element distances obtained from the 13 participants who completed the main grid study. As described in the Method chapter, possible inter-element distances range from 0 – 2. Higher scores depict greater dissimilarity between elements. The closer the inter-element distances to zero, the more similar they are, with zero difference equating to elements being identical. A score between 0.8 and 1.2 indicates that the elements are neither similar nor dissimilar.

Table 11. Repertory Grid Inter-Element Distance Descriptive Statistics

N = 13	**Min**	**Max**	**Mean**	**Median**	**SD**	**Skewness**	**SE**	**Kurtosis**	**SE**
Carer before and now	0.45	1.43	0.86	0.93	0.32	0.27	0.62	-1.03	1.19
BI before and now	0.57	1.76	1.14	1.13	0.38	-0.04	0.62	-0.96	1.19
Carer now and BI now	0.31	1.46	0.94	0.96	0.32	-0.65	0.62	0.37	1.19
BI now and BI as Ideal	0.88	1.85	1.43	1.34	0.30	-0.07	0.62	-0.97	1.19
BI now and in 5 yrs time	0.29	1.55	0.63	0.50	0.34	1.88	0.62	3.91	1.19
BI now and healthy	0.62	1.85	1.22	1.27	0.32	-0.38	0.62	1.01	1.19
BI 5yrs and BI as Ideal	0.50	1.51	0.98	1.06	0.36	-0.03	0.62	-1.58	1.19
Carer now and Ideal (self-esteem)	0.43	1.73	1.06	1.11	0.36	-0.23	0.62	0.10	1.19

The most extreme mean scores in Table 11 indicate that carers tended to construe the brain injured person they care for as they are now as dissimilar to how they would ideally like the person to be (mean 1.43; SD 0.30); quite dissimilar from a healthy person (mean 1.22; SD 0.32); and as unlikely to change very much in the next five years (mean 0.63; SD 0.34).

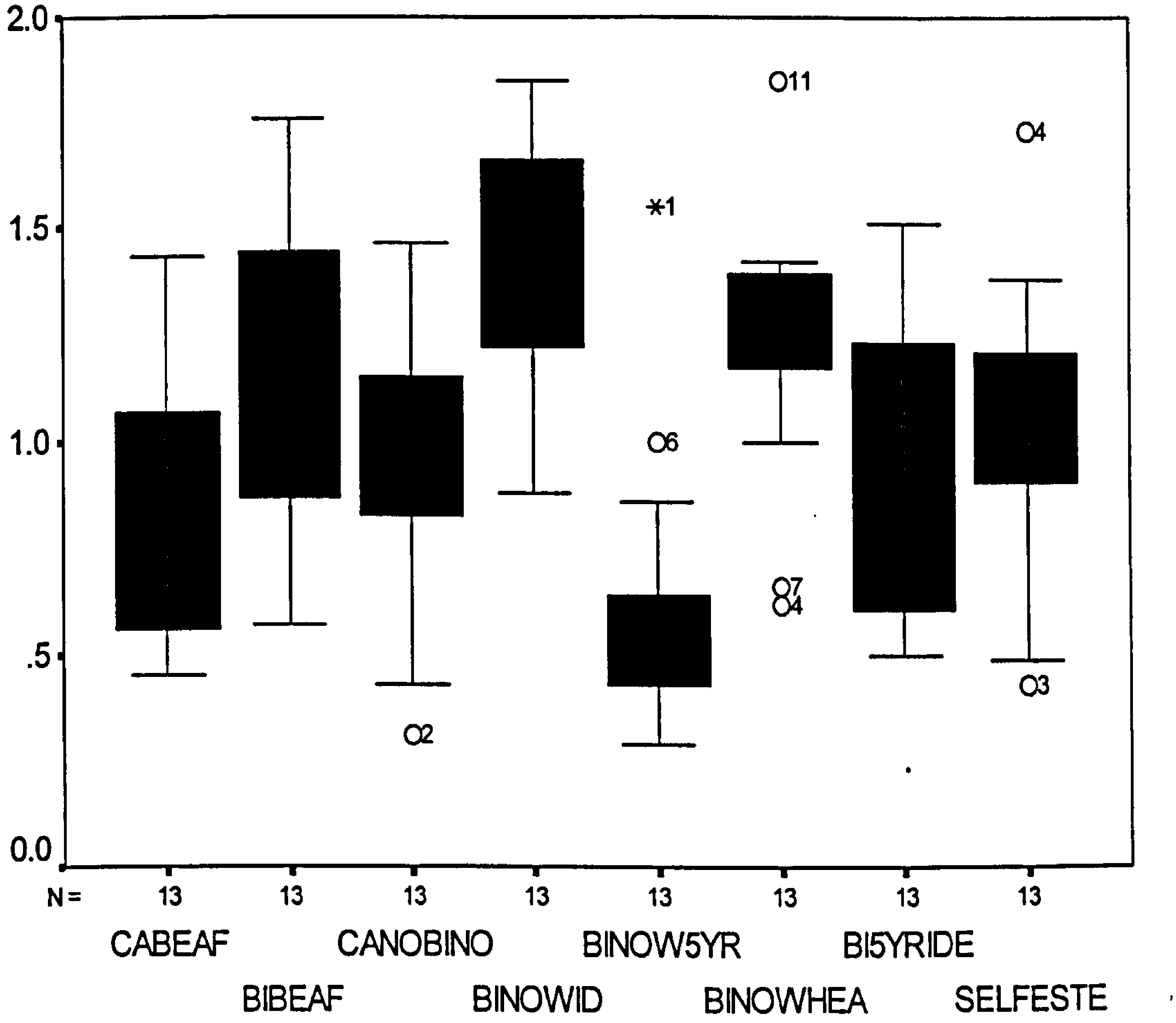


Figure 6. Boxplots for Inter-element Distance Scores

Figure 6 contains the boxplots for the inter-element distances. It is apparent that some of the distributions may violate assumptions of normality. In particular, BINOW5YR (BI person now – BI person in 5yrs time) is positively skewed, and an outlier and an extreme score are also evident. BINOWHEA (BI person now – Typical healthy person) is slightly negatively skewed and has three scores which are outliers.

3.4 Hypothesis Testing

Given the small sample sizes (N = 13, N = 19) obtained for hypothesis testing; the violations of assumption of normality of distribution reported on many of the research instruments; and the existence of outliers in some distributions, non-parametric tests were utilised to test research hypotheses. Adjustment of the significance level was required prior to hypothesis interpretation. Small sample sizes (N=19; N = 13) reduce the power to detect statistically significant results and increase the chance of a type II error. Due to this the α-level could be increased from 0.05. However, when balanced against the increased chance of type I errors, due to multiple hypothesis testing in this study, a reduced adjusted p-value of 0.025 was applied to hypothesis testing. However, results with a p-value between 0.25 and 0.05 will be reported as statistical trends.

3.4.1 Hypotheses Group 1

There will be positive associations between:

- Severity of cognitive problems in the brain injured person
- Severity of behavioural problems in the brain injured person
- Perceived burden

Table 12. Correlations Between Cognitive Problems, Behavioural Problems and Perceived Burden Scale (PBS)

N = 19	**Behavioural**	**PBS**
Cognitive Significance Level	rho = 0.48 p = 0.02* (1-tailed)	rho = -0.32 p = 0.09 (1-tailed)
PBS Significance Level	rho = -0.70 p < 0.01** (1-tailed)	

* significant at < 0.05, ** significant at < 0.01

Table 12 reports the first group of hypotheses to be tested. Perceived burden and behavioural problems in the brain injured person are shown to be strongly correlated ($r_s = -0.70, p < 0.01$). As high PBS scores are more negative, this shows that higher perceived burden is associated with more behavioural problems in the brain injured person. Levels of cognitive problems and behavioural problems in the brain injured person are positively correlated at the 0.05 significance level ($r_s = 0.48, p = 0.02$).

3.4.2 Hypotheses Group 2

There will be positive associations between:

- Tightness of construing
- Perceived Burden
- Depression
- Anxiety

Table 13. Correlations Between Tightness of Construing, Perceived Burden, Depression and Anxiety

N = 13	BAI	PBS	BDI – II
Tightness of Construing Significance Level	rho = -0.23 p = 0.46 (2-tailed)	rho = -0.41 p = 0.08 (1-tailed)	rho = -0.25 p = 0.41 (2-tailed)
Beck Depression Inventory – II Significance Level	rho = 0.83*** p < 0.001 (1-tailed)	rho = -0.29 p = 0.17 (1-tailed)	
Perceived Burden Scale Significance Level	rho = -0.57* p = 0.02 (1-tailed)		

* significant at < 0.05, ***significant at < 0.001

Table 13 reports the second group of hypotheses to be tested. Tightness of construing is not found to be correlated with the BDI-II, BAI or PBS. As the correlations between tightness of construing and the BAI and BDI-II are in the opposite direction to prediction, significance levels are reported as 2-tailed. The BDI-II scores are strongly positively correlated with the BAI scores ($r_s = 0.83$, $p < 0.001$). Perceived burden is moderately correlated with the BAI ($r_s = -0.57$, $p = 0.02$) suggesting that higher perceived burden is associated with greater levels of anxiety.

3.4.3 Hypotheses Group 3

Carers who are partners will be:

- more burdened than parental carers
- more depressed than parental carers
- more anxious than parental carers

Table 14. Mean Scores for Parents and Partners on Perceived Burden Scale, Beck Depression Inventory-II and Beck Anxiety Scale

	PBS (N = 19)	**BDI-II (N = 13)**	**BAI (N = 13)**
Relationship Type	Mean (SD)	Mean (SD)	Mean (SD)
Partner	•36.75 (12.00)	15.29 (13.62)	17.29 (11.74)
Parent	40.57 (12.48)	15.17 (7.89)	15.67 (11.74)

•PBS – Lower scores reflect higher perceived burden

All mean scores for partners and parents show small differences in the predicted direction.

Table 15. Mean Differences (Mann-Whitney U) Between Parents and Partners for Perceived Burden, Depression and Anxiety

	U	**Z**	**P (1-tailed)**
Perceived Burden Scale (N = 19)	32.50	-0.80	0.43
Beck Depression Inventory – II (N = 13)	19.50	-0.22	0.84
Beck Anxiety Inventory (N = 13)	19.00	-0.29	0.84

Table 15 reports the third group of hypotheses to be tested. The Mann-Whitney U non-parametric test for independent groups was used for hypothesis testing. None of the three hypotheses was supported. Thus, there were no differences found between carers who were partners and parental carers on measures of perceived burden, depression and anxiety.

3.4.4 Hypotheses Group 4

Carers who construe:

- they have changed more from pre to post injury will be more burdened
- the brain injured person has changed more from pre to post injury will be more burdened
- a greater difference between themselves now and the brain injured person now will be more burdened
- a greater difference between the brain injured person now and how the carer would ideally like them to be will be more burdened

- a greater difference between the brain injured person in 5 years time and how the carer would ideally like them to be will be more burdened
- a greater difference between the brain injured person and a healthy person will be more burdened

Table 16. Correlations Between Construing and Perceived Burden Scale

Element Distances	**Perceived Burden Scale**
Carer before BI – Carer now Significance Level	rho = -0.04 p = 0.45 (1-tailed)
BI person before BI – BI person now Significance Level	rho = -0.50● p = 0.04 (1-tailed)
Carer now – BI person now Significance Level	rho = 0.16 p = 0.30 (1-tailed)
BI person now – BI person as Ideal Significance Level	rho = -0.52● p = 0.03 (1-tailed)
BI person in 5 yrs – BI person as Ideal Significance Level	rho = -0.03 p = 0.46 (1-tailed)
BI person now – Healthy person Significance Level	rho = -0.21 p = 0.24 (1-tailed)

● statistical trend

Table 16 reports the fourth group of hypotheses to be tested. None of the six hypotheses is supported. However, statistical trends were evident for two of the hypotheses. Thus, carers who construed a greater dissimilarity between the person they care for now and the person prior to the brain injury experience greater perceived burden ($r_s = -0.50$, $p = 0.04$). Carers who construed the brain injured person now as more dissimilar to how they would ideally like the person to be also experience greater burden ($r_s = -0.52$, $p = 0.03$). Overall, however, it appears that similarity or dissimilarity between element pairs has little relationship to perceived burden.

3.4.5 Hypotheses Group 5

Carers who construe:

- the brain injured person has changed more from pre to post injury will score higher on caregiving ideology
- a smaller difference between the brain injured person in 5 years time and how the carer would ideally like them to be will have greater caregiving relationship satisfaction

- a smaller difference between the brain injured person now and a healthy person will have greater caregiving relationship satisfaction
- themselves now as more similar to their ideal self will have a higher level of caregiving mastery

Table 17 reports the fifth group of hypotheses to be tested. None of the four hypotheses is supported. However, for one hypothesis, a strong negative correlation, in the opposite direction to prediction, was established: carers who construe the person they care for now as more dissimilar to prior to the brain injury report lower caregiving ideology ($r_s = -0.69$, $p < 0.01$). Construing was not shown to be related to caregiving relationship satisfaction or to caregiving mastery.

Table 17. Correlations Between Construing and Scales from MCAS

Element Distances	**Caregiving Relationship Satisfaction Scale**	**Caregiving Ideology Scale**
BI person before BI – BI person now Significance Level		rho = -0.69** p < 0.01 (2-tailed)
BI person in 5 yrs – BI person as Ideal Significance Level	rho = 0.08 p = 0.39 (1-tailed)	
BI person now – Healthy person Significance Level	rho = 0.39 p = 0.09 (1-tailed)	rho = -0.69** p = < 0.01 (1-tailed)
Element Distances	**Caregiving Mastery Scale**	**Caregiving Mastery Experimental Scale**
Carer now - Carer as Ideal Significance Level	rho = -0.37 p = 0.10 (1-tailed)	rho = -0.11 p = 0.36 (1-tailed)

** significant at < 0.01

3.4.6. Unpredicted Correlation

A statistically significant result, which was not hypothesised, was found (see Table 17). Carers who construed a greater dissimilarity between the person they care for now and a healthy person reported lower caregiving ideology ($r_s = -0.69$, $p < 0.01$). Thus, considering the results in Table 17, it appears that caregiving ideology is related to differences between how the brain injured person is construed now in relation to uninjured or healthy people.

3.4.7 Additional Findings – Statistical Trends

Statistical trends were also noted for caregiving relationship satisfaction and depression ($r_s = -0.49$, $p = 0.04$ (1-tailed)), and caregiving relationship satisfaction and anxiety ($r_s = -0.46$, $p = 0.05$ (1-tailed)). Carers who appraised lower relationship satisfaction were more depressed and anxious than carers who appraised higher relationship satisfaction.

3.5.1 Idiographic Meanings

Qualitative analyses were undertaken of core constructs generated. From this process, themes reflecting meaning given to the role of "caring now" were established. Core constructs are very important constructs which we apply to ourselves (Butler and Green, 1998). They fundamentally guide the way we think of ourselves and influence our behaviour (ibid.); imminent change to core constructs may cause great threat and anxiety. They were identified as constructs which were rated with an extreme score (1 or 7) for "self now". In accordance with Caine, Wijesinghe and Winter (1981), and the aim to develop an idiographic understanding of the meaning of caring, the pole applied to the self now was analysed only. Previous classification systems for content analyzing constructs (Feixas, Geldschläger, and Neimeyer 2002; Landfield, 1971) were considered as organising systems. However, Landfield's system is extensive and would have resulted in very few of the 46 constructs being categorized in each theme. Feixas et al.'s (2002) method did not encompass the constructs satisfactorily, and indeed they have acknowledged that it is not an adequate system to content analyse self-constructs.

All relevant constructs (n = 46), were collated and grouped "bottom up" according to themes that the researcher found to emerge. Where the meaning of a construct was not clear the opposite pole was considered in allocating categorisation. Following the development of categories, an independent rater categorised the constructs in accord with the developed system. Cohen's Kappa was calculated at $\kappa = 0.92$ demonstrating very high agreement between raters.

The themes developed and constructs categorised by theme can be found in Table 18. As can be seen, more than half of the constructs (60.87%) can be subsumed under three categories: "life circumstances", "emotional states", "health and illness". Life circumstances covered a range of positive and negative experiences. Some carers considered themselves to have a "good quality of life", while a sense of "burden" and restriction was clear in others' core constructs. In line with previous research, and core constructs generated, many carers reported emotional difficulties; some also reported undergoing "counselling", or being on psychotropic medication currently. In relation to health, while two carers, who spoke of feeling depressed, felt "tired" and "physically and mentally stressed", many carers spoke of the value and importance they placed on their own good health. Interestingly, the "caring role" was represented by less than 10% of the core constructs, suggesting that carers did not necessarily find personal meaning in that label.

Table 18. Content Analysed Core Constructs

Categories	Constructs	Percentage Core Constructs
Life Circumstances	Difficulty with life/Good Quality of Life/Lucky /Life is controllable/ Burdened/Unable to let go, escape/ Has to do things due to situation/Independent/ Is in charge/ Discriminated against	23.91%
Emotional States	Happy/Lonely/Fed up/Worried/Sad/ Disillusioned/Emotional/Unhappy/Low	19.57%
Health and Illness	Healthy/Proactive with own health/Physically and mentally stressed/Tired/Sluggish/No medical complications/ Understands mental health	17.39%
Future	Uncertainty of future/Planning for a future/Developing/Optimistic/Wishful/In a void	13.04%
Caring Role	Supportive/Caring person/ Caring/Affectionate	8.70%
Coping	Making the best, coping/Puts on a front/Emotionally determined	6.52%
Interests	Interested in intellectual activities/Sporty/ Not enjoying social activity	6.52%
Miscellaneous	Finds it hard to remember things/Normal	4.35%

Tyson (2003) developed a categorical system for all constructs, generated by spouses in brain injury, which was largely negative. In this study, while the majority of the poles of core constructs could be construed as negative, there is evidence of positivity also. For example, not only did some carers construe themselves as "happy" and "healthy", others construed themselves as "lucky" and "optimistic" about the future. Moreover, some carers spoke of areas of personal development such as "understanding mental health" problems now, and learning to be "independent".

3.5.2 Participant Comments

Meaning in adversity was also reflected in the comments some carers made. For example, a 59 year old mother spoke of her son's previous drug and criminal past, in which she was thankful he could no longer participate due to the brain injury he had acquired. She described him "living longer" due to this. In the repertory grid this view was reflected in the constructs she used to describe him "now", which included "planning for a future" and "coping". A 43 year old mother spoke of being fortunate that she had been "able to get to know her son" since his brain injury as he had spent more time with her due to his increased level of dependence. This participant also spoke of her son's personality becoming more pleasant since the brain injury. This change was reflected in the rating on the construct "selfish (1) -----accepting (7)", on which he previously scored 3 before the brain injury, but was now rated as 7.

A 53 year old father spoke of a mixture of experiences, of fusion and shame, in his relationship with his son. He saw the experience of living through the trauma his son had experienced, and the support that he required, as bringing them closer together, "like twins almost". However, he also spoke of this similarity extending to other aspects including memory problems. Thus, he applied a core construct of "finds it hard to remember things" to his son (5) and to himself (7). Furthermore, the father spoke of shame as a parent when his son's behaviour drew attention to him. He described wanting to say, "We're not bad parents", "It's the injury" at these times.

Other participants spoke of ways they used to cope in the caring role. One 52 year old mother described a "Pandora's Box" of psychological difficulties that she must not open for fear she would not be able to cope; this was reflected in construing herself "facing mental health problems" (6). Interestingly she construed someone with a mental health problem as "not having a quality of life" (2) as opposed to the opposite pole, "lucky" (7), which was one of her core constructs. Perhaps these scores reflected her acknowledgement of mental health difficulties but fear of addressing them. Other examples of coping include a 53 year old spousal carer who spoke of finding it relatively easy to cope as she had "been a carer all of my life" to various family members; this concept was reflected in the core construct "being a caring person" that this participant held. One spousal carer did not construe her role as caring. This 34 year old spoke of the anger and disillusionment she felt towards the health and social care systems. She thought she "needed to fight" to access the help her husband needed. This stance was reflected in her core constructs of "discriminated against" and "emotionally determined".

3.5.3 Superordinate Constructs

Table 19. Superordinate Constructs

Participant	Emergent Pole ——Contrast Pole	% Variance
Female Spouse Age 46	Difficulty with life——Getting on with life	14.31
	Does things for the community ——Doesn't want to be involved	13.51
	Unhappy——Everlasting happiness	13.51
Female Parent Age 52	Able to do what want with life—Has to do things due to situation	14.86
	Facing MH problems——Has come to terms with MH problems	13.25
	Lucky——Not having a QoL	11.60
Female Spouse Age 53	Had a future planned——Has uncertainty of future	21.78
	Has a MH problem——No medical complications	16.37
	Satisfied——Dissatisfied	16.18
Female Parent Age 57	Healthy——Low	13.28
	Active, has "get up and go"——Sluggish	11.44
	Settled——Has everything disrupted	11.14
Male Spouse Age 61	Self-sufficient——Reliant	11.57
	Mentally healthy——Not mentally healthy	11.34
	Independent——Physically dependent	10.79
Female Parent Age 59	Free——Not free	18.00
	Emotionally and mentally content——Unhappy	17.26
	Confident——Lacks confidence	13.77
Male Spouse Age 43	Able to deal with things——Has limited abilities	20.63
	Healthy——Not healthy	15.33
	Understanding——Not understanding	14.66
Female Spouse Age 58	Independent——Dependent	15.71
	Active——Non-active	11.13
	Fighting to keep sanity——Normality	11.05
Female Spouse Age 61	Don't complain of illness——Is a hypochondriac	14.39
	Independent——Dependent	13.45
	Is in charge——Reliant on others	13.30
Female Parent Age 43	Satisfied——Lonely	15.98
	Fed up——Content	14.62
	Burdened——Has freedom	13.82
Female Spouse Age 34	Discriminated against——Valued	14.39
	Safe——At risk	13.10
	Vulnerable——Independent	12.97
Female Parent Age 51	Happy——Sad	12.64
	Restricted——Able to plan	11.41
	Normal——Unwell	11.55
Male Parent Age 53	Lucky——Unlucky	18.39
	Happy——Sad	14.25
	Hard to remember things——Brainy	13.71

In accord with the Organisation Corollary, construct systems are hierarchically organised (Kelly, 1955). Superordinate constructs define our value system. Superordinate constructs were identified for all participants (see Table 19). These constructs can be identified as the three constructs responsible for the greatest percentages of variance.

It is apparent from Table 19 that the superordinate constructs could be categorised in the system developed for core constructs with few exceptions. In particular, "confident/lacks confidence" and "understanding/not understanding" could be categorised as a new category: personality attributes.

3.5.4 Individual Case Examples

Individual case studies to elaborate meaning further were also undertaken. Two participants were selected to explore and represent different caring roles and experiences in greater depth (see Table 20). Both of the carers were age 43, but one was a female parental carer for a son (carer A) and the other a male spousal carer for a wife (carer B). The brain-injured wife had an acquired brain injury that had taken place 2 years 2 months before, while the brain-injured son had a traumatic brain injury which he had sustained 3 years 2 months before.

The female carer was clinically anxious and depressed on the screening instruments used (Beck and Steer, 1987; Beck et al., 1996), while the male carer's scores fell in the minimal range for depression and the mild range for anxiety. Furthermore, in a sample that was shown to construe very tightly, the female carer was the participant who construed least tightly (57% variance accounted for by first component), while the male participant construed the second most tightly (84% variance accounted for by first component). Scores on the PBS of the MCAS showed the degree of perceived burden was very similar.

A grid plot is a two-dimensional representation of an individual's construct system in which the loadings of elements and constructs on principal component 1 are plotted against those on principal component 2. Thus, the 12 elements are represented by the letters A to L, and the 10 bipolar constructs are represented by the numbers 1 to 10. Elements that lie within opposite quadrants are seen to be most dissimilar, and those that are furthest from the origin are the most extremely construed (Winter, 1992). Figure 7 shows the grid plot for carer A, and Figure 8 for carer B.

Table 20. Carer A and Carer B Study Variables

	Carer A	**Carer B**
Variable		
Age (years)	43	43
Sex	Female	Male
Relationship to BI person	Mother	Husband
Sex of BI person	Male	Female
Age BI person (years)	20	42
When BI occurred (months)	38	26
Cause of BI (ABI/TBI)	Road Traffic Accident (TBI)	Encephalitis (ABI)
Repertory Grid - First Component % Variance	57%	84%
BDI-II (clinical severity)	26 (moderate)	8 (minimal)
BAI (clinical severity)	37 (severe)	14 (mild)
PBS	32	31
CRSS	45	37
CIS	6	12
CMS	9	13
CMES	35	32

In the interview, carer A became quite tearful as she spoke of her current situation. She expressed how emotionally distressed she was feeling, and her decision to take anti-depressant medication and beta-blocker medication for anxiety. It is apparent that this carer construed herself as changed greatly since her son's brain injury. Elements A (carer now) and D (carer before brain injury) are far apart on the grid plot and the inter-element distance for them is 1.31. Moreover, she construed herself as dissimilar to how she would ideally like to be as shown by a large distance between element A (carer now) and element J (how she would ideally like to be) and an inter-element distance of 1.38. This inter-element distance is a measure of self-esteem in Personal Construct Psychology (Button, 1985).

This carer spoke of how much she had given up, and of diminished and changed personal relationships, since her son's injury. Moreover, her future plans to move overseas with her partner were now under threat, causing her to feel pulled between her son and partner. Of significance in relation to this, a Kellyan dilemma (Kelly, 1955) is apparent on the grid plot and grid analysis. Constructs 7 and 9 (Figure 7, see upper left and lower right quadrants) are correlated (r = -0.58) on grid analysis. Thus, for this carer to construe that she "has hope" she also has to be "selfish". If she is "accepting" of the situation, she must be "empty of feelings".

Carer B spoke of the difficulties that he and his family had faced, and overcome, since his wife's brain injury. He described feeling depressed previously but thought he was coping well currently. Of note, in relation to this, the distance between elements A (carer now) and H (someone with a mental health problem) are far apart on the grid plot (Figure 8) as reflected by an inter-element distance of 1.22 on grid analysis. Interestingly carer B construed himself as similar to both himself (element D, inter-element distance of 0.56) and his wife (element C, inter-element distance of 0.54) before the brain injury. However, the distance between how he construed himself (element A) and his wife (element F) currently had grown (inter-element distance of 0.90), although not to a degree that would be considered dissimilar.

In relation to carer B's experience of overcoming difficulties, construct 10 (able to deal with things......has limited abilities) was one of carer B's superordinate constructs (see Table 19), and one on which he rated himself as 5 (on the emergent pole of "able to deal with things").

Thus two carers, for a family member with a brain injury, who are the same age and perceive a similar degree of perceived burden, have been shown to differ in the structure and content of their construct systems.

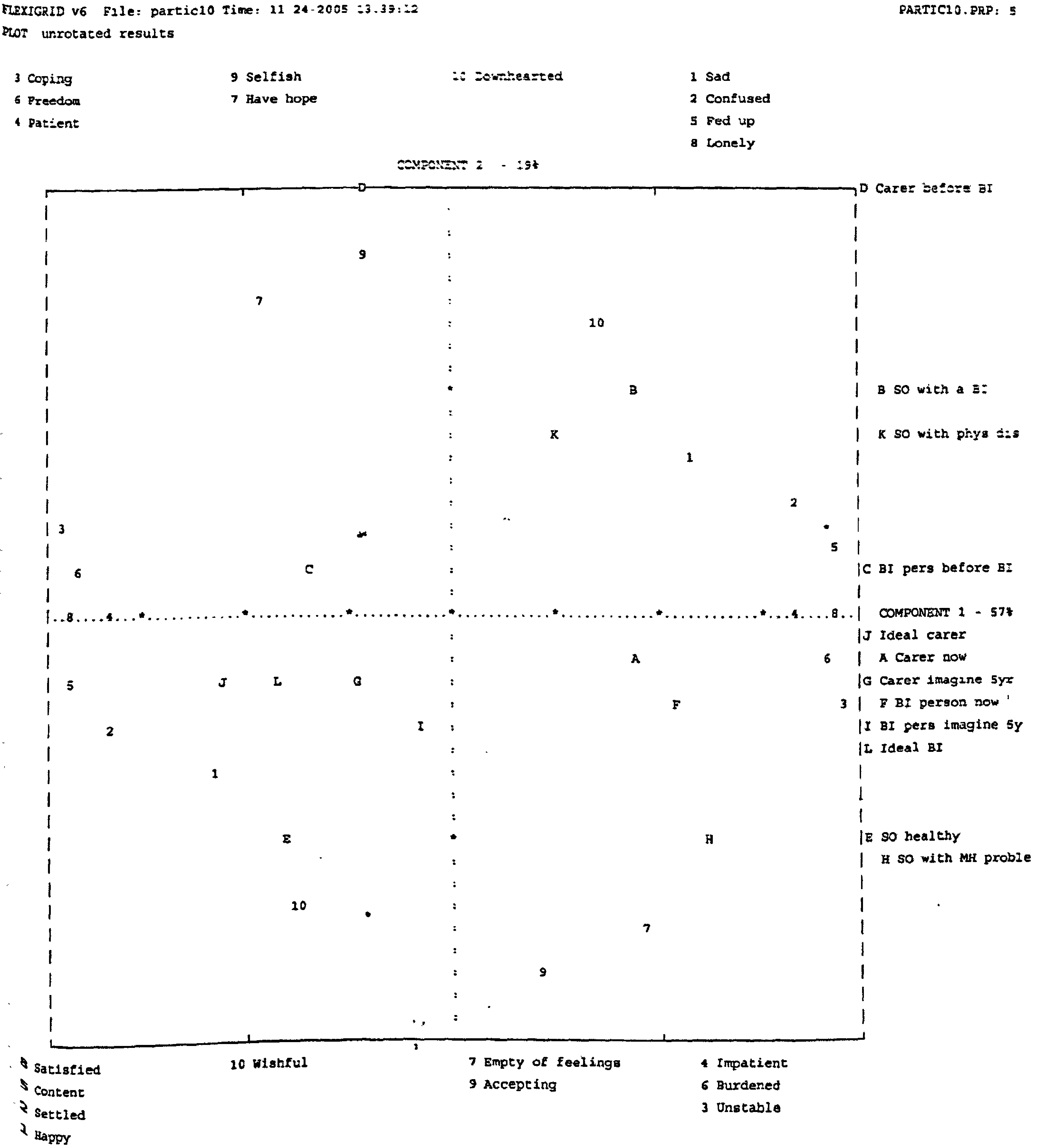


Figure 7: Grid Plot for Carer A

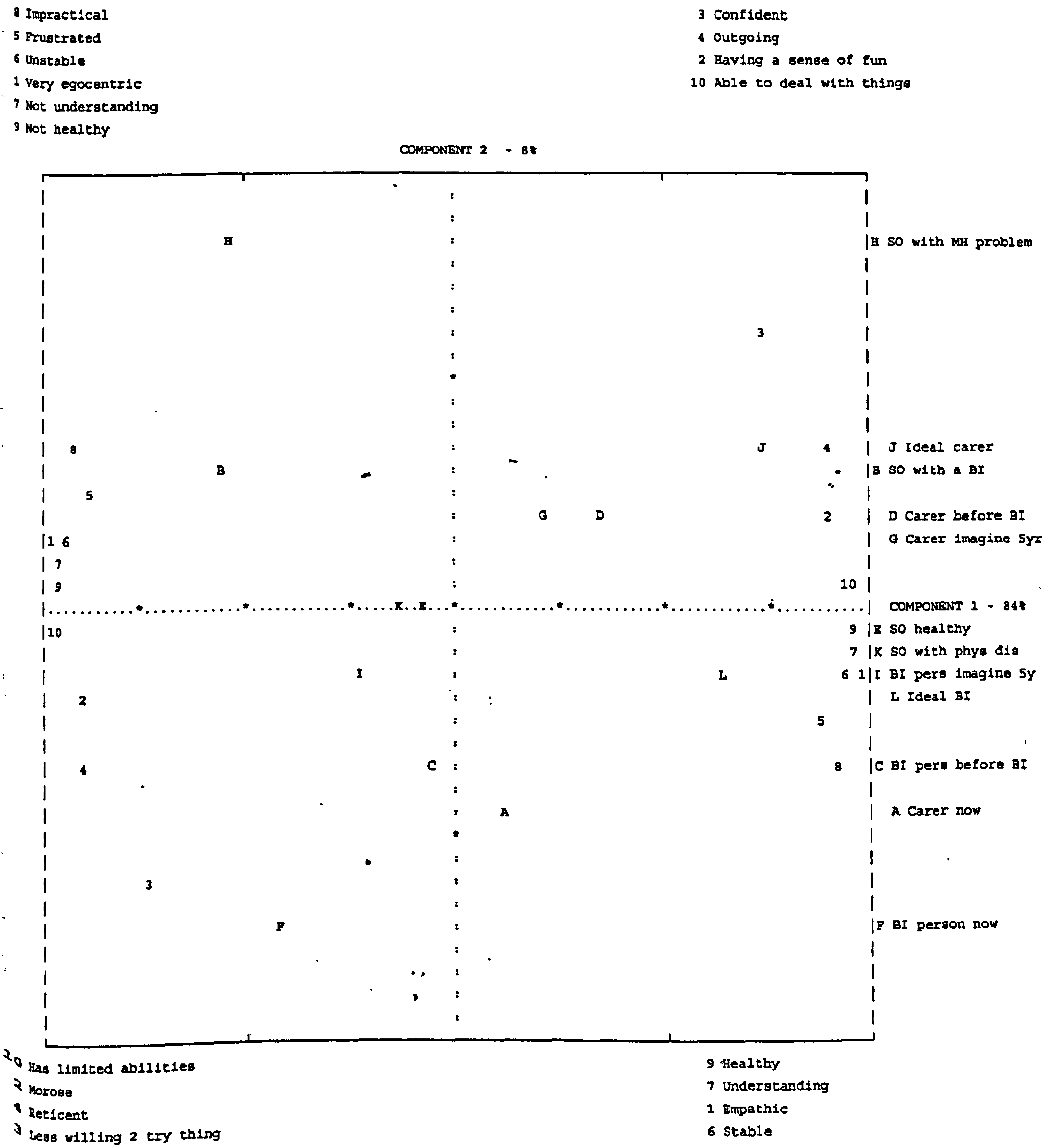


Figure 8: Grid Plot for Carer B

4.0 Discussion

4.1 Discussion Overview

This study explored the experience of carers for those with a brain injury. In particular, the study focused on the relationships between appraisal of the caregiving experience and the intrapersonal construct systems of carers. Furthermore, idiographic meanings, as construed by carers, were explored from a Personal Construct Psychology perspective.

The Discussion comprises four sections which will be structured in the following way. The initial two sections, 4.2 and 4.3, comprise research findings and relate them to the research aims and existing literature base. The final two sections, 4.4 and 4.5, address limitations of the current study, and propose ideas for future research. The relevance of the findings for clinical practice, including personal reflections on the research process, is addressed in the Critical Review paper (Crawford, 2006).

4.2 Study Findings

Section 4.2.1 reports the main quantitative research findings. 4.2.2 reports the main qualitative research findings focusing on meanings generated by carers.

4.2.1 Main Quantitative Research Findings

This section reports the main research findings by group of hypotheses as tested in the Results chapter.

4.2.1.1 Cognitive and Behavioural Problems and Negative Appraisal

The hypothesis that severity of the behavioural problems in the brain injured person and perceived burden would be positively associated was supported. Thus, those carers who rated the brain injured person as having the greatest behavioural problems appraised the caregiving situation most negatively. The hypothesis that severity of cognitive problems would be associated with perceived burden was not supported. However, the result suggests that with increased power, perhaps from a larger sample, this hypothesis might be supported. Ratings of behavioural and cognitive problems were found to be moderately positively correlated. Thus, carers who rated those they care for as having cognitive problems also rated them as having behavioural problems.

4.2.1.2 Structure of the Construct System, Negative Appraisal, Depression and Anxiety

No hypotheses for structure of the construct system were supported. As such, tightness of construing was not found to be related to perceived burden, level of depression or anxiety. However, the hypothesis that perceived burden and anxiety would be positively associated was supported. Thus, those carers who appraised the caregiving situation more negatively experienced greater anxiety. The hypothesis that perceived burden and depression would be positively associated was not supported.

4.2.1.3 Relationship to the Brain Injured Person, Negative Appraisal, Depression and Anxiety

No hypotheses for relationship to the brain injured person were supported. Carers who were partners were not found to experience greater perceived burden, depression or anxiety than parental carers.

4.2.1.4 Content of the Construct System and Negative Appraisal

None of the hypotheses for content of the construct system and negative appraisal was supported. The way carers construed themselves and the brain injured person was not found to be related to the amount of burden carers perceived. However, for two of the hypotheses, statistical trends were apparent. Thus, carers who construed the brain injured person as having changed more from pre-injury perceived greater burden. Furthermore, carers who construed the brain injured person as more dissimilar to how they would ideally like them to be, perceived greater burden. Thus, negative caregiving appraisal seemed to be linked to disparity between a premorbid or ideal state for the brain injured person.

4.2.1.5 Content of the Construct System, Neutral and Positive Appraisal, and Coping

None of the hypotheses for content of the construct system and neutral appraisal, positive appraisal, or coping was supported. Thus, the ways in which carers construed themselves and the brain injured person were not found to be related to caregiving ideology, caregiving relationship satisfaction or to caregiving mastery. However, one hypothesised relationship was strongly related in the opposite direction to prediction: carers who construed the brain injured person as having changed more since the injury reported lower caregiving ideology. Thus, they appraised weaker beliefs about the reasons for providing care.

4.2.1.6 Additional Findings

An additional relevant finding emerged via data analysis. Carers who construed the brain injured person now as more dissimilar to a healthy person reported lower caregiving ideology. Thus, appraising weaker beliefs about the reasons for caregiving appears to be linked to differences in how the brain injured person is construed now in relation to uninjured or healthy people.

Statistical trends were also noted for caregiving relationship satisfaction and depression, and caregiving relationship satisfaction and anxiety. Carers who appraised lower relationship satisfaction were more depressed and anxious than carers who appraised higher relationship satisfaction.

4.2.2 Main Qualitative Findings

Content analysis of core constructs reflected similarity of meaning in carers' construing. Three categories, "life circumstances", "emotional states" and "health and illness", subsumed 60% of the constructs. It was noteworthy that very few constructs reflecting a stereotypical caring role or identifiable coping methods were generated, suggesting these themes may not hold strong personal meaning for this group. Inter-rater reliability was extremely high providing evidence that the categorisation system developed reflected the researcher's interpretation of these constructs well. Moreover, superordinate constructs construed by carers also fitted the developed content analysis system, although there was an absence of constructs reflecting the "caring role" in the superordinate constructs generated. Given this, it appears that carers construe essential meanings, and the overarching way they shape and govern the experience of caring, in similar ways.

However, exploration of individual constructs, and the inclusion of participant comments, reflected individuality, as well as commonality, in the meanings and experiences of carers. Thus, it was apparent that carers construed a range of apparently positive and negative meanings in their experiences. Moreover, exploring idiographic examples offered the possibility that construing is dynamic and can be conflicted. These insights afford a new perspective on the experience of being a carer for someone with a brain injury, the clinical relevance of which will be expanded in a critical review paper (Crawford, 2006).

4.3 Research Findings in Relation to Research Aims and Published Literature

Section 4.3.1 addresses relevant sample characteristics, 4.3.2 focuses on the main quantitative findings from the study, and 4.3.3 discusses the qualitative aspects of the study results.

4.3.1 Relevant Sample Characteristics

Research undertaken on carer psychological distress and carer burden in brain injury has largely been carried out on a population of carers for those who have sustained traumatic brain injuries (Knight et al., 1998; Harris et al., 2001; Marsh et al., 2002; Struchen et al., 2002). It is noteworthy that while the majority of carers in this study were indeed supporting those with a traumatic brain injury, some participants cared for those with an acquired brain injury. However, in line with typical referrals to UK brain injury services, none of the people cared for with acquired brain injuries had progressive cognitive impairments. Thus, given the mixed sample, the findings from this study may need to be interpreted with caution solely for TBI carers. However, the majority of carers cared for people with severe to very severe brain injuries. This aspect of sample composition is very similar to the studies reviewed in Crawford (2004) and in the Introduction chapter (Knight et al., 1998; Harris et al., 2001; Marsh et al., 2002; Struchen et al., 2002).

Further similarities exist to previous research. More than one third of the sample of carers was found to be moderately to severely depressed and the same proportion was found to be equally anxious as measured on well-validated screening instruments (Beck and Steer, 1987; Beck et al., 1996). This finding shows that the carers in this study are at least as psychologically distressed as those in earlier studies (Harris et al., 2001; Marsh et al., 2002). Moreover, the scores on the subscales on the Modified Caregiving Appraisal Scale (MCAS) depict a sample appraising the caregiving situation in less positive ways than Struchen et al.'s (2002) study participants. As such, the carers in this study perceived greater caregiving burden, less caregiving relationship satisfaction, lower caregiving ideology and less caregiving mastery than in Struchen and colleagues' USA sample of carers of those with a TBI.

One demographic characteristic of note in the current study is the age of the partners and parents. The mean age of both groups was 52 years. This finding is contrary to other studies, which include parents and partners as carers, in which the mean age of carers has ranged from 36 to 47 years (Knight et al., 1998; Harris et al., 2001; Anderson, Parmenter and Mok, 2002; Marsh et al., 2002; Struchen et al., 2002).

The intrapersonal psychology of this sample of carers explored via Personal Construct Psychology was also remarkable. It was found that the carers construed very tightly. This suggests that they construe the world through limited, poorly elaborated meaning systems. As such, these carers would have limited flexibility in problem-solving, for example. Two previous studies utilising repertory grid methodology have focused on significant others (Winter et al., 1997) and partners (Tyson, 2003) of those with a brain injury. It was found that tightness of construing was positively related to better rehabilitation outcome (Winter et al., 1997) and that the majority of partners of those with a brain injury construed tightly (Tyson, 2003). As the current study includes parents and partners of those with a brain injury, this adds further weight to Tyson's (2003) findings, although more participants in this study construed tightly, and to a greater degree, than in Tyson's (2003) study. Thus, it appears that those closely involved with someone with a brain injury tend to construe tightly.

Given the ongoing difficulties that this group face, it is interesting to consider that constancy and predictability may be a helpful way of construing their situation; a way to gain some control, perhaps. Winter et al. (1997) proposed the thesis that tightness of construing in significant others can promote better rehabilitation outcomes in those with a brain injury as significant others can provide clear anticipations of their world for those with brain injuries. It is noteworthy that the brain injured sample in this study had lived with their injuries for at least two years longer than Winter et al's (1997) sample, and the majority of them were no longer in rehabilitation. Thus, perhaps, constancy and predictability in carers' construing afford the brain injured relatives a helpful framework beyond rehabilitation.

Hewitt's (2003) sample, of participants with a diagnosis of Multiple Sclerosis (MS), was found to construe very tightly also and was identical to the current study in the range of percentage variance accounted for by the first principal component. As there were no differences in the tightness of construing in relation to time since diagnosis, Hewitt (2003) suggested that tightness of construing was not related to threat of diagnosis. Instead tightness of construing could be related to the unpredictable nature of the symptoms of MS as they, "...cannot loosen their construct systems, as they are still open to invalidation as their illness fluctuates." (p 83). Both participants who declined to participate in the current study, and those who did participate, spoke of the unpredictable and crisis-laden nature of being a carer in brain injury. Given this, it may indeed be that tightness of construing is a way of coping for carers, which may also promote rehabilitation outcome in those with a brain injury.

4.3.2 Main Quantitative Research Findings

The main quantitative research findings are presented in the following section, 4.2.2.

4.3.2.1 Internal Consistency of the Modified Caregiver Appraisal Scale

One of the research aims was to establish if the Modified Caregiver Appraisal Scale has the same scale properties in a UK sample of carers as were found in the USA sample (Struchen et al., 2002). Given the small sample size available, internal consistency was the sole measure that was calculated. However, in spite of the small sample size in this study, the Cronbach's Alpha values for the subscales in both Struchen and colleagues' study and in this one are very similar. Indeed all subscales, bar measures of caregiving mastery (CMS, CMES), reached a very good level of internal consistency (Bland and Altman, 1997), and the perceived burden scale, PBS, reached a level of internal consistency that was close to excellent. There were no values available from Struchen and colleagues (Struchen, 2004, personal communication) for the revision of the caregiving mastery, CMS, to the experimental scale, CMES. However, the augmented mastery scale has increased internal consistency of this subscale, though not to a statistically acceptable level. These findings suggest that the Modified Caregiver Appraisal Scale may prove to be a robust measure of caregiver appraisal in the UK also, although this conclusion should be considered tentative until scale validation is undertaken on a larger sample.

4.3.2.2 Cognitive Problems, Behavioural Problems and Negative Appraisal

The majority of carers rated the brain injured people they cared for as having minor to moderate behavioural problems. As in previous studies (Kreutzer et al., 1994b; Knight et al., 1998; Marsh et al., 1998a; Marsh et al., 1998b), increased behavioural problems identified in brain injured people were found to be related to greater perceived burden. Thus, the PBS appears to perform as non-appraisal based measures of subjective carer burden. However, against previous research findings (Marsh et al., 2002), cognitive problems in the brain injured person were not found to be related to perceived burden. The majority of carers rated the brain injured sample as experiencing minor to mild cognitive difficulties, and this may explain the negative findings in comparison to other studies. Moreover, measurement issues and small sample size may also have influenced this finding, as will be discussed in section 4.4.

Irrespective of the findings, the data analysis was correlational, and it is therefore not possible to establish causation (Barker et al., 1994). Nonetheless, the finding regarding behavioural problems adds to an extensive body of literature that links behavioural problems in the brain injured person to the degree of burden experienced by carers.

4.3.2.3 Structure of Construct Systems, Negative Appraisal, Depression and Anxiety

Tightness of construing has been widely established as being positively correlated with anxiety and depression in populations referred to mental health services with depression and anxiety (Sheehan, 1985; Watson and Winter, 1999; Winter, 1992). However, in this sample it was not found to be related to anxiety and depression. Moreover, the correlations were in the opposite direction to prediction. It is noteworthy that Winter et al.'s (1997) study, of significant others in brain injury, also found the relationship between tightness of construing and rehabilitation outcome in the opposite direction to prediction, though their findings were statistically significant. If, as previously suggested, tightness of construing is helpful in this population, it is perhaps not surprising that it is not related to anxiety and depression. Indeed, if tightness of construing is related to rehabilitation outcome, there may be less psychosocial adversity in families where there is better rehabilitation outcome which may result in less anxiety and depression in the carer. However, such a thesis is beyond the remit of this study and would require methodology including a large multivariate model in which mediators could be evaluated.

Perceived burden and anxiety were correlated to a statistically significant level as predicted, and a large effect size (Cohen, 1992) was found. Thus, those carers who appraised the caregiving situation more negatively also experienced greater anxiety. While data on the existence of anxiety in a significant proportion of carers in brain injury has been known for some time (Livingston et al., 1985a,b; Marsh et al., 2002), the relationship between it and subjective carer burden has been neglected in the brain injury literature, and also in other carer burden literatures (Shreve and Andrea, 2005). The only relevant available previous research comes from the field of mild cognitive impairment where it has been shown that subjective carer burden is significantly associated with anxiety (Garand, Dew, Eazor, DeKosky and Reynolds, 2005). The finding from the current study is therefore an important development in the carer literature for brain injury.

Previously identified relationships between depression and subjective carer burden (Machamer et al., 2002), and depression and negative caregiving appraisal (Struchen et al., 2002), were not found in this study, however. Thus, perceived burden and depression, though correlated in the predicted direction, were not significantly related. While this finding may be an artefact of sample size, the small to medium effect size suggests that the relationship between negative caregiving appraisal and depression is not that strong (Cohen, 1992). This finding echoes previous research where a similar effect size and non-significant result was found (Knight et al., 1998). Knight et al. (1998) suggested that depression may be less directly associated with subjective burden. Work by Harris and colleagues (2001), in which they found that appraisal of stressors mediated the relationship between behavioural problems in the brain injured person and depression in the carer, provides support for this thesis. However, a larger sample size and multivariate methods would be required to pursue this hypothesis.

4.3.2.4 Relationship Differences in Carers

Previous research findings have suggested there are differences in carer burden (Minnes et al., 2000), and psychological distress, in carers (Kreutzer et al., 1994a; Gervasio and Kreutzer, 1997) dependent on the relationship they have to the brain injured person. Contrary to prediction, in this study no differences were found between parents and partners on measures of perceived burden, anxiety or depression.

It may be that the small sample sizes tested led to the negative findings. However, there may be other explanations for the negative findings. Tyson's (2003) study on marital satisfaction suggested that older individuals may have a stronger sense of duty and be able to cope with psychosocial changes in their head-injured partner, and enforced role changes within the relationship, better than younger individuals. Furthermore, Ergh et al. (2003) found that life satisfaction in carers in brain injury was positively related to the age of carers. The mean age of partners in this study, at 52 years old, was very similar to Tyson's (2003) sample, which had a mean age 50 years. Moreover, the mean age of parents in this study was 52 years also. It could similarly be hypothesised in this study that duration of relationship, sense of duty and life satisfaction influence the appraisal of burden in the partners in this study, leading to no discernible or statistically significant difference between partners and parents.

In relation to psychological distress, while research has found partners who are carers to be more psychologically distressed than parental carers (Gervasio and Kreutzer 1997; Minnes et al., 2000), this finding is not universal (Gillen et al, 1998; Knight et al., 1998; Harris et al., 2001). Injury severity was similar in this study and Knight, and Harris, and colleagues' studies. Moreover, in the present study, injuries occurred, on average, more than four years previously, which was similar to Knight et al.'s (1998) six years post-injury average. It may be therefore be that differences in time since injury could explain the disparate findings as Kreutzer et al. (1994a), and Gervasio and Kreutzer's (1997), samples were interviewed approximately 18 months post injury. From three years post-injury, it has been suggested that partners have either started to adapt to the multiple role changes and required aspects of marital adjustment, or, where this has not been possible, relationships have started to break down (Lezak, 1986; Tyson, 2003). Thus, it could also be hypothesised that parental carers, and those who were partners, did not differ on psychological distress or perceived burden as the partners who were most burdened or distressed had left the relationships and were therefore not included in this study.

4.3.2.5 Repertory Grid Content and Negative Appraisal in Caregiving

As a statistical trend showed, the extent to which carers construed the brain injured person as having changed since the injury was related to the degree of negative appraisal, or perceived burden, that they experienced. A further trend was found showing that those who construed the brain injured person as more discrepant from how they would ideally like them to be appraised the caregiving situation more negatively, by perceiving more burden. With increased power due to a larger sample, these results would be likely to reach the level of statistical significance set. However, with no opportunity to control for other variables, such as cognitive and behavioural problems, it is not possible to establish whether construing, in part, could be reflecting objective change. However, given that cognitive problems in the brain injured person were not correlated with perceived burden, it could tentatively be suggested that construing is measuring more than a single objective dimension.

Given the correlational nature of the results, an interpretation of these findings could be that those who construe the brain injured person as closer to an ideal or premorbid state appraise the caregiving situation less negatively. In Tyson's (2003) study, spouses who construed the brain injured person as being more similar to a healthy person reported higher levels of satisfaction. Moreover, it has also been shown that anticipating a future state favourably has been related to better rehabilitation outcome (Winter et al., 1997). It may therefore be that perceiving the brain injured individual in a state of less morbidity, and with a hopeful future, may be implicated in reducing the negative impact of caring.

4.3.2.6 Repertory Grid Content, Appraisal and Coping in Caregiving

Other hypotheses addressing repertory grid content and appraisal provided mixed results. Given the poor properties of the caregiving mastery subscales, it is perhaps not surprising that the hypotheses relating content of the construct system and coping were not supported. However, other explanations could be proposed for the remaining results.

Tyson (2003) reported a strong correlation between marital satisfaction and the distance between the grid elements "partner in three years time" and "ideal partner". In the current study participants were both partners and parents, and the relationship satisfaction measured was related to caregiving, rather than other aspects of the relationship. These differences may explain the lack of findings between the inter-element distance "BI person in 5 yrs – BI person as Ideal" and caregiving relationship satisfaction. However, other explanations may also be valid. Hewitt (2003) reported that participants found it difficult to construe a particular element: "a stereotypical person with multiple sclerosis". In this study, several participants reported difficulty construing the "brain injured person in 5 years" time. Moreover, at times it was obvious they were construing this element in the same way as the element reflecting how they would ideally like the brain injured person to be. For many carers, coping with day-to-day life is very arduous and stressful and thought to the future is not given due to lack of time and fear of what it might mean if the situation has not improved or has deteriorated. Thus, it may be that the "brain injured person in 5 years" element was not within the range of convenience (Kelly, 1955) for some carers and therefore could not be construed leading to null findings.

A non-significant correlation, of a moderate effect size, was found between the inter-element distance "BI person now – Healthy person" and caregiving relationship satisfaction. With increased power from an augmented sample, this finding is likely to lead to a statistically significant result. This result would be in line with the previous finding that spouses who construed the brain injured person as being more similar to a healthy person reported higher levels of relationship satisfaction (Tyson, 2003). As such it suggests a relationship between different forms of relationship satisfaction and styles of construing.

Carers who construed the brain injured person as having changed more since the injury, and those who construed the brain injured person now as more dissimilar to a healthy person, reported lower caregiving ideology. One explanation for these findings would be that carers who construe the brain injured person as very discrepant from uninjured or healthy people require less reliance on strong beliefs in caregiving reasons as the apparent need to provide care is so strong. Other explanations could also be valid, however.

Caregiving ideology relates to the beliefs people hold about the reasons for providing care, and is described as a neutral form of appraisal by Struchen at al. (2002). Neutral appraisals are purported to "provide meaning without any connotation of an evaluative stance being associated with meaning" (Lawton et al., 1989: 62). However, as the scale items include family tradition, religious principles, an opportunity to repay the brain injured person, and carer self-esteem, it seems unlikely that carers would perceive neutral appraisals in areas that can be so personally meaningful. Indeed, Foley, Tung and Mutran (2002) discovered white carers derived a sense of individual reward, or self gain, from holding strong ideological beliefs around caregiving. An alternative interpretation of the results stems from the hypothesis that caregiving ideology is actually a positive form of appraisal. As with Tyson's (2003) findings on relationship satisfaction, and Winter et al.'s (1997) findings on rehabilitation outcome, construing the brain injured person in a less changed or unhealthy way may lead to a more positive outcome; in this case to more positive appraisals of the situation.

4.3.2.7 Quantitative Findings Summary

While few predicted hypotheses were empirically supported, further evidence for tightness of construing in this population was apparent. Furthermore, unpredicted relationships between carers' construing of the brain injured person and caregiving ideology were found. The MCAS (Struchen et al., 2002) showed the potential to be a robust measure of caregiving appraisal in a UK population. Furthermore, the relationship found between perceived burden and anxiety may be a novel addition to the brain injury carer literature.

4.3.3 Meaning in Caregiving

The following section approaches the topic of meaning in caregiving from a Personal Construct perspective. Thus, section 4.3.3.1 explores core construing as a measure of meaning, and discusses it in relation to published literature. Participants' quotes are included to contextualise the constructs, and examples from the two individual carers, Carer A and

Carer B, are included where relevant. The clinical relevance of these findings is discussed in the Critical Review paper (Crawford, 2006).

4.3.3.1 Core Constructs as Meaning

Construing is defined as "giving meaning" (Scheer, Hundertmark and Ellis, 1997). Thus, the construct systems of participants were content analysed to derive the meanings this cohort of carers were constructing. As the focus of the research was on the experience of caring now, core constructs were content analysed. Where relevant, individual comments were included to contextualise the meanings derived. As reported in the Results chapter, three categories accounted for 60% of constructs: life circumstances; emotional states; and health and illness. However, findings must be interpreted cautiously as, due to the experience corollary in Personal Construct Psychology (Raskin, Weihs and Morano, 2005), it must be acknowledged that the meanings derived were valid for participants, and for the researcher, at the times they were made, and, through ongoing experience, may be revised. Moreover, the individuality corollary (Kelly, 1955) proposes that people construe individual meanings; the researcher, too, has construed her unique meaning in the system she chose for content analysis.

The commonality corollary (Kelly, 1955) acknowledges that people can construe the same meaning in a situation, though verbal labels used to represent constructs may not have universal meaning (Button, 1985). In line with literature on the family impact of brain injury (Lezak, 1978), and the brain injury "carer burden" literature (Chappel and Reid, 2002), the "life circumstances" category appears to reflect commonality in construing. Thus, constructs comprised "difficulty with life", being "burdened" and a need to do things "due to the situation". Moreover, role changes, recognised as part of family system changes following brain injury (Tyerman, Young and Booth, 1994), were also apparent in a construct of one carer who described her new role as "is in charge" now. However, "life circumstances" were not all adverse. Indeed, some carers construed themselves as "lucky", "with a good quality of life", in a life which "is controllable". This range of positive and negative constructs suggests that carers construed an array of meanings in their experience.

Similarly, "health and illness" comprised various constructs along a spectrum from positive to negative. Thus, while some carers considered themselves to be "healthy" and "proactive with own health", others were "physically and mentally stressed", "tired" and "sluggish". It has been shown that the caring role can be related to health problems (Marsh et al., 2002) and it appears this has been replicated in this study. However, the apparent range of meanings in "life circumstances" and "health and illness" demonstrates breadth and variety in the way carers make sense of their situation. Thus, the findings could be considered in light of the Positive Psychology literature, in which it has been stated that research should understand "... the entire breadth of human experience, from loss, suffering, illness, and distress through connection, fulfillment, health and well-being." (Linley, Joseph, Harrington and Wood, 2006: 6).

An area which did not appear to contain so much balance in meanings construed was "emotional states". In accord with the literature on carer depression and anxiety (Harris et al., 2001; Marsh et al., 2002), many carers construed meanings relating to affective problems including "fed up", "worried", "sad", "unhappy", and "low". However, once again the meanings carers construed from their experience were not all negative as one carer construed herself as "happy". Moreover, as suggested by the experience corollary (Raskin, Weihs and Morano, 2005), meanings can change. Thus, Carer B described mood being dynamic as he had previously felt depressed, but currently considered he was coping well and feeling less distressed.

While it was not possible to categorise the constructs in pre-existing systems (Feixas et al., 2002; Landfield, 1971; Tyson, 2003), some constructs from all the above categories could be reflected in Viney's (1989) "Images of Illness" categorisation. For example, constructs reflecting "depression" and "anxiety" were apparent. Moreover, the construct "discriminated against" from the category "life circumstances" could be considered as a form of "social exclusion" in Viney's system. However, the majority of other categories did not fit into Viney's system. Thus, it seems that carers of those with a brain injury may share some, but not all, similar meanings to people living with chronic illness.

One area of much disparity between Viney's system and the current one is "future". Viney developed a category of "uncertainty of future". While the meaning of being a carer in this study meant being "in a void" and experiencing "uncertainty of future" for some carers, others construed themselves as "developing", "planning for a future", or were "optimistic". Moreover, hope for the future was not confined to carers, as reported in the Results section. Thus, the meaning in adversity one carer found from her son's brain injury was that he too was now "planning for a future".

It has been reported that carers have the potential to grow and derive meaning from the challenges they face (Farran, Keane-Hagerty, Salloway, Kupferer and Wilken, 1991). Indeed, one of the tasks of adaptation to brain injury has been described as growing through adversity (Perlesz, Furlong and McLachan, 1989). Meaning in adversity, though reported in other carer literatures (Cohen et al., 2002; Hollis-Sawyer, 1998; Noonan and Tennstedt, 1997), has not been reported specifically in brain injury research. However, as reported in the Results chapter, section 3.5.2, some parental carers appeared to have found meaning in their circumstances. It is noteworthy that qualitative comments in an earlier study reflected similar parental sentiments (Knight et al., 1998). In particular, one mother said, "It's made me appreciate and love my daughter more..." (p 476). Knight et al. (1998) also reported that some wives who were carers said their relationships with their husbands had improved. However, this was not replicated in the current study.

Konstam et al. (2003) suggested that for carers of those with Parkinson's Disease, finding meaning in life beyond the carer role led to carer well-being. No research has been undertaken in this vein for carers in brain injury. Moreover, the focus of this study was on the experience of being a carer. However, perhaps it could be hypothesised that some aspects of meaning could generalise beyond the caregiving situation. For example, the carer who found meaning as a "caring person" also spoke of being a carer to various family members throughout her life. Moreover, it could be hypothesised that "future" constructs, such as being "optimistic" and "developing" could provide meaning to other areas of life.

Thus, it appears that carers construed a range of meanings in the role of "carer now". Significantly, while many categories established included a mixture of what appeared to be positive and negative meanings, "emotional states" largely reflected psychological distress.

4.4 Study Limitations

Several study limitations have been highlighted throughout the Discussion. However, section 4.4 addresses limitations in the current study in relation to sample, instrumentation, methodology and data analysis.

4.4.1 Sample Limitations

As previously mentioned, the small sample size limited statistical power, thus reducing the possibility of detecting statistically significant results for the quantitative hypotheses tested. Moreover, the use of an opportunity sample meant it was not possible to control for all sample differences, possibly introducing confounding variables and greater error, impacting on the results. Furthermore, the external validity of the study findings could have been diminished due to the use of an opportunity sample and also selection biases. As described in the Method chapter, staff members at both the brain injury rehabilitation unit and Headway branches de-selected particular carers before the researcher recruited participants; a Headway branch also explained there was a quorum of carers who "always do research when asked", and this transpired to be the case. Moreover, with no funds available for translators, a group of first generation Asian participants who spoke Urdu, and accessed one branch of Headway, could not be approached. However, the reasons why the majority of participants did, or did not, participate in the research were unknown. For example, possible reasons for non-participation could be that carers were coping well, did not consider themselves to be carers, or were very busy and stressed and could not find the time or resources to participate. Given this, the findings of the study can only tentatively be considered valid for carers of those with a brain injury who have contact with services or a support organisation.

4.4.2 Study Instruments

The choice of study instruments selected could also be criticised. Thus, the use of single item measures of behavioural and cognitive problems may not have reflected the range of problems that carers considered the person with the brain injury to experience. However, carers reported that the qualitative descriptions for different problem levels were comprehensive; moreover, the items were developed for this population by a previous member of the host brain injury unit staff. Further criticisms could be levied at certain subscales of the Modified Caregiver Appraisal Scale. As previously noted, the two subscales purporting to measure mastery were shown not to be internally consistent. Furthermore, although the measure of negative caregiving appraisal, the perceived burden scale, was found to reach an excellent level of internal consistency, a scale with this number of items should be tested further on a larger sample before conclusions about its properties in the UK in an acquired brain injury cohort should be drawn.

A concern in relation to use of the use of the repertory grid revolved around completion time, which ranged from 45 minutes to 2.5 hours. This may have been a deterrent to participation for some participants. It also raises issues ethical issues about designing research that is so time-consuming for a sample that may have little time to spare.

4.4.3 Methodological Considerations

Methodological issues regarding the use of the repertory grid are also pertinent. One of the study's main, and most interesting, findings was the degree of tightness of construing found in carers. However, size of the repertory grid can affect tightness of construing (Fransella et al., 2004), with smaller grids leading to tighter construing. The inclusion of a repertory grid with 12 elements and 10 constructs could have led to results regarding tightness of construing based on a methodological artefact. Thus, a control group completing the same size of grid would be required to establish if tightness of construing is particular to this group of carers; this will be further considered in relation to future research, section 4.5. From a methodological perspective there could be further limitations. The use of a non-experimental, non-randomised, cross-sectional design has limitations. Thus, causal relationships cannot be determined from this design, though it has been argued that hypotheses about causation can be made from it (Barker et al., 1994).

4.4.4 Data Analysis

As mentioned, due to sample size, it was not possible to undertake data analysis approaches that controlled for possible differences and confounding variables. Moreover, analyses were largely non-parametric correlations, and thus causation cannot be extrapolated from the findings.

In relation to the qualitative aspects of the study, the development of a unique system for content analysis of constructs requires further testing to establish if it is appropriate for this cohort. The inclusion of constructs generated in Winter et al.'s (1997) and Tyson's (2003) studies could afford the opportunity to undertake such an exercise.

4.5 Future Research

Based on the findings of this study, in consideration with limitations in the study as reported in section 4.4, suggestions for future research are addressed in this section.

A study employing a larger, randomised sample could be carried out in order to establish if the current study's findings could be replicated, and if statistical trends found would indeed become statistically significant. This larger sample would also afford the opportunity to validate the Modified Caregiver Appraisal Scale in the UK. The inclusion of two brain injury groups in the study, traumatic brain injury and acquired brain injury, as well as a third group of carers, for people with chronic disability and psychosocial adversity, could provide the appropriate design to test whether tightness of construing is a methodological artefact of repertory grid size, or is related to the specific role of carers in brain injury. A large sample could also support the application of multivariate data analysis to control for sample differences, such as time since injury, and degree of behavioural problems. A model in which appraisal acts as a mediator between construing and psychological distress could also be tested with a large sample. Moreover, the identified relationship between negative caregiving appraisal and anxiety could be explored in order to understand whether appraisal predicts anxiety; this understanding would be very helpful from a clinical perspective in order to understand which carers may be vulnerable to developing anxiety problems.

Given the current study's findings, and previous findings in brain injury research of the relationship between significant others' construing and rehabilitation outcome (Winter et al., 1997), and wives' construing and relationship satisfaction (Tyson, 2003), it seems important to undertake further research using Personal Construct methodology. Further studies could explore whether carers' construing of the brain injured person can be found to be related to perceived burden, caregiving relationship satisfaction at a statistically significant level, and whether the relationships between construing and caregiving ideology could be replicated. Moreover, the relationship between carers' construing and psychological functioning of the brain injured person, for example apathy and depression, could also be considered. Interventions could then be formulated for carers to promote positive appraisal and minimise negative appraisal of the caregiving situation. Follow-up studies could be undertaken to establish whether these changes impacted on the psychological distress of the carers and brain injured people; the impact on rehabilitation outcome and marital satisfaction could also be investigated where appropriate. Therapeutic implications of interventions derived from Personal Construct Psychology will be discussed further in the Critical Review paper Crawford, (2006).

As previously suggested, the system of content analysis for constructs could be applied to other research in this population, (Tyson, 2003; Winter et al., 1997). This seems particularly important given that it was mainly through qualitative data analysis that positivity in the carer role was apparent. Other qualitative methods could be included to provide enriched data, and triangulation of grid data. For example, carers could be interviewed using a brief semi-structured interview developed based on meanings that arose in this study, and hypothesised findings derived from other carer literatures. The responses could then be analysed using interpretative phenomenological analysis, a method previously combined with repertory grid methodology (Smith 1990; Smith 1995; Smith 1999).

4.6 Conclusion

This study provided a preliminary investigation into the experience of carers for those with a brain injury. In particular, the study focused on the relationship between the intrapersonal construct systems of carers, caregiving appraisals and psychological distress. Replicating previous findings, a significant proportion of carers in brain injury were found to be anxious and/or depressed. Moreover, the relationship between behavioural problems in the brain injured person and carer perceived burden was replicated.

Novel findings include the previously unreported relationship between perceived burden and anxiety, while the finding that carers had very tight construct systems strengthens the recent evidence of this finding in this cohort. As discussed this finding may be of clinical importance for carers and those they care for. Furthermore, other findings suggest that the way carers construe the brain injured person is related to the appraisals they form, thus adding to the evidence of the importance of the role of construing of the brain injured person by family members; this has already been established in relation to rehabilitation outcome and marital satisfaction. A range of meanings of the caregiving experience was derived from the carers' construct systems suggesting that in spite of potentially adverse circumstances positive meanings can be construed.

Due to study limitations, and the need for further investigation of these findings, proposals for future research were discussed.

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Final thanks go to various University of Hertfordshire course team members who have been supportive over the recent years, including my personal tutor Steve Davies.

Appendix 1

Invitation Letter to Participants

Brain Injury Rehabilitation Unit
Address

Tel: 0XX XXX XXXX

Mrs Xxxxx
Address

Date

Dear Mrs XXXXX,

Adeline Crawford, Trainee Clinical Psychologist, has chosen to study the experience of caring for someone with a brain injury for her major research project. Please take a few minutes to read the information sheet and decide if you would like to take part in this research study.

If you **do not wish** to be contacted about this study, please contact the Brain Injury Rehabilitation Unit within the next **three** weeks, and leave a message that you **do not wish** Adeline Crawford to phone you about "The Experience of Caring in Brain Injury" study. If we do not receive a message from you, Adeline Crawford will assume that you are happy to be contacted by her. She will phone you, answer any questions you may have about the research, and arrange to meet with you should you consent to take part in the study.

Yours sincerely,

Mrs Xxxx Xxxxxx
Consultant Clinical Psychologist
Head of Clinical Psychology Services – Acquired Brain Injury

Appendix 2

Information Sheet

Information Sheet Version 4, 01/09/2004

INVITATION TO TAKE PART IN A RESEARCH PROJECT

Title: The Experience of Caring in Brain Injury

Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Contact the main researcher, Adeline Crawford, or her NHS supervisor, Ana Bajo, (details at the end of this form) if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?

The main purpose of the study is to explore how those who care for someone with a brain injury make sense of their experience, and establish whether this has a link to how they perceive caring, and whether they feel emotionally distressed. One of the questionnaires is relatively new and it is hoped this may be found to be helpful in identifying carers' differing perceptions of their role. It is also hoped that greater understanding of how carers make sense of their experience will help in the long-term to identify why being a carer is more distressing for some people than others.

Why have I been chosen?

You have been chosen as you have been identified as the main carer of someone who has had a brain injury. The main researcher aims to recruit a total of 30 people identified as carers for someone with a brain injury.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. However, you may still decide to withdraw at any time without having to give a reason.

If you decide not to take part, or if you withdraw, this will not affect the standard of care you, or the person you care for, receive. Your legal rights will also not be affected.

What do I have to do?
If you do decide to take part, you will be contacted by the main researcher. She will arrange to meet with you at a time and place that is convenient for you, and send you 3 questionnaires to complete before you meet her. The questionnaires require you to rate your responses on a rating scale (i.e. simply ticking, circling or underlining the most appropriate response for you). These questionnaires ask for your views on the experience of caring for someone with a brain injury, and how you feel emotionally. It is estimated they take up to half an hour to complete.

During the meeting, with the main researcher, you will be asked a few questions about the health and day-to-abilities of the person with a brain injury. You will then be asked to complete a "repertory grid" which the main researcher will guide you through. This asks you to think of differences between yourself, the person with a brain injury and people with other kinds of health problems, and then rate them. Full details will be given at the meeting and the researcher will be happy to answer any questions prior to the meeting. The meeting is estimated to take approximately one and a half hours of your time.

What are the possible benefits of taking part?
You may find the opportunity to meet with, and talk to, a researcher about your caring role can be a positive experience. You will also be contributing to testing a questionnaire, which has only been used in the USA previously, to begin to establish if it could be used in the UK to assess carers' differing perceptions of their role. It is also hoped that this research can provide an understanding of why carers experience and find different meanings in their role.

What are the possible disadvantages of taking part?
Taking part in the research may lead you to think about your role as a carer. For some people this may cause them to feel quite emotional. In the unlikely event that you feel very distressed, the main researcher will spend time talking through how you are feeling. She will discuss with you whether some further support or counselling may be advisable, and will provide details of relevant services where necessary.

What if something goes wrong?
This study is covered by the Barnet, Enfield and Haringey Mental HealthTrust indemnity insurance. If you wish to make a complaint, or have any concerns about any aspect of the way in which you have been approached or treated during the course of this study, the normal NHS complaints mechanisms are available to you.

Information Sheet Version 4, 01/09/2004

Will my taking part in this study be kept confidential?
All information which is collected about you during the course of the research will be kept in a locked cabinet. Only the main researcher will have a record of your name as you are provided with a number on the questionnaires and repertory grid information to maintain anonymity. It will not be possible to identify you in any publication of the research findings.

What will happen to the results of the research study?
The main researcher will write the study up for her thesis which is part of her Doctorate in Clinical Psychology programme of studies. It is also planned to write the research study up for publication in a professional journal. All results of the study will be presented in an anonymous way.

A summary of the results will also be sent to all who consent to participate in the study.

Who has reviewed the study?
This study has been reviewed by the Camden & Islington Community Health Services Local Research Ethics Committee.

Contact for Further Information

Ms Adeline Crawford
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You are entitled to, and will be given, a copy of this form. Thank you for your consideration of this research study.

Appendix 3

Consent Form

Consent Form Version 2, 01/09/2004

Patient Identification Number:

CONSENT FORM

Title of Project: The Experience of Caring in Brain Injury

Name of Researcher: Adeline Crawford

	Please initial box
1. I confirm that I have read and understand the information sheet dated...01/09/2004...(version 4) for the above study and have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I agree to take part in the above study.	

Name of Participant	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

1 for participant, 1 for researcher

Appendix 4

Invitation Letter – Headway 2

Brain Injury Rehabilitation Unit
Address

Tel: 0XX XXX XXXX

Dear Carer,

I am currently training to be a clinical psychologist and have elected to study “The Experience of Caring in Brain Injury” for my research project. This research is being undertaken in conjunction with the Brain Injury Rehabilitation Unit, XXXXXX XXXXXX Hospital. I am including carers of patients from the Brain Injury Rehabilitation Unit and those who attend Headway in this study.

Enclosed is an information sheet about my research study. A consent form is also enclosed. Please take the time to read the information sheet and decide if you would like to take part. If you do decide to take part, or would like to talk to me to find out more information to help you decide, please phone XXXX XXXXX, Manager of XXXX XXXXX, Headway, on 0XXXX XXXXXX, within three weeks. With your consent, XXXXX will pass on your contact details to me and I shall contact you to discuss the study.

I hope you decide to take part, and look forward to talking to you.

Yours faithfully,

Adeline Crawford
Trainee Clinical Psychologist

Appendix 5

Demographic and Injury Questionnaire

(including items from Fleminger and Powell, 1999)

Participant Number____

Demographic and Injury Questionnaire

The questions below ask about yourself and the person for whom you are a carer. There are two types of question to answer. One type of question requires you to circle the appropriate answer, e.g. male or female, and the other type requires you to insert your own answer, e.g. your age. Please complete them all as accurately as you can.

Section A - Information about person with the brain injury

1. What is the sex of the person? (Please circle as appropriate)			Male		Female
2. How old is the person?					Years Old
3. What is the ethnic identity of the person? (Please circle as appropriate)					
Black/ Black British	Asian/ Asian British	Chinese	Mixed Heritage	White	Other
4. When did the brain injury occur?					
5. How did the brain injury happen?					
6. (i) Did the brain injury cause unconsciousness? (Please circle as appropriate)			Yes	No (go to question 7)	
(ii) If Yes, how long was the period of unconsciousness?					
(iii) Was the person sedated for part of this time? (Please circle as appropriate)			Yes	No	
7. Following a brain injury, many people experience a period of disorientation, with problems with attention and having no memory for day-to-day events. (i) Did the person with the brain injury experience the above for a period of time? (Please circle as appropriate)			Yes	No (go to question 8)	
(ii) If Yes, how long after the brain injury did the person's memory for events become clear and continuous?					

8. (i) Does the person currently show disturbance in social behaviour e.g. overactivity, aggression, disruptive or agitated behaviour, uncooperative or disinhibited behaviour?
(Please circle as appropriate) Yes No (go to question 9)

(ii) **If Yes**, which of the following **best describes** the behaviour?
(Please circle the appropriate number)

1. Occasional irritability, quarrels, restlessness, but generally calm and co-operative
2. Uncooperative at times, requiring encouragement and persuasion; aggressive gestures, e.g. pushing/pestering others and/or verbal threats; significant overactivity or agitation; intermittent restlessness and/or wandering at day or night; slight damage to objects, e.g. broken cup.
3. Physically aggressive to others; more serious damage to objects or property; more serious and/or persistent overactivity or agitation; frequent restlessness and/or wandering day and night; mainly resistant to help/assistance; mild sexually inappropriate talk.
4. At least one serious physical attack on others; major and/or persistent destructive activity; persistent and serious threatening behaviour; severe overactivity or agitation; sexually disinhibited or other inappropriate behaviour; virtually constant restlessness and /or wandering; severe problems related to uncooperative behaviour.

9. (i) Does the person currently show cognitive problems e.g. problems with memory, language, planning and organisation, visual-spatial information, attention, being orientated?
(Please circle as appropriate) Yes No (go to question 10)

(ii) **If Yes**, which of the following **best describes** the behaviour?
(Please circle the appropriate number)

1. Minor problems that need no action, e.g. some difficulty with orientation to time; slightly distractible and slight problems with concentration; difficulties prioritising tasks or attending to two things at once; a little forgetful but can learn new information; occasional speech mistakes that do not change the meaning of what's being said.
2. Mild problems but definitely present, e.g. often disorientated in time; difficulty finding his/her way in new surroundings; some difficulty concentrating; limited attention span; difficulty organising complex tasks; definite problems learning new information, e.g. names, recalling recent events; able to deal with simple spoken material but some difficulties with understanding and/or expressing more complex language.
3. Moderate problems, e.g usually disorientated in time and often to place, has lost the way in familiar places; problems with attention interfere with ability to think clearly; perseveration disrupts thinking sometimes; has difficulty organising everyday activities; only material that has been very well learned remembered over time; occasional problems recognising familiar people; problems with recognition and production of speech.
4. Severe problems, e.g. consistently disorientated in time and place; hardly able to carry out simple tasks, e.g. make a cup of tea; problems with attention disrupt thinking; severe perseveration; very poor memory, hardly able to learn any new information; unable to recognise or name close friends/relatives; no verbal communication possible.

10. (i) What was the person's occupation before the injury?

(ii) Is the person able to work now? Yes No (go to question B 1)
(Please circle as appropriate)
(iii) If Yes, what is his/her occupation?

Section B - Information about carer

1. Are you Male Female
(Please circle as appropriate)

2. How old are you? Years Old

3. What is your relationship to the person with the brain injury?
(Please circle as appropriate)

wife husband partner mother father son daughter friend other relationship

4. What is your ethnic identity?
(Please circle as appropriate)

Black/ Black British Asian/ Asian British Chinese Mixed Heritage White Other

5. (i) What was your occupation before the injury?

(ii) Are you able to work now? Yes No (go to question 6)
(Please circle as appropriate)
(iii) If Yes, what is your occupation?

6. Do you live with the person you care for? Yes No

7. People who have experienced a brain injury may experience changes in ability in a number of different areas, e.g. planning and organising, memory, emotional aspects, language, physical ability etc. In your view, what are the main difficulties which the person you care for requires help or support with?

8. How many hours per week approximately do you spend supporting or caring for the person with the brain injury? Hours

Thank you for taking the time to complete this questionnaire.

Appendix 6

Modified Caregiver Appraisal Questionnaire

(Struchen, Atchison, Roebuck, Caroselli, and Sander, 2002)

MODIFIED CAREGIVER APPRAISAL SCALE

(Struchen et al., 2002 (Adapted from Lawton et al., 1989))

SUBJECT NUMBER:__________________ DATE:____/____/________

Please complete the following sentence by circling the number of the response that best fits your situation.

I am the ________________ of a person with a brain injury.

(01) Spouse
(02) Parent
(03) Brother/Sister
(04) Son/Daughter
(05) Boyfriend/Girlfriend
(06) Other relative
(07) Friend
(08) Professional Caregiver
(77) Other:____________________

The following statements describe feelings that caregivers of persons with brain injury sometimes have. We are interested in knowing how you are feeling regarding your situation as a caregiver at the present time. The information you provide will help us to understand your concerns and will help us to understand how you have been affected by your role as a caregiver. (In the following statements *this individual* refers to the person with the brain injury.)

Please show us how you are currently feeling by circling the response that corresponds to your answer.

Indicate whether you:
(SD) Strongly disagree
(D) Disagree
(N) No strong feelings either way
(A) Agree
(SA) Strongly agree

1. My health has suffered because of the care I must give this individual.. SD D N A SA

2. My social life has suffered because I am caring for this individual.. SD D N A SA

3. I can fit in most of the things I need to do in spite of the time taken by caring for this individual........................ SD D N A SA

Indicate whether you:
(SD) Strongly disagree
(D) Disagree
(N) No strong feelings either way
(A) Agree
(SA) Strongly agree

4. I feel isolated and alone as a result of caring for this individual.......... SD D N A SA

5. A strong reason for taking care of this individual is to be true to family traditions.......... SD D N A SA

6. I feel confident in my ability to care for this individual's needs.......... SD D N A SA

7. Caring for this individual has interfered with my (my family's) use of space in my home.......... SD D N A SA

8. I am very tired as a result of caring for this individual.......... SD D N A SA

9. I should be doing more for this individual.......... SD D N A SA

10. I can usually come up with different ways to solve problems when caring for this individual.......... SD D N A SA

11. Other people look to me for advice on how to help this individual.......... SD D N A SA

12. I am angry when I am around this individual.......... SD D N A SA

13. I really enjoy being with this individual.......... SD D N A SA

14. It's hard to plan things ahead when this individual's needs are so unpredictable.......... SD D N A SA

15. Frequently, I feel unsure of how to help this individual manage daily problems.......... SD D N A SA

16. Taking care of this individual is a way for me to live up to my religious principles.......... SD D N A SA

Indicate whether you: **(SD) Strongly disagree**
(D) Disagree
(N) No strong feelings either way
(A) Agree
(SA) Strongly agree

17. It makes me happy to know that this individual is being cared for by his/her family.. SD D N A SA

18. Taking responsibility for this individual gives my self-esteem a boost.. SD D N A SA

19. I know that I am doing all I can to help this individual... SD D N A SA

20. I could do a better job in caring for this individual......... SD D N A SA

21. I am pretty good at figuring out what this individual needs... SD D N A SA

22. I am resentful of other relatives who could but who do not do things for this individual................................ SD D N A SA

23. It's mostly this individual's needs that determine how my days are spent.. SD D N A SA

24. This individual seems to expect me to take care of him/her as if I was the only one he/she could depend on.. SD D N A SA

25. I am pretty good at knowing what to do to help this individual.. SD D N A SA

26. This individual's pleasure over some little thing gives me pleasure.. SD D N A SA

27. I have lost control of my life since this individual's injury.. SD D N A SA

28. Caring for this individual doesn't allow me as much privacy as I would like... SD D N A SA

29. The things I do for this individual keep him/her from getting worse.. SD D N A SA

Indicate whether you: **(SD) Strongly disagree**
(D) Disagree
(N) No strong feelings either way
(A) Agree
(SA) Strongly agree

30. Nothing I do seems to please this individual.............. SD D N A SA

31. Taking care of this individual gives me a trapped feeling.. SD D N A SA

32. The knowledge that I am doing my best gets me through the rough times with this individual................. SD D N A SA

33. Helping this individual has made me feel closer to him/her.. SD D N A SA

34. I think of the help I give this individual as an opportunity to repay him/her....................................... SD D N A SA

35. I don't have enough money to care for this individual in addition to the rest of my expenses.......................... SD D N A SA

36. This individual shows real appreciation of what I do for him/her.. SD D N A SA

37. I can take care of this individual with no help – or I could if I had to... SD D N A SA

38. A strong reason to care for this individual is to provide a good model for others to follow............................. SD D N A SA

39. Because of the time I spend with this individual, I don't have enough time for myself...................................... SD D N A SA

40. This individual is beyond being helped by most things I do for him/her... SD D N A SA

41. This individual asks for more help than he/she needs.. SD D N A SA

Appendix 7

Beck Depression Inventory-II

(Beck, Steer and Brown, 1996)

BDI-II©

Date:

ame: ____________________ Marital Status: ________ Age: ______ Sex: ______

ccupation: ____________________ Education: ____________________

structions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and en pick out the **one statement** in each group that best describes the way you have been feeling during the **past two eeks, including today.** Circle the number beside the statement you have picked. If several statements in the group em to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one atement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

0 I do not feel sad.
1 I feel sad much of the time.
2 I am sad all the time.
3 I am so sad or unhappy that I can't stand it.

2. Pessimism

0 I am not discouraged about my future.
1 I feel more discouraged about my future than I used to be.
2 I do not expect things to work out for me.
3 I feel my future is hopeless and will only get worse.

3. Past Failure

0 I do not feel like a failure.
1 I have failed more than I should have.
2 As I look back, I see a lot of failures.
3 I feel I am a total failure as a person.

4. Loss of Pleasure

0 I get as much pleasure as I ever did from the things I enjoy.
1 I don't enjoy things as much as I used to.
2 I get very little pleasure from the things I used to enjoy.
3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

0 I don't feel particularly guilty.
1 I feel guilty over many things I have done or should have done.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.

6. Punishment Feelings

0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7. Self-Dislike

0 I feel the same about myself as ever.
1 I have lost confidence in myself.
2 I am disappointed in myself.
3 I dislike myself.

8. Self-Criticalness

0 I don't criticize or blame myself more than usual.
1 I am more critical of myself than I used to be.
2 I criticize myself for all of my faults.
3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10. Crying

0 I don't cry anymore than I used to.
1 I cry more than I used to.
2 I cry over every little thing.
3 I feel like crying, but I can't.

Continued on Back

______ Subtotal Page 1

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11. Agitation

0 I am no more restless or wound up than usual.
1 I feel more restless or wound up than usual.
2 I am so restless or agitated that it's hard to stay still.
3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0 I have not lost interest in other people or activities.
1 I am less interested in other people or things than before.
2 I have lost most of my interest in other people or things.
3 It's hard to get interested in anything.

13. Indecisiveness

0 I make decisions about as well as ever.
1 I find it more difficult to make decisions than usual.
2 I have much greater difficulty in making decisions than I used to.
3 I have trouble making any decisions.

14. Worthlessness

0 I do not feel I am worthless.
1 I don't consider myself as worthwhile and useful as I used to.
2 I feel more worthless as compared to other people.
3 I feel utterly worthless.

15. Loss of Energy

0 I have as much energy as ever.
1 I have less energy than I used to have.
2 I don't have enough energy to do very much.
3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0 I have not experienced any change in my sleeping pattern.

1a I sleep somewhat more than usual.
1b I sleep somewhat less than usual.

2a I sleep a lot more than usual.
2b I sleep a lot less than usual.

3a I sleep most of the day.
3b I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

0 I am no more irritable than usual.
1 I am more irritable than usual.
2 I am much more irritable than usual.
3 I am irritable all the time.

18. Changes in Appetite

0 I have not experienced any change in my appetite.

1a My appetite is somewhat less than usual.
1b My appetite is somewhat greater than usual.

2a My appetite is much less than before.
2b My appetite is much greater than usual.

3a I have no appetite at all.
3b I crave food all the time.

19. Concentration Difficulty

0 I can concentrate as well as ever.
1 I can't concentrate as well as usual.
2 It's hard to keep my mind on anything for very long.
3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

0 I am no more tired or fatigued than usual.
1 I get more tired or fatigued more easily than usual.
2 I am too tired or fatigued to do a lot of the things I used to do.
3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

______ Subtotal Page 2
______ Subtotal Page 1

______ Total Score

Appendix 8

Beck Anxiety Inventory

(Beck and Steer, 1993)

ME ______________________________ DATE ______________________

ow is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by each ptom during the PAST WEEK, INCLUDING TODAY, by placing an X in the corresponding space in the column next to each symptom.

	NOT AT ALL	MILDLY It did not bother me much.	MODERATELY It was very unpleasant, but I could stand it.	SEVERELY I could barely stand it.
1. Numbness or tingling.				
2. Feeling hot.				
3. Wobbliness in legs.				
4. Unable to relax.				
5. Fear of the worst happening.				
6. Dizzy or lightheaded.				
7. Heart pounding or racing.				
8. Unsteady.				
9. Terrified.				
10. Nervous.				
11. Feelings of choking.				
12. Hands trembling.				
13. Shaky.				
14. Fear of losing control.				
15. Difficulty breathing.				
16. Fear of dying.				
17. Scared.				
18. Indigestion or discomfort in abdomen.				
19. Faint.				
20. Face flushed.				
21. Sweating (not due to heat).				

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Appendix 9

Repertory Grid

(Kelly, 1955)

The Experience of Caring in Brain Injury – Repertory Grid Interview Form

	Carer Now	Typical person with a BI	BI Person Before the BI	Carer Before the BI	Typical Person who is Healthy	BI Person Now	Carer as Imagine be in 5 years time	Typical Person with a MH Problem	BI Person as Imagine be in 5 years time	Carer as Ideally like to be	Typical Person with a Physical Disability	BI Person as Ideally like to be	Emergent	Contrast
1	7	5	2	2	1	7	1	5	1	1	1	1	Disillusioned	Supported
2	1	4	7	7	7	1	7	5	2	7	7	7	Have a future	In a void
3	5	5	5	6	7	2	6	4	3	7	6	7	Healthy	Unhealthy
4	7	5	7	7	7	2	7	5	3	7	7	7	Optimistic	Negative
5	6	4	3	3	1	7	3	3	6	1	2	1	Exhausted	Content
6	7	4	3	5	7	1	7	4	2	7	7	7	Emotionally Determined	Deluded
7	1	7	3	3	1	7	1	4	7	1	1	1	Vulnerable	Independent
8	2	2	7	3	7	1	3	3	1	7	7	7	Safe	At Risk
9	5	4	5	7	7	2	6	4	3	7	7	7	Enlightened	Uninformed
10	7	7	1	1	1	7	4	4	6	1	1	1	Discriminated Against	Valued

Appendix 10

Standardised Order of Element Presentation

Elements - Order of Presentation

1.
   1. Carer (now)
   2. Typical person with a brain injury
   3. Person you care for before had the brain injury

2.
   1. Carer (now)
   3. Person you care for before had the brain injury
   4. Carer before the brain injury

3.
   1. Carer (now)
   4. Carer before the brain injury
   5. Typical person who is healthy

4.
   1. Carer (now)
   5. Typical person who is healthy
   6. Person with the brain injury you care for (now)

5.
   1. Carer (now)
   6. Person with the brain injury you care for (now)
   7. Carer in 5 years time

6.
   1. Carer (now)
   7. Carer in 5 years time
   8. Typical person with a mental health problem

7.
   1. Carer (now)
   8. Typical person with a mental health problem
   9. Person with the brain injury you care for in 5 years time

8.
   1. Carer (now)
   9. Person with the brain injury you care for in 5 years time
   10. Carer's Ideal Self

9.
   1. Carer (now)
   10. Carer's Ideal Self
   11. Typical person with a physical disability

10.

1. Carer (now)
11. Typical person with a physical disability
12. BI Person you care for

Appendix 11

Covering Letter to Participants

Brain Injury Rehabilitation Unit
Address

Tel: 0XX XXX XXXX

Address of Participant

Date

Dear (Name),

Thank you for agreeing to participate in the research study "The Experience of Caring in Brain Injury". Further to our telephone conversation of (date), I have enclosed 3 questionnaires for you to fill in. Please complete the questionnaires prior to our meting on (date) at (location).

If you have any further questions, please do not hesitate to contact me on XXXXX XXXXXX. If you leave a message with a contact number and convenient times for me to phone, I shall return your call as soon as possible.

Thank you for supporting this research. I look forward to our meeting.

Yours sincerely,

Adeline A Crawford
Trainee Clinical Psychologist

Appendix 12

Ethics - Favourable Opinion Letter

Enclosu

Camden & Islington Community
Local Research Ethics Committee
Room 3/14
Third Floor, West Wing
St Pancras Hospital
4 St Pancras Way
London
NW1 0PE

22 September 2004

Ms Adeline Crawford
Trainee Clinical Psychologist
University of Hertfordshire
Hatfield Campus
College Lane
Hatfield
AL10 9AB

Dear Ms Crawford,

Full title of study: The Experience of Caring in Brain Injury: Intrapersonal Aspects From A Personal Construct Perspective
REC reference number: 04/Q0511/28
Protocol number: 5a

Thank you for your letter of 20 September 2004, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chair and Dr Gill Livingston.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the following research site:

Site: NHS - Barnet, Enfield and Haringey Mental Health Trust.
Principal Investigator: Ms Adeline Crawford

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type: Application
Version: 1
Dated: 07/05/2004
Date Received: 18/05/2004

Enclosure 1

Document Type: Investigator CV
Version: 1
Dated: 07/05/2004
Date Received: 18/05/2004

Document Type: Protocol
Version: 5a
Dated:
Date Received: 15/09/2004

Document Type: Copy of Questionnaire
Version: 1
Dated: 20/05/2004
Date Received: 18/05/2004

Document Type: Letters of Invitation to Participants
Version: 1
Dated: 05/05/2004
Date Received: 18/05/2004

Document Type: Participant Information Sheet
Version: 4
Dated: 01/09/2004
Date Received: 15/09/2004

Document Type: Participant Consent Form
Version: 2
Dated:
Date Received: 20/09/2004

Document Type: Response to Request for Further Information
Version:
Dated: 02/08/2004
Date Received: 05/08/2004

Document Type: Response to Request for Further Information
Version: 2
Dated: 12/09/2004
Date Received: 15/09/2004

Document Type: Response to Request for Further Information
Version:
Dated: 20/09/2004
Date Received: 20/09/2004

Document Type: Other
Version: 1
Dated: 02/08/2004
Date Received: 05/08/2004

Document Type: Other
Version: 1
Dated: 07/05/2004
Date Received: 18/05/2004

Enclosure 1

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Notification of other bodies

We shall notify the research sponsor, Barnet, Enfield and Haringey Mental Health Trust via R&D at the North Central London Research Consortium that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 04/Q0511/28 Please quote this number on all correspondence

Yours sincerely,

pp

Stephanie Ellis
Chair

Enclosures　*Standard approval conditions*

Critical Review

of

Brain Injury and the Experience of Caring:

Intrapersonal Aspects from a Personal Construct Perspective

Critical Review

1.1 Summary of Study

A summary of the study by Crawford (2006) is reported below.

Title

Brain Injury and the Experience of Caring: Intrapersonal Aspects from a Personal Construct Perspective

Summarised Research Aims and Hypotheses

1. To establish if the Modified Caregiver Appraisal Scale has the same scale properties in a UK sample of carers as were found in the USA sample
2. There will be positive associations between the severity of cognitive problems in the brain injured person, severity of behavioural problems in the brain injured person and carer perceived burden
3. There will be positive associations between tightness of construing, carer perceived burden, depression and anxiety
4. Carers who are partners will perceive more burden, be more depressed and more anxious than carers who are parents
5. The content of carers' construing will be associated with perceived burden
6. The content of carers' construing will be related to caregiving relationship satisfaction and caregiving mastery
7. Themes reflecting meaning given to the role of caring will be established by qualitative analyses of core constructs

Design

The study used a non-experimental, non-randomised, cross-sectional design.

Setting

The research was set in three centres: an NHS brain injury rehabilitation unit, and two Headway branches that provided day care and rehabilitation.

Participants

All participants had the role of the primary informal carer of someone with an acquired brain injury. They were all partners or parents of the brain injured person. Thirteen carers undertook the complete repertory grid study, and a further six carers completed the Modified Caregiver Appraisal Scale (Struchen, Atchison, Roebuck, Caroselli and Sander, 2002) and the required demographic and injury-related information only.

Main Research Measures

The Modified Caregiver Appraisal Scale (Struchen et al., 2002)
The Beck Anxiety Inventory (Beck and Steer, 1993)
The Beck Depression Inventory-II (Beck, Steer and Brown, 1996)
The Repertory Grid Technique (Kelly, 1955)

Main Findings

Quantitative Findings

1. The Modified Caregiver Appraisal Scale (Struchen et al., 2002) was found to have good internal consistency
2. More than one third of carers were rated as moderately to severely depressed
3. More than one third of carers were rated as moderately to severely anxious
4. Behavioural problems in the brain injured person were positively correlated with perceived burden
5. Perceived burden and anxiety were positively correlated
6. Statistical trends:
   a. Caregiving relationship satisfaction and depression were positively correlated
   b. Caregiving relationship satisfaction and anxiety were positively correlated
7. Structure of carers' construct systems showed very tight construing
8. Content of the construct system:
   a. Construing change in the brain injured person from pre to post injury was negatively correlated with caregiving ideology
   b. Construing difference between the brain injured person post injury and a healthy person was negatively correlated with caregiving ideology
9. Statistical Trends - Content of the construct system:

a. Construing the brain injured person as more changed from pre to post injury was positively correlated with perceived burden

b. Construing difference between the brain injured person post injury and how the carer would ideally like them to be was positively correlated with perceived burden

Qualitative Findings

Three main categories of meanings were construed: life circumstances, emotional states, health and illness

2.1 Implications of Study Findings for Clinical Practice

The study findings (Crawford, 2006) have a range of implications for clinical practice, which are addressed in sections 2.2, Applied Clinical Implications, and 2.3, Service-Related Implications.

2.2 Applied Clinical Implications

The finding that more than one third of participants were depressed, and one third anxious, on clinical screening instruments replicates the results of earlier studies (Harris, Godfrey, Partridge and Knight, 2001; Marsh, Kersel, Havill and Sleigh, 2002), and shows that a significant proportion of carers in brain injury experience psychological morbidity at different time points post injury. This finding validates the need for carers to be addressed as a group with their own needs, rather than being considered merely as having a caring role for those with a brain injury. Moreover, it demonstrates that carers require ongoing assessment of their needs.

As mentioned in Crawford (2006), hypotheses about causation can be made from the results of a non-experimental, non-randomised, cross-sectional design (Barker, Pistrang and Elliott, 1994). The findings that anxiety was positively related to perceived burden, and that there were statistical trends of negative relationships between caregiving relationship satisfaction and anxiety and depression, present possible hypotheses regarding the causes of psychological distress. A much reported relationship between behavioural problems in the brain injured person and perceived burden (Knight et al., 1998; Kreutzer, Gervasio and Camplair, 1994; Marsh, Kersel, Havill et al., 1998a; Marsh, Kersell, Havill et al., 1998b.), which was replicated, also offers a further possible cause of carer distress. As discussed in Crawford (2006), these potential causal factors could be investigated further.

Thus, given the identified needs of individual carers, it is important to consider whether they should be offered a psychological assessment as part of a carer's assessment. Regarding the aforementioned factors that could be predictive of anxiety and depression, a possible option would be to utilise the Modified Caregiver Appraisal Scale (MCAS) (Struchen et al., 2002) as part of the assessment process. Any increase in risk factors could be tracked with the use of this questionnaire before the carer becomes depressed and/or anxious and, should an intervention be undertaken, the MCAS could subsequently be used as an outcome measure. This process would allow early intervention and may appear more relevant to carers than measures of psychological distress.

Intervention could be considered in relation to the study findings regarding tightness of construing. Previous research hypothesised that tightness of construing in significant others can promote better rehabilitation outcomes in those with a brain injury as significant others can provide clear anticipations of their world for those with brain injuries (Winter, Metcalfe and Shoeb, 1997). The carers in this study were also found to construe tightly and, against prediction, tightness of construing was not found to be related to psychological distress. Promoting a tighter structure in the construct system of carers, in the range of convenience (Kelly, 1955) related to the caring role, could therefore prove to be a helpful intervention for carers, with benefits for those with a brain injury too. As it has been found that completing a repertory grid can promote tightening of the construct system (Watson and Winter, 1999), this could provide a clinical intervention to increase tightness of construing in carers.

If carers require a clinical intervention, the question regarding the appropriate type of intervention needs to be considered. Previous studies (Laroi, 2000; Laroi, 2003) have utilised systemic therapy approaches where family functioning has been problematic. Given Tyson's (2003a) findings, and the statistical trends between caregiving relationship satisfaction and depression and anxiety found in this study, systemic therapy may be helpful for relationship difficulties. However, based on the need some carers had for time away from caring, and from being with the brain injured person, individual therapy may be more appropriate. Moreover, findings regarding the content of construct systems of individual carers, reported in section 3.5.4 of Crawford (2006), may mean that a Personal Construct Psychology (PCP) approach could prove beneficial for some carers to enable them to elaborate construing of the brain injured person, or to re-construe possible Kellyan dilemmas. As PCP can be presented in a systemic format (Proctor, 2005), this approach could be used individually, in couples or in families, depending on the clinical formulation.

The findings that the majority of carers were not psychologically distressed, and that qualitative analysis demonstrated the existence of positive meanings in the caring role, suggests a need to understand the factors that are related to these outcomes, in order to be able to promote them in other carers. However, there may be ethical caveats in this process as the promotion of positive meaning in the situation could lead to the carer remaining in a problematic situation.

2.2 Service-Related Implications

Regarding service development, based on the study findings, it may be prudent to consider introducing a workshop to brain injury rehabilitation services for family members. The workshop would afford an opportunity for family members to meet families in a similar situation at the point of accessing services, thus developing possible social supports. The workshop contents could include topics such as the possible relationships between the way the brain injured person is perceived and carer appraisal, and between carer appraisal and psychological distress. Explanations about possible stages of adjustment, and reactions carers may go through, could be included. It could also be advisable to include simple psycho-educational strategies for stress management, including relaxation, making time for oneself, and accessing social support.

It also appears that brain injury services need to evolve in a manner which provides appropriate interventions for carers where necessary; part of this process could include service-user consultation. Thus, psychologically distressed carers, and those who are coping well too, could be consulted to establish what could benefit carers. Moreover, given the findings that carers at various time points post injury may perceive burden, and become psychologically distressed, services should develop to support carers from the point of accessing services onwards.

Indeed, given models of adjustment discussed by Lezak (1986), and Tyson (2003b) in relation to marital satisfaction, it was noteworthy that some carers in this study appeared to fit the stage models well. Thus, the carer at the point of accessing rehabilitation services seemed to fit stage 2 of Lezak's (1986) model in the Evolution of Family Reactions to TBI, in that she felt anxious about the future, and uncertain about what to expect. Moreover, she construed her partner as being selfish and no longer helping, rather then doing things for the community; this seems somewhat similar to Lezak's (1986) description of "unmotivated" and "self-centred". For carers for whom the brain injury had happened earlier, some were depressed and feeling burdened due to their life circumstances; this could be considered stage 4 of Lezak's model. Other carers who appeared to have adjusted well would have reached stage 6 in the model. These findings provide further evidence that carers' needs may change over time, reinforcing the requirement for ongoing services. One implication of this could be the need for a service policy allowing carers to self-refer should further difficulties develop.

Potential models of intervention were discussed in section 2.2. However, various difficulties carers may encounter, as explored in section 3.4, may mean that, whatever services are available, practical obstacles may mean they are inaccessible for carers. Due to this, services may be planned in several ways. Thus, to be able to attend services, some carers may require respite care for the brain injured person, or the service needs to be set up to allow the brain injured person to attend while the carer accesses services. Moreover, the nature of sudden crises experienced by some carers may mean that policies for non-attendance at appointments may need to be less stringent than in other services.

3.1 Reflections on the Research Process

The following section covers the researcher's reflections on the research process.

3.2 Ethical Issues

3.2.1 Opt-Out Procedure

The NHS host organisation for the study has an active research arm. Prior to my study they had adopted an "opt-out" process for recruitment in some studies. While potentially controversial, this had not been considered problematic by the local research ethics committee. Moreover, the studies had similarly been targeting family members of someone with brain injury, or the person with the brain injury, and no negative feedback had been received by those approached in this way.

The brain injury rehabilitation unit (BIRU) requested that I use the same method of recruitment in my study, in part as it had been successfully adopted previously, and, in part, due to staffing constraints there was no administrative time officially allocated to my research, for example for opening mail and taking phone messages. It was also hoped that this method of recruitment could maximise participation as the most recent clinical psychology project had required re-designing owing to the recruitment of only five participants.

The local research ethics committee (LREC) did not receive an adequate number of ethics application forms leading to my application being forwarded to an alternative ethics committee. This ethics committee were very concerned about the method of recruitment and three separate responses to their concerns about this method were required, with the inclusion of letters from other members of the brain injury rehabilitation unit staff, before the study was granted ethical permission.

The protracted ethics process delayed the start date of recruitment for the study greatly. During recruitment, those participants who did not opt out, and were contacted by the researcher, did not express any concerns about the "opt-out" method of recruitment, and, when contacted, some did not wish to participate in spite of not opting out previously. The problems regarding the recruitment method during the ethics process were inconvenient and stressful for the researcher, and the carers apparently did not have concerns about the method of recruitment. However, the researcher would endorse the caution shown by the ethics committee and would not advocate the use of an "opt-out" procedure again on principle.

While participants may not have objected to the use of this method, there is the expectation that participants, who may already be struggling with many responsibilities and their own difficulties, make the time to "opt-out". Moreover, some carers may have felt obligated to the BIRU for the service provided to them and the brain injured person and, due to that, a form of reciprocity norm (Gouldner, 1960) may have operated and carers may not have "opted-out". Issues of powerlessness in relation to "professionals", and the need for reliance on the service may also have influenced carers' decisions. An "opt-in" procedure would have freed the participants from this potential pressure and therefore seems a more ethical approach.

3.2.2 Over-Researched Population

As previously described, the need to consider the above recruitment procedure was, in part, due to adverse experiences with recruitment by a recent clinical psychology trainee. An "opt-out" recruitment procedure may have appeared a possible solution to this problem if one hypothesises that participants are happy to be recruited, but just do not execute opting in. However, as previously described, there may be other explanations for low participation.

Various studies undertaken in the BIRU had included family members as participants, including a recent clinical psychology study on marital satisfaction in which there were recruitment problems (Tyson, 2003a). Although none of the participants recruited for this study had taken part in the most recent clinical psychology studies, two of them spoke of previous participation in studies at BIRU. It may be that some of the participants who opted out of the study had previously participated in research at the BIRU, and were "research-fatigued".

As described in the Discussion chapter of Crawford (2006), some of the participants from one of the participating Headway branches regularly participated in research, and indeed one had previously taken part in a BIRU research project. The amount of research undertaken in the BIRU, and the repeated participation by carers from Headway, raises issues about over-researching a population. Ethically, it could be considered inappropriate to research a population repeatedly that has been shown to be coping with difficult life circumstances, and, in at least a third of cases, to be reaching clinically significant levels of anxiety and depression on screening instruments (Beck and Steer, 1993; Beck et al., 1996). Issues concerning generalisability of results, and alternative study designs will be considered in relation to this issue in sections 3.6 and 3.7.

3.3 Recruitment Process

Given difficulties with recruitment, the process was protracted and involved accessing carers from three centres: the BIRU and two Headway branches. As described in Crawford (2006), certain carers were excluded from being approached for recruitment, and the large majority of those approached did not participate. At the BIRU, those excluded from being approached for recruitment included carers known to be coping with a current acute crisis, such as marital problems, and those where the carer or person with a brain injury may have posed a risk to the researcher. This situation relates to issues of balancing the need for undertaking valid research against risk and the ethics of approaching potential participants who are reported to be in crisis.

Some of the above issues were also apparent in other recruitment centres. The Headway branch staffed by paid employees initially appeared very supportive of the research project, but did not want carers approached who seemed to be emotionally distressed. Moreover, this team at Headway did not want carers to be given the Beck Anxiety Inventory or Beck Depression Inventory-II (Beck and Steer, 1993; Beck et al., 1996). It became apparent that one Headway employee felt overwhelmed in her role and had previously tried to facilitate the access of local mental health services for carers unsuccessfully, including for a carer who later attempted suicide and was found by this Headway staff member. It therefore appeared there were fears regarding access to services based on past failings in services, but it also transpired that the Headway employee held beliefs that talking with someone about their distressing feelings was dangerous and could provoke a rapid deterioration in mental health.

This situation has implications for the ethics of undertaking research with limited service back-up, and the importance of the researcher having knowledge of, and liaising with, local mental health services. Moreover, the need to develop strong working relationships with recruitment centres is of paramount importance, as is the need for the researcher to maintain ongoing dialogue with research supervisors as well as research centres. The experience with Headway also throws up issues around the type of training required for services to be involved, both with this population and with research projects. Finally, given the biases in recruitment, the generalisability of the research findings is also worthy of consideration.

3.4 Reasons for Participation and Non-participation

Generalisability of findings is one aspect that is also pertinent in relation to reasons for participation and non-participation by carers. Some carers recruited from BIRU and from Headway spoke of wanting to "do anything" that could help other carers in the future; this could perhaps be seen as an example of "meaning in adversity" for some carers. Of those from BIRU, six of them also spoke of how grateful they were for the help and support they had received from BIRU and of being happy to participate in any research taking place there. As the researcher did not recruit carers of those who had been discharged from BIRU, the ongoing link with the service may explain this finding. One participant whose husband was being assessed for BIRU asked if participation would speed up access to services for her husband. In spite of advising her that the researcher's role was not related to services and could therefore not expedite access to services, this woman still participated. However, her query about services became more meaningful when it became apparent how at risk she was, how stressful her circumstances were and, moreover, that she construed herself as "discriminated against" (Crawford, 2006).

In the Headway branch voluntarily staffed by carers, other sentiments were expressed by some of the staff. One of the carers who participated described consenting to participate in order for it to be known how bad "the plight" of carers was. Similar views were expressed by two other carers who participated from that Headway branch. This branch was looking for more funding to develop its service at the time, and this need for more money or help may have been reflected here. Moreover, the participants who expressed these sentiments held various roles as they were carers as well as "staff" and committee members at Headway. This may have influenced their outlook and reasons for participating.

Some of those who did not participate expressed reasons for this. One carer spoke of focusing on work now that her husband's difficulties had improved; she also mentioned that she was not sure that she would really be seen as a carer now. Another carer said that she was too busy looking after her husband, but wanted the researcher to present her situation. This carer spoke of "feeling like screaming" at her husband, of listening to him repeat himself "day in and day out", and of having very little time for herself. Another carer spoke of finding it hard to manage everything she had to do for her husband, and said she was fearful that if she participated in the research she would stop and think about her situation and would not be able to cope.

In the voluntarily staffed Headway, two carers who were going to participate faced crises, and could no longer participate. Similarly, one carer in the BIRU faced the breakdown of respite care arrangements and had to re-schedule participation. An amendment to the study was approved, by the appropriate research ethics committee, for qualitative interviews to be undertaken with a small number of participants. However, the circumstances of the two carers who agreed to participate changed and this meant it was not possible to undertake this part of the study.

Thus, the possible reasons carers chose to participate encompassed an altruistic desire to help others; gratitude to services; and a desire to publicise the difficulties carers of those with a brain injury face. Limited evidence suggests possible reasons for non-participation include improved circumstances, with accompanying self-construing of no longer being a carer; being over-burdened and stressed; and being fearful of the impact of talking about what life is really like. For those carers who wished to participate, but could no longer do so, breakdown in support of the caring role was sometimes the reason.

3.5 Research Design

The selection of a non-experimental, non-randomised, cross-sectional design meant the researcher only met with carers of those with a brain injury and at one time point. Moreover, the cross-sectional nature of the design meant carers were seen at different time points post injury. While one injury had only happened five months previously, and the brain injured person was at the assessment stage for rehabilitation services, the majority of people with brain injuries were no longer receiving active rehabilitation. However, the inclusion of carers covering a diverse range of times post brain-injury could be considered a strength in relation to service planning, as described in section 2.3.

To maximise recruitment, and to accommodate participants' needs given the pressures they were under, the researcher saw carers at the location of their choice. For the majority of participants, this meant travelling to their home. This aspect of the study design was time and resource heavy for the researcher, as it involved travelling up to 40 miles to meet with participants. Moreover, in spite of taking various risk-reducing precautions, the researcher felt a degree of vulnerability and, on one occasion, some personal risk meeting carers in their own homes. However, given recruitment problems, expecting carers to spend time and money, and to arrange respite care for the brain injured people who may have required it, would have reduced recruitment. Moreover, such an expectation would have seemed unethical given the pressures with which some carers were faced. Furthermore, it was helpful to have the opportunity to meet other family members, including the brain injured person, and respite carers sometimes. However, meeting family members, and the person with the brain injury, also highlighted the difficulties with which they too were often struggling.

The research measures chosen appeared well-suited to the study design. Several carers commented that the Modified Caregiver Appraisal Scale (Struchen et al., 2002) reflected their views well. Moreover, in spite of concerns about the use of the Beck Anxiety Inventory and Beck Depression Inventory-II (Beck and Steer, 1993; Beck, et al., 1996) from one recruitment centre, carers expressed no reservations about completing the instruments. In fact, many carers spoke of their responses and related them to current circumstances, such as the use of anti-depressants, or to past times when they had felt more or less depressed and/or anxious.

The repertory grid was chosen to provide a unique intrapersonal psychological perspective on the carers, and to depict the meanings they experienced. Moreover, the strength of the repertory grid is the range of data, qualitative and quantitative, that can be derived from a single method. A few carers initially found it difficult to understand the process of completing the repertory grid, and, as reported in Crawford (2006), the element for the brain injured person in 5 years time appeared hard to construe for some carers. However, all participants managed to complete the repertory grid, and some commented on it favourably, including the fact that they realised they construed their situations in ways that they had not previously considered. However, this increased awareness of construing (Raskin, Weihs and Morano, 2005) provoked a tearful response in two carers, though both of them said it was also helpful to have undertaken this process.

3.6 External Validity of Results

External validity, defined as "the degree to which the results of the study may be generalised over time, settings or persons to other situations" (Barker et al., 1994: 145), may have been affected by some of the issues considered in the researcher's reflections. The selection procedures introduced selection biases, while two of the host research centres may have biased results owing to the potentially over-researched populations therein. Moreover, the varied positions taken by staff at the research centres could also have affected the generalisability of the results, as carers may not have been representative of their carer populations. As certain research measures had only been validated on an English-speaking sample (Struchen et al., 2002), and there were no funds for translators, first generation Asian carers from one Headway branch had to be excluded from the study, introducing further doubt about the representativeness of the sample. Furthermore, the research design meant carers were interviewed at only one time point. As there were too few carers in the sample to control for time post injury, it is not possible to generalise results to particular times post injury. Future studies could endeavour to design studies in such a way that would reduce these weaknesses in the hope that the findings could then be more externally valid, and hence have a broader clinical utility.

3.7 Role of the Researcher

The role the researcher took, and was expected to take, varied and proved a challenging part of the research process. Headway services and all participants were made aware verbally, and in the study's information sheet that, although the researcher was a trainee clinical psychologist, she would not be taking a clinical role should unaddressed psychological needs be identified in the research process. However, while the researcher did not provide a clinical intervention, at times carers talked openly of the many difficulties they were facing and the distress they felt. Through liaison with all participating centres, it had been arranged that they would offer extra support should it prove necessary. During research meetings with a few participants, discussion regarding their available supports was undertaken, but further involvement from participating services was not required. However, it was found to be particularly important to use traditional counselling skills of reflective listening and empathy (Egan, 1998) in some research meetings. Moreover, some carers reported that, although they had felt emotionally distressed, the meeting with the researcher had been beneficial. Indeed it became apparent that, for some carers, a degree of experiential avoidance (Hayes and Smith, 2005) was taking place, and the research interview allowed access to the avoided thoughts and feelings.

While there were times that the researcher felt torn between the role of researcher and that of therapist, it became apparent that the Headway branch staffed by unpaid carers may have had alternative, or at least hopeful, thoughts about the role of the researcher. Thus, it was noticeable that some core members of Headway would talk of difficulties other members were having and mention to the researcher that "talking" to her could be very helpful. Moreover, the researcher was invited to attend carer support groups for the entire group rather than for a small period of time for recruitment purposes. Furthermore, the need for a "friendly psychologist" to take an interest in their branch was also spoken about in the researcher's presence. The researcher had to remain very clear about the role she held, and the associated boundaries, but in the face of apparent need, and good relationships with the Headway branch, it felt very awkward at times.

Other anticipated blurring of roles was also experienced. As previously mentioned, a participant recruited from the BIRU asked directly if I could enable rapid access services due to participation. It therefore seems that the accumulated researcher's experiences not only reflect the need for repeated clarification of role, and the maintenance of firm boundaries, but may also highlight the true gaps in health and voluntary services. On a personally reflective level, it proved challenging for the researcher to remain within the research role, not least because she construes herself as a "clinician", rather than a "researcher".

4.0 Conclusion

This critical review was of Crawford (2006) which explored the intrapersonal psychology and idiographic meanings of carers in brain injury using a PCP methodology. Carer appraisals and psychological distress were also measured. The main findings were shown to have a variety of implications for clinical practice and service development, including the need to develop brain injury rehabilitation services to provide assessment and intervention for carers at various time points post injury. Modes of referral, and policies regarding non-attendance at services, were discussed. Furthermore, appropriate models of intervention and presentation, including a workshop format, were also proposed.

Personal reflections on the research process highlighted a number of ethical issues, recruitment difficulties, methodological aspects and boundary issues regarding the role of the researcher. Suggestions regarding how to address some of these areas were also made.

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