

# **DClinPsy Portfolio**

## **Volume 1 of 2**

A portfolio submitted in partial fulfilment of the requirements of the University of Hertfordshire for the degree of Doctor of Clinical Psychology including a thesis entitled:

Shattered Narratives and the Search for Meaning: The Experience of Parents who's child Sustained Traumatic Brain Injury

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# **Volume 1**

## **Table of Contents**

<b>1. Written Exercise 1.....</b>	<b>Page 2</b>
<b>2. Written Exercise II.....</b>	<b>Page 26</b>
<b>3. Small Scale Service Research Project.....</b>	<b>Page 45</b>
<b>4. Literature Review.....</b>	<b>Page 68</b>
<b>5. Thesis.....</b>	<b>Page 98</b>
<b>6. Journal Ready Article.....</b>	<b>Page 209</b>

## **Front Page**

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**Critically review the role and importance of evidence-based practice for clinical psychologists, but with particular reference to working in older adult settings.**

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## 1.0 INTRODUCTION

[1]...scientifically strong randomised designs are now beginning to provide the basis for determining the appropriate mix of therapies for a population...[2] On the one hand, psychotherapies have an established place in mental health treatment [3] on the other, the promulgation of lists of empirically validated treatments for specific disorders is at best hazardous, and at worst may mislead and retard progress.

Shapiro, in Roth and Fonagy (1996: p.xiii) (numbers added)

Shapiro's (1996) comment, although ten years old, will form the basis of this essay. It is of particular relevance as it alludes to the complexities of evidence-based practice (EBP) and its place in the National Health Service (NHS). It will illustrate the strengths and weaknesses of EBP in establishing evidence that clinical psychologists can utilise in the delivery of psychological services to older people.

The initial discussion will consider the role and importance of EBP in relation to current health care trends in the context of NHS legislation and Department of Health guidelines for older people's services. A brief overview of clinical psychology's role and application to older people will follow. This will lead to the first two distinct aspects of Shapiro's observation that EBP has established the efficacy of psychological interventions, and the political implications of this.

Much of the critique will focus on Type 1 evidence (DoH, 1999b) only, as this is regarded as the highest standard in establishing efficacy of therapies. On this issue, Shapiro's (1996) third point will be used to illustrate that while EBP has a place in contributing to knowledge and practice it is a highly complex process which brings many dilemmas: ethical, conceptual, practical and financial. Along with issues in using the evidence base in everyday practice, possible obstructions in its production will be hypothesised, and discussed briefly as they may be relevant to older people's settings.

## **1.1 The role and importance of EBP in the NHS.**

Proponents of the current EBP movement can acknowledge its beginnings in clinical psychology. The Maudsley staff's attack on the efficacy of psychotherapy in the 1960's, using meta-analysis can be cited in this way (Pilgrim, 2003). For clinical psychologists, however, efforts to organise and utilize health research can be traced back to the Boulder Conference in 1949, which saw the creation of the Scientist-Practitioner model of training, where psychologists contribute to research as well drawing on it in relation to their own clinical work. In this regard, the scientist-practitioner model of clinical psychology shares some similarities with the principles of EBP (Milne, 1999).

It is only recently however, that attempts to apply research evidence to everyday NHS clinical practice in a systematic way have made a significant political impact (Rowland and Goss, 2003). This has been achieved mainly by the Government's attempt to 'modernise' the NHS. With principles originally derived from medicine, EBP is a movement that has underpinned government strategies designed around improving standards of care in the NHS through legislation, guidance and recommendations (Department of Health, 1998: 1999b: 2000) the role of which is to guide all professionals in the delivery of safe, effective and cost effective health care. EBP is central to government strategies to increase quality and equity of care for older people through models such as the National Service Framework for Older People (NSF OP) (DoH, 2001). Standard seven of the NSF OP (DoH, 2001), for example, is geared specifically to promoting good mental health in older people and providing access and integrated services to those with mental health problems.

As the NHS is a publicly funded system, there is pressure on limited resources. Evidence based practice attempts to inform commissioners, practitioners, and service users of the most – and least – effective interventions (Roth and Fonagy, 1996). Research – and EBP in particular – and its place within clinical governance (DoH, 1998) are therefore service

*and* politically driven. On the one hand is the political need to contain costs in a publicly funded healthcare system and on the other, to reduce variations in levels of health status across the country, as highlighted by the Black Report (1980). Further, service planning is increasingly based on research evidence and commissioners interpretations of it (Guinan, 1994).

## **2.0 DISCUSSION**

### **2.1 Clinical psychology and ‘older people’**

Clinical psychologists can be distinguished from other specialties working with older people primarily through Level III skills, which are unique to the profession (Boyle and Whitely, 2004). Level III skills can be broken down into the four activities of assessment, formulation, intervention and evaluation: skills, which are directed towards the amelioration of distress among clients. Level III skills, in addition to research expertise and consultancy skills, can lead to a multiplicity of roles for clinical psychologists, which can be extended to service evaluation and development.

There is a growing body of evidence to suggest that older people (decreed by the Government (DoH, 2001) to begin at age 60 for women and age 65 for men) respond well to psychological interventions (Hepple, Pearce and Wilinon, 2002; Woods, 2003). Research indicates that older people can present to services with similar difficulties that are seen in other client groups (depression and anxiety disorders, for example (Roth and Fonagy, 1996)). Research also suggests that older people often present to services with difficulties more commonly associated with the process of later ageing (Stuart-Hamilton, 1994), Difficulties such as depression, anxiety disorders and the dementias can be compounded by the older person’s ability to cope with loss (eg, death of a spouse, loss of health, adjusting to retirement), which are more common to this group than their younger counterparts.

## **2.2 The (current) Type 1 evidence base for older people**

As highlighted above, a significant role for clinical psychologists working with older people involves psychological intervention. Interventions often take the form of some type of therapy (cognitive behaviour therapy (CBT), interpersonal psychotherapy, and behaviour therapy are examples of many). Some evidence of the efficacy of these interventions comes from what is regarded as the 'gold standard' or Type 1 research evidence (DoH, 1999): the randomised control trial (RCT).

The epitome of the efficacy trial lies within the various components of the RCT. This includes narrow measurement procedures with a focus on symptomatic change, categorizing clients by diagnosis without reference to aetiology and employing therapeutic techniques unrepresentative of 'normal' clinical practice (Roth, 1999). The advantage of this scientifically rigorous methodology is internal validity.

Internal validity allows causal inferences about the efficacy of the treatment. A great strength of efficacy research is that it is designed to be unbiased. That is, differences found between the groups cannot be attributed to other factors. Bower (2003) notes that without efficacy research, the possibility exists that a treatment is being credited with potency it does not possess. There are numerous examples of treatments, which were initially thought to be effective, but turned out not to be so under RCT conditions (Cochrane, 1972). Hence RCT status as the 'gold standard' of evidence making up the material of the evidence base through meta-analysis and systematic reviews, which is considered to be the best way to inform practice. One of the earlier triumphs for advocates of EBP was the production of clinical practice guidelines for clinicians working in mental health faced with clients presenting with a variety of conditions (DOH, 2001). It is an appropriate point to remind the reader of Shapiro's comment which began this analysis that:

scientifically strong randomised designs are now beginning to provide the basis for determining the appropriate mix of therapies for a population.

Shapiro, in Roth and Fonagy (1996: p.xiii)

This observation is pertinent and serves as a good illustration of how randomised designs demonstrate the efficacy of psychological interventions for older people. In their comprehensive review of the evidence-base for effective psychotherapy practices for diagnosable disorders, Roth and Fonagy (1996) cite several outcome studies that substantiated the efficacy of interventions (including behavioural, cognitive and brief psychodynamic therapies, reminiscence, group psychodynamic, and self-help bibliotherapy) for older adults with depression, anxiety disorders, sleep disturbance and dementias. Hepple *et al.*, (2002) report similar findings through CBT, cognitive analytic, interpersonal, and systemic therapy. Shapiro's (1996) assertion that, 'psychotherapies have an established place in mental health treatment' (p.xiii) is now clear. This is also important politically, as Roth (2004) comments:

psychotherapy research has established the broad efficacy of short-term interventions, and this has the important political impact of establishing legitimacy for the talking treatments.

Roth (2004: p.494)

By establishing legitimacy for the talking treatments, which may have important political ramifications of funding and service developments for older adults, EBP has demonstrated its role and importance. Yet, with the exception of 'Everybody's Business' (DoH, 2005) the Department of Health has been slow to produce guidelines specifically for older people that promote psychological therapies or clinical psychology. Indeed, the picture is far from clear, and appears to present complexities on several levels.

Analysis of the literature suggests that compared to working age adults, for example, there is a paucity of evidence for older adults. Roth and Fonagy (1996) note that research in the area of anxiety disorders, for example, is severely insufficient. The reason for this is not clear although clues do exist that allow tentative hypotheses. Lee (2003) found poor attitudes among trainee Clinical Psychologists of the amenability of older people to respond to psychological interventions. Such stereotypes may be reinforced by the dominance of the biological or organic model in old age psychiatry and neuropsychology which has focused on 'brain-based' rather than 'psyche-based' explanations for all illnesses and distress in later life. Hepple (2004) has suggested that with the exception of Erickson (1966) psychotherapy research has neglected later life as a developmental stage. With the recent adoption of a 'lifespan' approach to psychological treatments, training courses may begin to remedy this. In addition, Roth and Fonagy (1996) suggest conditions such as dementia are notoriously difficult to research, which may also be a reason for the paucity of evidence. For example, obtaining control groups for research outcomes in dementia is difficult, and without a control group, stability of function and decline are difficult to discern. Further, the success of interventions varies depending on the stage of the dementia.

Although peripheral to the central discussion, the above issues may at best prejudice and at worse impede the evidence base (and its development) for older people. The comparative lack of evidence for older adults suggests they are thought to be less amenable to psychological interventions compared to other client groups (Woods, 2004). Without contradictory evidence, such stereotypes are likely to persist. This is supported by research: if you are a woman over 60 and a man over 65 years of age, and present to your general practitioner with a possible mental health difficulty, you have a far less chance than anyone younger of being referred to, or of receiving, psychological services (Roth and Fonagy, 1996: Woods 2003).

This is particularly important, given the rising numbers of older people and their status as a potentially vulnerable group (DoH, 2001). Woods (2003) predicts that there will be 6.8 million people over-75 years of age in the United Kingdom by the year 2034, compared to 4 million in 1996. This is significant, as in the UK almost half of Department of Health and local authority social services expenditure is accounted for by the 16% of the population over 65 (Audit Commission, 1997). This suggests an effective (and *relevant*) evidence base for interventions for older people is a matter of urgency.

### **3.0 CRITIQUE**

#### **3.1 The definition and utilisation of the evidence base for older people**

The definition of EBP is taken from Sacket *et al.*, (2000) in the medical literature, and is laudable in its intentions: ‘the integration of best research evidence with clinical experience and patient values’ (cited by Leyin, 2002: p.5).

As it originates in the medical literature however, one question immediately raised is how well in principle - and practice - integrating individual clinical expertise with the best available external evidence actually transfers from medicine to mental health, and psychotherapy research in particular. One of the problems in this 'translation' is an issue of measurement. Measuring medical symptoms can be less complex than measuring psychological distress, and its amelioration. Advances in medical technology, for example, allow accurate measurement of someone's white cell count in their blood. As illustrated below, measuring the amelioration of mental health difficulties is fraught with difficulties.

Where evidence exists, applying the philosophy of EBP in everyday clinical work is hardly straightforward, and can raise more questions than it attempts to answer. On a practical level, staff may have difficulty accessing evidence due to lack of time. Literature

searches and interpretation of findings can be a time-consuming process, and perhaps one that service managers may not prioritise given the long waiting lists that most psychology departments have. Also, research evidence often falls short of the 'gold standard' of the RCT, compounding the difficulties staff can have in identifying evidence on which to base their practice. These are just some of the practical problems staff may have in accessing and interpreting evidence. Some limitations of EBP methodology are discussed next.

### **3.2 Randomised control trials – more bronze than gold standard?**

The foundation of the EBP paradigm rests on efficacy research, which in turn rests on the natural sciences paradigm, where observation and measurement are the pillars of scientific investigation. Despite its reverence among advocates, RCT methodology has attracted much criticism. Indeed, while the methodological rigour of the RCT is its scientific foundation, it is also potentially its Achilles' heel.

Shapiro (2002) notes that research findings produced from an RCT may be an unrealistic and over-optimistic guide to the benefits that evidence-based treatments can bring to everyday NHS care. Closer inspection of RCT methodology suggests that a series of trade-offs are made, which has advantages and disadvantages in the way that findings can be generalised to other, less-controlled settings. While such tight controls in design methodology can be commended as 'good science', such 'clear-cut' conditions are rarely seen in ordinary clinical practice. This can be illustrated with a brief discussion of a client on the author's current case-load (details given with client's consent).

### **3.3 A random - and diagnostically messy - clinical case**

A 67 year old male, presenting mainly with depression, but also has a difficult relationship with one of his children, as well as physical health problems which distress

him and his wife. The evidence base (e.g. DOH, 2001; Roth and Fonagy, 1996) suggests that CBT may be useful in working with him to alleviate his depressive symptoms. It is also clear that the other aspects of his presentation appear to influence his depressive symptoms. However, no such guidance from the evidence base exists for his other difficulties, which clearly impact on his psychological functioning. Moreover, this client would probably be screened *out* of an RCT due to his multiple difficulties. His presentation would be considered co-morbid and heterogeneous, and along with his more numerous life experiences as an 'older person', he is too complex to include in an RCT, if indeed such an RCT was commissioned. He is an example of a client who would present too many potentially confounding variables that are difficult, or impossible, to control in such a design. His other problems may be difficult to operationalise, and produce variance that is 'unaccounted for', which will compromise the internal validity of RCT design.

As this case suggest, there are costs to this methodology, and in the next section, problems of measurement within this paradigm, and their application to less-controlled settings are considered further.

### **3.4 RCT: the cost of internal validity and other problems of measurement**

In their meta-analysis of treatments for a variety of conditions (including depression, panic disorder and generalised anxiety disorder ) Weston and Morrison (2001) draw our attention to several inherent problems with the RCT which highlight the trade-offs necessitated by the methodological purity of the design. Clients are screened for their inclusion into a design to maximise homogeneity and minimise the presence of co-occurring conditions that could make findings difficult to interpret. Treatments are usually designed for a single disorder, rather than for non-specific or multiple problems (such as the above case) and are controlled tightly so that within-treatment variance can be minimised. Weston and Morrison (2001) found evidence to suggest that in efficacy

research, the higher the exclusion criteria (that is, the more specific and less co-morbid the diagnosis of the client) the more effective was the treatment. Data (from an American sample) show that co-morbidity among older people is common, for example, between depression and many Axis I and Axis II disorders (APA, 1994) and that this can affect treatment response (Kessler *et al.*, 1996). Co-morbid conditions are therefore outside the scope of an evidence based treatment, as treatment of one condition can, and often does have secondary effects on other symptoms (Weston and Morrison, 2001.) Measuring and subsequently interpreting the outcome of the treatment on more than one condition becomes highly problematic. While no research methodology is without bias, exclusion criteria of an RCT clearly leads to selection bias, which raises ethical questions in terms of who receives what treatment. This suggests that steps taken through RCT design to maximise internal validity are done so at the expense of external validity. In other words, generalisability to other settings is limited. For clinicians who can not pick and choose their clients, the applicability of findings from a RCT to 'ordinary' clinical practice remain unknown. External validity is one problem of transporting research findings to ordinary settings. There are others.

Weston and Morrison (2001) have argued that 'success' of an intervention has no agreed definition. They highlight many ways that efficacy is measured, suggesting each has its own drawbacks. They identify no fewer than four distinctions that are essential in drawing accurate inferences from the data they analysed. These include the multiple potential meanings of efficacy: initial response verses sustained efficacy: treatment states verses treatment of disorders, and empirically unsupported verses empirically *untested* therapies. This latter point resonates with Roth's (2004) comment that research has established the efficacy of *short-term* interventions only. It seems certain modalities are given research 'preference' over others. For example, psychodynamic and eclectic psychological therapies have received little evaluation compared to the therapy of the moment, the ubiquitous cognitive behavioural therapy - which appears rapidly to be becoming the therapy for all difficulties. This may be because short-term therapies are

easier to research than longer-term therapies, which can suffer higher attrition rates, again rendering interpretation of findings difficult. Further, in relation to the multiple meanings of efficacy, decisions about what to include in the numerator *and* denominator of the equation used to measure efficacy (ie, effect size) can lead to very different conclusions of outcome (Weston and Morrison, 2001). Moreover, group means tell us nothing about individual changes. Measurement of 'success' of psychological therapies then is another issue in the interpretation of efficacious treatments from controlled designs.

As the whole thrust of EBP is to influence which treatments are provided and how, the divide between highly controlled research studies and the messy world of clinical practice, is of great importance. It is a divide that Type 1 evidence is doing little to bridge. It is timely then to revisit Shapiro's (1996) assertion and the final part of the quote that began this analysis, that:

the promulgation of lists of empirically validated treatments for specific disorders is at best hazardous, and at worst may mislead and retard progress.

Shapiro, in Roth and Fonagy (1996: p.xiii)

This point highlights the implications of over-reliance on EBP methods. Other critics have argued that the view of evidence adopted by the EBP movement – possibly representing the cultural dominance of scientific positivism - essentially reducing the complex and diverse realm of human distress to numbers through quantification, is not the most helpful or effective way to study human problems as it does not reflect the reality of complex psychological and cultural processes underlying mental distress (Boyle, 2002).

Pilgrim (2002) has suggested that developments in critical realism and social constructivism offer a rich basis for exploring mental health problems in the clinic. The belief that people create their own realities and narratives is a basic tenet of therapeutic

practice, and is derived from social constructionist ideas (Gergen, 1985). For example, in a therapeutic context, meaning is created through language and interaction, where the psychologist works from the client's perspective, exploring their distress through *their* meanings and interpretations of events and experiences. This exploration is often enabled through the bond between therapist and client: the therapeutic alliance. Although critical in the effective delivery of treatment (Roth and Fonagy, 1996) another trade off is between process and outcome where, ignoring psychologist effects appears to be a legacy of RCT design.

### **3.5 The therapeutic alliance in RCT: an uncontrolled variable?**

Wampold and Bhati (2004) argue that RCT methodology treats the psychologist as a fixed-factor. Consequently, the therapeutic alliance in therapeutic outcome is one of the 'great omissions' (p566) from the evidence based movement. They argue that ignoring the providers of treatment (eg., psychologists!) has two consequences. Firstly, ignoring variability among psychologists inflates treatment effects because observed differences between treatments are due, in part, to the variation among psychologists selected for a particular study. Secondly, when psychologists' variability has been examined, it appears that the variability among psychologists is far greater than the variability among treatments. Wampold and Serlin (2000) suggest that few studies, if any, have been designed to evaluate psychologist effects, despite the fact that ignoring them biases results. It appears that clinical researchers have been focusing on the one aspect of therapy that seems to make little difference (that is, the type of therapy delivered) while ignoring an important source of variance that does matter - the psychologist.

To support this, Wampold (2001b) has found that adherence to protocol does not seem to be related to better outcomes: rather, strict adherence seems to detract from the alliance and results in poorer outcomes. Therapists in daily settings who do not have the luxury of all-variable control but may have a wide variety of skill and experience, may routinely

change their therapeutic strategies depending on the progress of the client, rather than adhering to a single approach (as dictated by RCT design). Perhaps this has made therapist-client variables operationally difficult and therefore measuring the alliance is acknowledged as problematic by several authors, (eg. Bordin 1979), and may be a reason why controlled trials have attempted to standardise this aspect of the process.

### **3.6 EBP: limited but valuable**

Given the preceding discussion, it can be argued that current sources of evidence are limited, and therefore provided limited evidence. The emphasis on specificity of RCT design can result in a lack of replication and demands many trade-offs: another important one is that between effectiveness and efficaciousness.

On a speculative level, the effectiveness dilemma can be extended to efficiency. It is particularly interesting in mental health, given the number of 'did not attend' (DNA's) that sometimes occur. Should we use a highly 'effective' intervention when it has relatively poor uptake by clients or use a not-so-effective intervention that has high uptake by clients? Broader tensions exist too. The numerous trade-offs made by the methodology show the difference between research and clinical populations, and may be symptomatic of the disparity in the relationship between theory, research and practice, each motivated by and acting with its own interests (Harper *et al.*, 2003).

Despite the limitations of 'gold standard' methodology, EBP has a contribution to make in indicating appropriate therapies for clients. In some respects, it is succeeding where the scientist-practitioner model has made comparatively far less impact (if research is defined as publication in scientific journals). Indeed, despite over 50 years of effort, the scientist-practitioner model remains an unattained aspiration in successfully connecting research and practice (Milne, 1999).

### 3.7 The evidence base and Level III skills

With its emphasis on the n=1 methodology (Milne, 1999), the individual approach of the clinician may appear to be incompatible with the ethos of EBP which (presently) values demonstrating cost-effective interventions for a *particular group* which characterises methods of investigation such as randomised designs. This does not suggest the two models are entirely incompatible. It is in the therapeutic context where clinical psychology can combine research findings with Level III skills, particularly in assessment and formulating the cause(s) of distress, where the clinician applies clinical judgement, titrating knowledge of research findings to ask pertinent questions about which interventions would be most suitable and effective to help clients (Roth, 2002). The evidence base could inform decisions about an intervention: it is where the evidence base is lacking (in terms of individual client characteristics, personal history, severity of presentation etc) that scientist-practitioner skills are at their strongest and most valuable (Shapiro, 2002) through hypothesis testing, as they can reduce the problems of external validity produced by research findings

This can be illustrated with a rare example of an RCT *specifically* for older people with dementia. Spector *et al.*, (2002) found that compared to a control group, numerous activities based around reality orientation (RO) made a significant improvement in cognition and quality of life for clients in the intervention group. While this was a group intervention, it could be applied at individual level, through Level III skills. For example, assessment and formulation might highlight strengths and difficulties of the client, and give an indication of the fourteen activities that might be beneficial to the client. Where learning may be problematic, principles of operant conditioning, combined with our knowledge of implicit memory (there are many examples of skills learning being preserved in dementia) (Woods, 2003) could be applied with appropriate reinforcement to aid the intervention.

This idea is summarised in Figure 1 (included as the Appendix). Although simplified due to lack of space, the principle is clear. It proposes how ‘real life’ clinical practice, in all its diverse complexity can interact with and compliment EBP, through the activities of Level III skills. To aid this integration, perhaps an increased recognition (and familiarity!) of other approaches (eg., the qualitative paradigm) in conjunction with the quantitative paradigm might increase our understanding of human distress, and inform better our ability to ameliorate it.

#### **4.0 CONCLUSION**

In an NHS which is increasingly being run as a book-balancing organisation, EBP is becoming the mechanism of accountability of resource allocation in a supply-demand model. Despite the conceptual and practical problems that accompany EBP (are service commissioners and budget holders even aware of these?) it would be safe to assume it will be with us for some time to come. It is demonstrating itself to be a potent force with some benefits for service users and providers alike. EBP could become a detrimental enterprise, however, if we head in the direction suggested by Wampold (2004) where EBP has the potential to mandate the kind of treatments clinical psychologists conduct. It is already influencing a top-down system of health care, where ‘experts’ and commissioners’ knowledge of effective therapies comes from the gold standard of research, and subsequently provide funds for them. However, without the evidence that EBP has so far produced for psychologists, the possibility is that we might be more medically led and resourced than we are currently – which might be an even worse situation!

Today’s political climate requires an awareness of the strengths of EBP: to be aware of its weaknesses is even better. As has been argued, with the emphasis on ‘scientific’ rigour that characterise RCT methods, weaknesses include how that ‘evidence’ is derived through methods of measurement, and inclusion and exclusion criteria. Also, ignoring

process factors like the therapeutic alliance will only limit the contribution EBP can make to our understanding of the complexities involved in therapy.

Progress is achieved through constructive challenge. It is therefore imperative that psychologists understand this movement. While some commentators (eg., Bohart, 2003) have shown outright hostility to the whole enterprise of EBP, Winter (2006) argues that our participation in, and contribution to the debate around EBP is vital, however unpalatable its current methods may be with our own theoretical and practical orientations and paradigms. Our participation may influence the future course of events and one of the (potential) benefits of this may be advocacy for our clients.

The challenge faced by clinical psychologists – on individual, service, organisational and political levels - in the NHS is huge, but not impossible. The models of EBP and scientist practitioner are not entirely incompatible, and each can benefit from what the other has to offer, and the therapeutic context is the forum to achieve this. Indeed, if our clients are to benefit greatest from what we have to offer, perhaps the models of EBP and scientist-practitioner, like the NHS, may themselves need modernising to cope better with the increasingly complex demands of modern health care provision. To take Feltham's (2003) assertion a step further, this might be achieved by uniting pragmatism and ambition with methodological purity, which could produce a powerful engine of scientific research.

In relation to older people, it seems clinical psychologists have the additional task of educating colleagues and other professionals to the amenability of many older people's capacity to benefit from psychological interventions. Negative stereotypes of older people are at odds with Government guidelines that stipulate services should be designed around the needs of clients. The NHS Plan (DoH, 2000) states that the NHS of the 21st century must respond to the needs of different individuals and groups within society, and challenge discrimination on the grounds of age.

In educating professionals to the amenability of older people benefiting from clinical psychology services, discrimination can be challenged and services developed. Government rhetoric around issues of 'equality', 'dignity', 'diversity' 'improving quality of life' and 'making sure that the best and most effective treatments are widely and consistently available' (DoH, 2005, p.4) could then be translated through skills, knowledge and service development into something more tangible and effective, like evidence-based practice.

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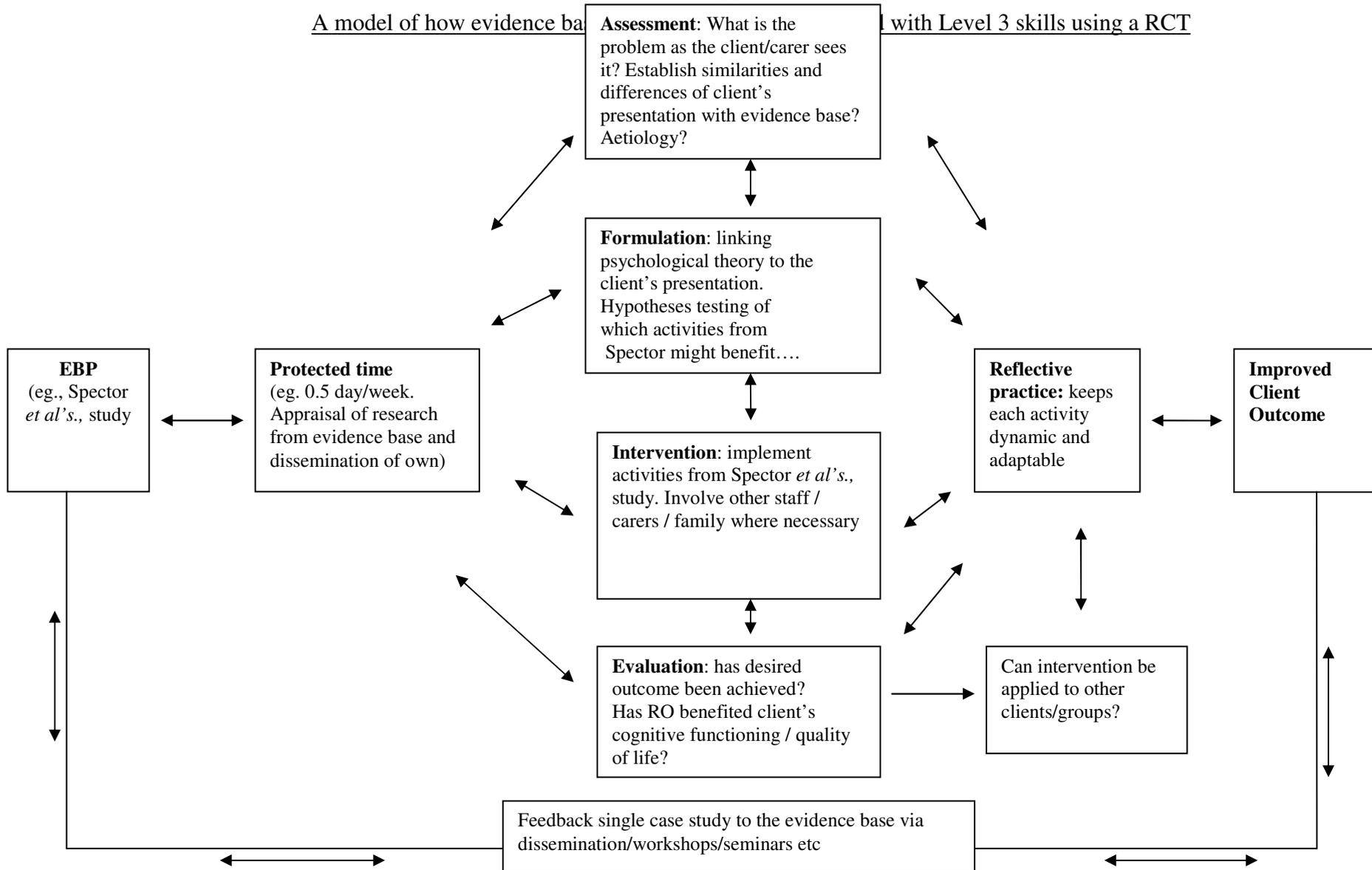
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### Appendix

A model of how evidence base work with Level 3 skills using a RCT



# **Front Page**

## **Essay 2**

Title: Discuss your experiences of working in multidisciplinary teams. How might a psychological understanding of organisations or teams help you make sense of your observations?

University of Hertfordshire  
Doctor of Clinical Psychology Training Course

July 2007: Year 2

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## 1.0 INTRODUCTION

‘To be personally effective in our roles, we need to be clear about the task we have to do; to be able to mobilise sufficient resources, internal and external, to achieve it; and to have some kind of understanding of how our own task relates both to the task of the system in which we are working and to the task of the institution as a whole.’

Roberts (1994: 38)

Roberts’s comment will form the basis of this essay. It is of particular relevance as it alludes to the complexities of multidisciplinary team (MDT) work within the National Health Service (NHS). Multidisciplinary teamwork has emerged over recent years as an increasingly favoured way of organising service delivery, and is a feature of government strategies to improve healthcare provision, such as the NHS Plan and National Service Frameworks (Onyet, 2003). It is one of the key components though which care is currently managed in the NHS. MDT working is thought to convey many benefits to service users and mental health professionals alike such as continuity of care, the ability to take a comprehensive, holistic view of the service user’s needs, the availability of a range of skills, and mutual support and education (Mental Health Commission (MHC) 2006). It has been widely argued that ‘successful’ teams promote positive outcomes for service users (McGrath, 1991).

There is a comprehensive literature dedicated to MDT working (Foster and Roberts, 1998: MHC, 2006: Onyet, 2003). However, in trying to make sense of my observations in MDTs from a psychological perspective I will focus in detail on a considerable and varied body of psychological theory, research and knowledge that when applied to my experience of MDT working can explain processes and dynamics that seem absent from the ‘standard’ literature. My experience suggests that there is much variation in the way teams are set up and operate. Common elements shared by the teams included professional representation, clearly identified leadership structures and the aims of the teams. However, large differences existed in the way the teams functioned, the processes

by which they negotiated the achievement of their aims, and the relationships amongst members. Discussion will focus slightly more on one team rather than the other because of its apparent chaotic functioning.

My arguments are divided into two sections, each incorporating a separate level of analysis. Section 1 will briefly highlight the literature around MDT working by placing the MDT within its historical context, the rationale underlying its functioning and refer briefly to some factors identified in effective and less effective team working. Section 2 will begin with a brief outline of my personal experience of two very different teams, and introduce the second level of analysis. This will incorporate research from Open Systems theory (Roberts, 1994), the psychoanalytic literature around work teams, leadership, and findings from the social psychological study of 'informal groups' (Brown, 2000). Contributions from each will be used to formulate hypotheses to explain my observations.

For example, the psychoanalytic literature around work teams argues that a core generic feature of the MDT is that it constitutes professionals who are trained to work with and are in constant proximity to people in great emotional pain, which is a major source of stress and anxiety for staff working in the helping professions (Stokes, 1994). This view argues that anxiety can be a powerful moderator in the way MDTs function in effecting the roles of individual staff and the goals of the teams.

### **1.1 Rationale for MDT working**

The delivery of mental health treatment and care by multidisciplinary teams has developed in parallel with the demise of large psychiatric institutions (Leff, et al, 2000) and the changing context of mental illness (Moss, 1994). Since the 1950s mental health care has moved from hospitals to community based care, as a result of key social, political and economic trends: factors that all contributed to 'de-institutionalisation'.

De-institutionalisation was also the result of increasing knowledge of the course of mental illness and recovery, which made it clear that psychological concerns and the social environment of the service user needed to be addressed. To do this, a wide range of

skill was essential, and called for occupational therapists, psychologists, and social workers to join with psychiatric nurses and psychiatrists within mental health teams. Thus the multidisciplinary team was established as a central feature of almost all forms of modern mental health care. This has led to current government policy (Department of Health, 2002a) emphasising the value of the multidisciplinary in working together, and is based on the assumption that professions will work together to pursue patient goals.

## **1.2 Multidisciplinary teamwork – what is it?**

The Mental Health Policy Implementation Guide (MHPIG) (Department of Health, 2001a: 2002a) states that, ‘CMHTs...have an important, indeed integral role in supporting service users and families in community settings...they will also continue to care for the majority of people with mental health problems in the community’ (Department of Health, 2001:6-7). Core skills, knowledge and attitudes for MDT working include: assessment, treatment and care management, collaborative working, management and administration, and interpersonal skills (MHC, 2006) which in theory assure the delivery of all bio-psycho-socio-cultural components of intervention and care.

There are two well-established models of MDT working: the key worker model and the case management model. The key worker model has been in use in the UK for some time, whereas the Case Management model is used mainly in the US. The key worker model sees key workers as the prime therapist for each service user, and can come from any of the professional disciplines. Key workers coordinate and lead the care plan and act as the service user and carer’s main point of access to the team. Other key roles in this team include the clinical leader, team coordinator and business manager.

Given this description, the MDT is a task-oriented team that has a defined common purpose and a membership determined by the requirements of that task. Thus, each member of the MDT has a specific contribution to make and its task should be clear. Other factors are known to influence the working of multidisciplinary teams, and the degree to which they are effective. These are highlighted next.

### **1.3 Promoters and inhibitors of effective teams.**

Much has been written about what promotes effective teamwork (Foster and Roberts, 1998: MHC, 2006: Onyett, 2003). The literature is consistent in highlighting a critical factor among these elements as the identification of the team's 'primary task', defined by Rice (1963) as the task it is to perform if it is to survive, and that members understand and work towards this.

However, literature also indicates that a number of potential obstacles need to be addressed in establishing 'best practice' in teamwork. The Mental Health Commission (2006) notes that one of the key barriers to multidisciplinary team working is that mental health (like all) professionals are trained separately with different values and preoccupations – often referred to as the 'silo effect'. Professionals can, for example, find themselves torn between allegiance to their profession and working towards team goals: team members often report low team identification but high professional identification (Onyett et al, 1997b), and may have to overcome more personal obstacles to effective functioning like professional jealousies, role boundaries and communication problems (Atwal, 2005). Not only do different disciplines rarely encounter each other until they are expected to come together and function as a 'multidisciplinary team', but they rarely if ever receive training in multidisciplinary working – a skill in itself (MHC, 2006). This may bring challenges for team members around issues of management, leadership, confidentiality and conflict management and resolution.

These potential obstacles could lead one to infer that there are 'mysterious ingredients' to effective teamwork. However, the psychology literature can demystify and illuminate the complexities of my experience of teamwork. This will be illustrated through reference to two teams in which I have worked.

## **2.0 MY EXPERIENCE OF MDT WORKING**

I have two years experience working in very different multidisciplinary teams. The composition of the teams was identical in terms of professional-representation

(occupational therapist, social worker, clinical psychologist, assistant psychologist, psychiatric nurse, and consultant psychiatrist) and both teams were very well established, but the client groups were different as was their operational structure.

The first was an MDT on a medium-level secure forensic unit. The client group were adults aged 18-65 with severe and enduring mental health problems who had committed offences and were subsequently involved in the criminal justice system, detained under the Mental Health Act (1983). My observations suggested that this team operated in a genuinely democratic way. There was a clear hierarchy and structure of authority operating: the consultant psychiatrist made final decisions regarding the planning and implementation of client care – but only through consultation with team colleagues. My sense was that the psychiatrist valued highly the opinions of all team members, and would only make a decision when consensus within the team was agreed. When there was no consensus, discussions would continue until consensus was reached. Morale seemed high and team members felt valued and empowered.

My most recent experience of MDT working was in a community mental health team in adult mental health. This team supported community based clients aged 18-65 with mental health problems. Clients' involvement with the team was usually voluntary (apart from clients discharged from hospital, some having been detained under section (MHA, 1983)). The leadership structure was such that a business manager led the team and a consultant psychiatrist provided clinical leadership. This team had a much less democratic feel to it, and my sense was that morale was low and there was lots of 'burn-out' amongst team members.

On joining both teams, although my *role* was fairly clear (i.e., psychometric assessment and therapeutic interventions) the definition of the primary task of the teams was never delineated to me. Did this suggest that the task was clearly understood by all, or were they in the same position as me: left to infer the goal of the team? One would assume the primary task of a mental health MDT to be fairly straightforward: to alleviate the emotional and psychological distress of its clients within the parameters of budgets and operational policy guidelines?

## **2.1 Contributions from psychology: Applications through hypotheses**

Examining my experience of MDT working in the context of theory and knowledge from research in Opens Systems theory, the psychoanalytic study of group processes and experimental social psychology can contribute to understanding the observations I have made as part of each MDT. The literature enables hypothesising about the processes and behaviours that I observed in terms of the pursuit of the primary task by the teams and the professional issues discussed above.

## **2.2 Teams as ‘open systems’**

Both teams could be described as ‘open systems’ (Roberts, 1994). According to open systems theory (Miler and Rice, 1967) a crucial factor in effective organisational functioning is the management of boundaries, as boundaries need both to separate and to relate to what is inside and what is outside the system. The boundary needs to be managed so that all the parts function in relation to the overall primary task (Miller and Rice, 1967).

Where most models of management locate the manager above the team, the open systems model instead locates managers at the boundary of the systems they manage. This has the advantage of the manager being able to carry out their function of relating what is inside to what is outside the system. This includes being clear about the primary task, attending to the flow of information across the boundary, ensuring that the system has resources to perform the task, monitoring the task, and how this relates to the wider system.

The psychiatrist on the forensic unit appeared to manage the boundary between the task of the team and that of the wider organisation in a coordinated way that promoted the functioning of the team. Information was disseminated through effective mechanisms, roles were clear and consensus (or conformity – see below) about client progress on the unit seemed highly valued. Conflict in discussions around clients sometimes ensued in the drive for consensus, but this did not interfere with the aim of the task. On occasions I witnessed the psychiatrist (leader) being challenged by different people, which Stokes

(1994) suggests is a 'healthy' element of the leader-follower relationship.

However, I wonder to what extent the apparent effective functioning of this team was enabled by it being a highly specialised Tier 4 service with many resources from the Home Office due to the nature of the client group. Boundary management of the forensic MDT I think was easier than the CMHT, because as it was more 'insulated' and protected from issues often facing 'mainstream services' in terms of resource availability and allocation.

By contrast, the CMHT had a fragmented feel to it. Allocation of new clients to team members was often fraught with resistance by team members due to already heavy caseloads among staff. This may have had serious implications for the primary task, which in turn effected the operation of the team. However, these issues could have responded positively to appropriate boundary management - something that appeared lacking. This may partly explain the seemingly chaotic nature of the CMHT.

My observations suggest that the manager lost her boundary position (Miller and Rice, 1967) as she was too cut off from the system as she was often absent from meetings. This not only distracted her from the primary task, but prevented her from attending to the flow of information across boundaries, particularly from the 'inside out'. Moreover, lack of resources was an ongoing issue in terms of staff for both the manager and team members. My sense was that she was perceived as a manager who could not manage effectively.

On the occasions she attended meetings, she tried to promote a sense of equality within the team through a 'democratic' style of management. This did not work however, as team members looked to her for leadership and support to reduce their anxieties around issues like excessive workloads which clearly induced distress in team members, causing them to question the quality of care they were able to provide to clients. Under these circumstances, along with poor boundary management, anti-task boundaries may have emerged, serving defensive rather than constructive, task-oriented functions (Roberts, 1994). Team members appeared buried in their busy day-to-day clinical work, and new

referrals seemed only to increase anxiety and resistance. This raises the issue of unconscious processes in MDTs and is discussed next.

### **2.3 Teams and unconscious processes**

Despite there being no exact parallel between individuals and institutions, psychoanalysis has contributed one way to think about what goes on in institutions, based on ideas developed in individual therapy in terms of unconscious processes at the institutional level. Using Klein's (1924) ideas of intra-psychical processes that allow us to accept or reject aspects of our selves we find unacceptable, Halton (1994) argues that like individuals, institutions develop defences against difficult emotions, which are too threatening or too painful to acknowledge and geared to one goal: the avoidance of pain. Some institutional defences are healthy but some can obstruct contact with reality and in this way prevent the organisation fulfilling its primary task. This is the position of Wilfred Bion (1961).

Bion distinguished two main tendencies in the life of a group: the tendency to work on the primary task or work-group mentality and a second, often unconscious tendency to avoid work on the primary task, which he termed basic assumption mentality. In work group mentality, members are intent on carrying out a specifiable task and want to assess their effectiveness in doing it. This relates to survival in relation to the external environment. In basic assumption mentality, however, the group's behaviour is directed at attempting to meet the unconscious needs of its members by reducing anxiety and internal conflicts, driven by the demands of the external environment and anxieties about psychological survival. These opposing tendencies represent a wish to face and work with reality, and the wish to evade it when it is painful or causes psychological conflict within or between team members. The extent to which a group engages in either position is determined by Bion's (1961) concept of 'valency': the innate tendency of individuals to relate to groups and to respond to group pressures in their own highly specific way, based on their own complex internal dynamic worlds.

Given that each profession operates through the harnessing of either sophisticated or aberrant forms of basic assumptions in order to further the task (Stokes, 1994) this raises

a difficulty in making a team out of different professions. This is why there is conflict when team members meet, since the emotional motivations involved in each discipline differ.

However, conflict need not impede collaboration on a task or the goal of the team, provided there is a process of clarifying shared goals and the means of achieving these.

This seemed to be the case on the forensic unit. Team members appeared to tolerate frustration, face reality, recognised differences among group members and learnt from experience, which results in effective work (Stokes, 1994). This suggests that team members were able to mobilise their capacity for cooperation and to value the different contributions each could make. In other words, maintaining a balance between their individual anxiety and the aims of the group.

The way the CMHT operated differed greatly from the forensic team. Here, there appeared little capacity to bear frustration and quick solutions were always favoured. Where the forensic team had leadership that enabled the identification of problems and their subsequent resolution, the CMHT appeared to be void of this mechanism. This appeared to manifest in a number of ways.

There seemed to be a lack of responsibility for taking decisions within the team. For example, the manager would open to team members' topics that required decisions, and team members would pass the decision-making responsibility back to the manager. This is in line with Stokes' (1994) description of collusive interdependence between 'leader' and followers, where the identification of a problem requiring attention, action and a solution, seemed lost in other issues.

Such behaviour can indicate that the primary task has been lost sight of. Consequently, I am hypothesising that the team was caught up in anti-task position of managing their individual anxiety, which compromised work towards the primary task. Despite the pace of organizational change the team was required to absorb, this anti-task position may explain the paradoxical feeling of stagnation within the team. This leads me to hypothesise further that an aberrant form of basic assumption was operating, with the

team focusing on their unconscious demands, and defensive functions in particular, rather than the task. This may in turn have led to the emergence of various anti-task phenomena such as defining the methods of the team instead of its aims, and avoiding conflict over priorities (Roberts, 1994), which frequently characterised team meetings. Through such basic assumption, the team followed the leader in an automatic way resulting in group-members losing their individual critical faculties, which are critical in healthy challenging of the leader. This fits with Obholzer's (1994) description where a passive, accepting state of follower-ship is found in a demoralised organisation.

There also seemed to be a culture of paranoia operating, where the team seemed preoccupied with an external enemy (possibly policy changes). This fits with Bion's (1967) notion of aberrant basic assumption fight-flight (baF); the assumption being that there is a danger or 'enemy' that should either be attacked or fled from.

During meetings, there appeared much conformity among staff on issues, yet in 'private' there were regular verbal attacks on the manager. On one level this fits with Moscovici's (1980) conversion theory that sees team members publicly complying with a majority view with little, or no, private attitude change on a particular issue. Obholzer (1994) argues that attacks on the authority figure are a sign of unconscious envy in the group. Envy is a defensive institutional constellation that not only gratifies unconscious wishes but also attacks the pursuit of the primary task. This reduces the amount of pain experienced by the individuals and transfers into team functioning which can prevent the taking up of either a leadership or follower-ship role and is often the result of staff rivalry among team members, but projected onto the leader. The pseudo-democratic style of management adopted by her may have been an attempt to avoid such rivalry, jealousy and envy. However, this 'democracy' only undermined the manager's authority and ability to lead (Obholzer, 1994).

My understanding is that in the last three years, six members of staff have left the team.

#### **2.4 Teams, leadership...and medical dominance**

Such anxieties within the team could have been managed and contained through effective

leadership. Leadership in a team is necessary as it is directly related to the aims of the primary task of the organization (Obholzer, 1994). My experience suggests there are at least three issues in terms of leadership in MDTs: teams need leadership in order to focus on the primary task: the dominance and power of the medical profession in team leadership: that this dominance is reinforced by other members as a result of group processes. Obholzer (1994) suggests that the formal appointing of a 'leader' serves another function by reducing anxiety in the other group members given the nature of their jobs through working with distressed clients. Power therefore can be projected by team members onto the leader which enables them further to take the leadership role.

Clarity is also important in authority, leadership and organisational structure, and essential for the competent functioning of any organization, and its focus on the primary task. Here, authority is defined as 'the right to make an ultimate decision...which are binding on others' (p39) and is derived from one's role in and exercised on behalf of that system. Psychoanalytic thinking suggests that the way in which that authority is exercised by the person holding authority can also depend on the nature of their relationships with the figures in their inner world, particularly the way past authority figures are internalized from their formative years (Halton, 1994). The attitude of such 'in-mind' authority can be crucial in affecting to what extent, how, and with what competence external institutional roles of authority are exercised.

In both teams, consultant psychiatrists held seemingly powerful positions, and ultimately decided client treatment plans. Gair and Hartery (2001, p4) define medical dominance as '...the exercise of disproportionate power and influence in the process of...decision-making by doctors: disproportionate that is, to their position as only one of several professions represented within teams.' The reason for this dominance is not clear to me, although I think a host of variables operate that consciously – and unconsciously – sanction the authority of medics in MDTs by other team members. This is supported by the literature (e.g., Bates and Lapsey, 1985).

Leadership in the forensic team appeared to work well. Obholzer (1994) suggests that when a judicious mix of power and authority is exercised, it makes for effective on-task

management. Perhaps because of the way power and authority was exercised by the psychiatrist, he appeared well respected by team members. Problems identified by the team that required attention and action were not avoided or lost among other issues. Perhaps because of these factors, the team had a strong sense of cohesion and integration within it. I would therefore hypothesise that through effective leadership, this team was operating at a level of work group mentality by making sophisticated use of basic assumptions, which enables constructive pursuit of the primary task (Stokes, 1994). Another contributing factor in the pursuit of the primary task may have been identification with the leader, which is thought to promote many positive aspects of team functioning. My sense was that team members identified with him in his role as clinical leader. Stokes (1994) suggests that follower-ship occurs when group or team leaders personify certain ideals of the followers. Such shared ideals in the context of this MDT could be the desire to improve quality of life for clients.

By contrast, leadership in the CMHT came from two sources – which may have been one reason for the fragmented feel of the team, as neither people had the personal qualities to exercise authoritative leadership. Clinical leadership came from a consultant psychiatrist, and ‘business’ leadership came from the team manager. Both however, were often absent from meetings. This may have given the team the sense that clinical and business ‘boundaries’ were neither consistently nor effectively managed.

The study of ‘informal’ groups offers another insight into leadership and dominance – albeit organisationally sanctioned elevated status in MDTs - of one profession over others.

## **2.5 Teams: Observations from ‘informal groups’**

Studies from social psychology have demonstrated that in informal groups not all roles within a group are equally valued or carry the same power to exert influence or control over others (Brown, 2000). Status differentials within informal groups were first discovered by Sherif and Sherif (1964) in their studies of adolescent gangs. It was found that role positions carry with them expectations of the kind of behaviour that the person occupying them will engage in. Ordering the group in this way may help stabilise the

group and allow it to concentrate more effectively on achieving its goals – in the case of the MDT, its primary task. Sometimes, this can generate self-fulfilling prophecies so that people conform to the level expected of them.

This also facilitates conformity within a group (Martin and Hewstone, 2000). Conformity has been shown to be a moderator in the functioning of a group, although this may not be so powerful in the context of an MDT due to its professional membership with (theoretically) clearly defined roles and expectations. Nonetheless, authority is promoted by the ‘prototype’ of a professional role held by team member ‘x’, which may cause that member to behave ‘normatively’, to the extent that people within the team agree on that prototype. This is most clearly explained by the role of psychiatrists in MDTs. The ‘prototype’ of how the psychiatrist should behave (as being ‘in charge’ and providing clinical leadership?) will generate what Hogg (2001) calls ‘attitudinal consensus and normative homogeneity’ (p63). So, not only does the psychiatrist have organisationally-sanctioned power and authority within the team, but the way the way s/he is perceived as a prototypical ‘authority’ figure means this power and authority is endorsed by team members of self-perceived lower status, their perception of which is reinforced by organisation structure. Jones’s (2006) finding that non-medical staff felt inferior to psychiatrists may in part explain this.

A facilitator of influence and subsequent conformity is conversion theory (Moscovici, 1980). This posits that all forms of influence result in conflict and individuals are motivated to reduce that conflict. In the face of a discrepant majority, as may be the case in team discussions, individuals engage in social comparison and since identification with a majority is desirable those disagreeing with the majority view conform to a majority decision without the need for a detailed appraisal of the majority’s message. Such perceptions of power and the process of conformity to the majority decision invariably impact on team decision-making. Moscovici defines conversion as ‘...a subtle process of perceptual or cognitive modification by which a person gives up his/her usual response in order to adopt another view or response, without necessarily being aware of the change or forced to make it’ (Moscovici and Personnaz, 1980, p271). Moscovici’s account of

influence is a cognitive explanation where influence results from the degree of elaboration of the source's message – in the case of MDTs, the psychiatrist.

The MDTs I have worked in have by definition through their structure and operation formalised and promoted role and status differentials and conformity between and within members in the pursuit of the primary task. In combination with boundary management, the unconscious motivation to reduce anxiety and the notion of formal leadership within teams, Moscovici's (1980) account of influence and conversion enables another hypothesis of how agreement and decisions were reached, and team functioning in the broader context.

### **3.0 CONCLUSION**

As the MDT is a human service enterprise, its 'dominant throughput' is people – and usually people in pain (Roberts, 1994). People enter this system in one state and - as a result of the conversion or transformation process within – leave in a different state. Thus, defining the primary task requires thinking first about what this intended or desired 'different state' is, and then about how the system proposes to bring this about in the context of the team. While the literature agrees that defining the primary task is paramount, that definition is itself complex and can vary according to one's position in the team and larger organization.

I have separated different elements of the literature both in an attempt to bring clarity to my arguments, and to illustrate that the process and behaviours by which the primary task is achieved is mediated by a number of variables that interact simultaneously in highly complex and dynamic ways. While the literature is replete with issues associated with team working, the psychological literature has enabled hypotheses in explaining the processes and behaviours that I have witnessed in two very different multidisciplinary teams.

One team – through clear and effective clinical leadership, effective boundary management, healthy challenging of leadership that enabled constructive harnessing of

individual and collective unconscious processes – seemed to achieve this goal. The other – through ineffective management strategies, poor boundary management, authoritarian styles of leadership and conformity, and lack of containment of the team’s conscious and unconscious anxieties, did not.

As publicly funded entities with a specific remit of delivering high quality health care to those in need, one would hope multidisciplinary ‘teams’ are effective in working towards their primary task. However, to the extent that such powerful influencing mediators are present within multidisciplinary teams, the degree to which this aspiration is realised is not clear to me. My experience suggests that when the variables discussed above interact in a constructive way, this task-oriented team that has a defined common purpose and a membership determined by the requirements of that task can work in the way for which it was designed - to improve healthcare provision for service users and their families.

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**Small Scale Service Related Project**

**An Audit of the Provision and Accessibility of Psychological  
Therapies in Older People's Community Mental Health  
Services**

**Graham Williams**

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## **ABSTRACT**

This audit attempted to measure the provision and accessibility of psychological therapies for older people in community settings in an NHS Foundation Trust over summer 2006. In addition to audit questions, the findings were compared to standards from local, national and government guidelines.

In relation to these standards, results were disappointing. 'Therapeutic conversations'- a type of therapy that has no evidence base was by far the most frequently accessed and available psychological therapy. Evidence-based formal psychological therapies were delivered by only a handful of trained staff, and there is little choice in the therapies that older people received. Staff training was also an issue. There was a broad perception among staff that the waiting list for psychological therapies was too long, which deterred staff from making referrals for psychological intervention. The level and frequency of supervision also fell short of recommended standards.

By comparison, there was far greater range and quantity of therapy available in adult mental health services, although supervision also fell short of standards within this service.

Recommendations are made and limitations of the study discussed.

## CONTENTS

	Page
1. Introduction	48
2. Design and Method	52
3. Results	54
4. Discussion	59
5. Conclusion	62
6. Recommendations	62
7. Limitations of the Survey	64
8. References	66
9. Appendix	67
The Audit Tool	

## **INTRODUCTION**

### **Collaborators**

A Consultant Clinical Psychologist and Head of Psychology Services for Older Adults supervised the audit. Another trainee and my self conducted the audit jointly with the support of the Trust Audit Department and Research Tutors at the university DClinPsy Programme,

### **Ethics**

Consultation with the Trust's Research and Development Department, and research tutors suggested that as the method of investigation was a survey that sought to identify whether or not standards of practice had been met, it was classified as an audit and as such ethical approval was not required. Moreover, the audit targeted only staff and involved no service users.

The questionnaire stated clearly that participants were not obliged to take part, and could refuse to do so without penalty or prejudice.

### **Background**

Of interest to this audit was what therapies were available to older service users, who provided therapy, what training and supervision staff had in relation to therapy and what training they would like.

The availability and accessibility of psychological services is politically topical, both in terms of targets set by the government to improve standards, make psychological approaches a core part of modern mental health services (e.g. DoH, 1999a: 2001: 2004) and service user demand. Users of mental health services consistently place access to psychological therapies at the top of their list of unmet needs (Mind, 2002). In terms of

Department of Health guidance, Standard two of the National Service Framework for Mental Health (DoH, 1999) 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, and
- be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it.’ (p28)

Roth and Stirling (2005) observe that psychological treatments for mental health problems are now well established, with a particularly good evidence base for Cognitive Behavioural Therapy (CBT). Although the evidence base for psychological treatments for older people is smaller than that for working age adults, it still supports the efficacy of psychological approaches with this client group (Roth and Fonagy, 1996) and is growing exponentially (Woods, 2003). Despite this growing evidence base, lack of access to psychological services is also identified by Roth and Stirling (2005), which means that the prevalence of people with mental health problems in the community not receiving psychological therapies is high.

Standards exist specifically for the provision and delivery of psychological services for older people with mental health difficulties (DoH, 2001). Standard Seven of the National Service Framework for Older People (NSF- OP) requires that ‘Older people who have mental health problems have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support, for them and their carers’. Standard seven also stipulates the hallmark of good mental health services as being ‘comprehensive, multidisciplinary, accessible, responsive, individualised, accountable and systematic’ (p91).

The Department of Health (2004) states that attention needs to be drawn to the psychotherapeutic needs of different groups, that include older people. Recommendations include that psychological therapies have an important place amongst the range of treatments available as part of comprehensive, user-centred mental health services. Finally, there are issues of accessibility relating to the timing of psychological therapy

services concerning long waiting lists and waiting times. There is also Department of Health and Trust pressure to meet 13 week waiting targets. Service users and carers are particularly concerned about this (DoH, 2004).

This audit assessed availability and accessibility of psychological therapies within older peoples' community settings in relation to these standards and recommendations. It compared findings with a recent similar audit in adult mental health services. The rationale for this is that psychological therapies for younger and older people should be comparable given that Standard One of the NSF-OP (DoH, 2001) requires that there is no age-discrimination to older people in terms of accessibility and availability of health services, and that Services should be available on the basis of need rather than age.

Finally, within the Trust there is considerable recognition of the need to develop psychological services to older people. The Assurance Framework for 2005-6 set an objective for older people's services to "review present skill mix and posts and take action to increase skills of existing staff to increase access to therapies for older people". Similarly the older people's clinical governance plan 2005-6 set an objective of "undertaking a review of psychological services within older people's services, agreeing priority areas in line with NICE guidance on depression and anxiety and improved provision and access to psychological services; working towards equal access to available resources". Given these governance plans within the Trust and the ever-increasing evidence base to support the application of psychological therapies to older people in conjunction with key Department of Health recommendations, this audit of the provision and accessibility of psychological therapies was both timely and necessary.

### **Audit Questions**

The audit attempted to address the following questions:

- 1) What psychological therapies are available to older service users in terms of range and quantity?

- 2) Who provides psychological therapies to older people?
- 3) How much supervision did staff receive for psychological therapies they provide?
- 4) How many staff had trained in the delivery of psychological therapies to older people but not using their skills for any reason?
- 5) How many staff wanted the opportunity to train in the delivery of psychological therapies to older people?
- 6) To what extent did the waiting list impact on staff's likelihood to refer older people for psychological therapies?
- 7) How did the provision of psychological therapies in older people's psychology services compare to the provision of psychological therapies to younger people's services?
- 8) Of additional interest were talking approaches used by mental health practitioners with the intention of being beneficial to service users but which were *not* recognised as formal psychological therapies. For the purpose of this audit, these were referred to as 'therapeutic conversations'. This was included in the recent audit of psychological therapies in AMH services, and thus inclusion here enabled a comparison between the services. A hypothesis underlying the audit was that little formal psychological therapy was being provided to older people and that 'therapeutic conversations' would be the most popular.

The findings of the audit were compared to four standards:

*Standard 1:* 'Psychological therapies should be routinely considered as a treatment option when assessing mental health problems.' (Everybody's Business, 2005, p50)

*Standard 2:* 'Access to psychological therapies should not be unreasonable restricted by

waiting lists.” (Everybody’s Business, 2005, p50)

*Standard 3:* ‘All staff involved in psychological therapies services should have formal clinical supervision and continuing professional development programmed into their work.’ (Everybody’s Business, 2004, p50)

*Standard 4:* ‘NHS services will be provided regardless of age, on the basis of clinical need alone.’ (Standard 1 National Service Framework for Older people, p16).

## **DESIGN AND METHOD**

The audit was cross-sectional. The data was gathered over summer 2006.

### **Participants and inclusion criteria**

The audit targeted only community staff working within older people’s mental health services, all of who were invited to take part. The rationale for this was that as the ‘target’ group they could provide the information to answer the audit questions.

These included staff from five Community Mental Health Teams (CMHT) and four day hospitals. Target staff included: occupational therapists, physiotherapists, psychiatrists (including consultants, specialist registrars and junior doctors) nurses, psychologists, social workers, and support workers. Staff working on in-patient settings, were excluded. The total number of staff eligible to participate was identified by this and compared to those who *actually* participated, so that an accurate response rate was ascertained.

### **Procedure**

The Trust Information Directorate was contacted to obtain a list of all staff working with older people in community settings. This included individual staff members, their professional group and their base.

Team managers were telephoned by the trainees and the audit and the rationale behind it was introduced to them. Permission was then sought for the trainees to visit team meetings to meet team members.

Having gained consent, the trainees visited teams of all staff groups between July 2006 and September 2006 to collect data. On arrival at team meetings, the audit was introduced to staff and they were invited to participate. It was also made clear to them that they could decline to participate without penalty.

It was hoped that attending team meetings would have the advantage of yielding a higher response rate than a postal survey (typically producing on average around 30%) and therefore increase reliability of the findings. This hypothesis was borne out in part although it brought its own methodological problems (discussed below). Different geographical regions of the Trust were covered by each trainee, so no data collection was replicated. I covered the East part of the Trust, my colleague the West. The data for each region was then pooled together for analysis.

## **Measures**

A questionnaire was used to gather data. This was based on a similar recent audit of adult mental health services, which had the advantage of enabling a comparison of service provision of psychological therapies between older people's and adult mental health services. The measure was modified for use with clinicians working with older people and was piloted with a small sample of staff to assess its user-friendliness, and is included as Appendix I.

## **Analysis**

Descriptive statistics were used to analyse audit questions, using SPSS software. The first step in interpreting the data was a plausibility analysis, the purpose of which was to remove responses that were unreliable. No such responses were found or removed.

## RESULTS

In terms of the response rate, questionnaires were completed by 72 out of 130 (55%) staff working with older people in the community. From this response rate of 55%, the range and quantity of psychological therapies delivered by staff are summarised in Table 1

It should be noted that Question 1 was multiple response, where by respondents could tick all types of therapy they as individuals delivered, hence the responses exceed 72 cases and 100%, respectively.

**Table 1. Number of Cases Delivering Types of Therapy**

Type of Therapy	Responses	
	Number of Responses	Percent of Responses
Formal Therapy	13	18%
Therapies specific to older people	40	56%
Therapeutic conversation	51	71%
Other type of therapy	8	11%
No Therapy	14	19%
<b>Total</b>	<b>72</b>	

The data indicate that many staff provided at least one and frequently more than one type of therapy. 18% of cases deliver 'formal' psychological therapy. The most frequently delivered therapy - by the large majority cases (71%) - is 'therapeutic conversations'. This is a particularly interesting finding given there is no evidence base for its efficacy. Eight respondents delivered 'other' types of therapy. These include, for example, solution focused therapy, eclectic counseling and anxiety management. Forty cases (56%) deliver therapies specific to older people. This type of therapy is of great value for clients with dementia, and this finding raises an interesting question in relation to the number of

clients involved in older peoples' services with dementia as opposed to any other presentation (e.g., OCD, bereavement, etc.).

In relation to the context in which the different types of therapy are delivered, the results are summarized in Table 2.

Table 2 shows that many individual staff delivered therapy in a number of modalities.

**Table 2 Therapies Provided and their Mode of Delivery**

Mode of Therapy Delivery	Responses	
	Number of Cases	Percentage of Cases
Individuals	56	78
Couples	21	29
Groups	27	38
Family/Carer	43	60
Computer	4	6
Internet	1	1
Telephone	29	40

78% of respondents deliver therapy on an individual basis, with family/carer therapy the next most frequently practiced. Therapy conducted by telephone is practiced by 50% of cases. Therapy through Information Technology (i.e., the internet) does not seem to have made much of an impact on services.

An interesting finding is that there is a split in terms of responses about whether or not staff feel they devote enough time providing (any type of) therapy that meets clients' needs. 46% reported they do think the time they spend delivering therapy is adequate to meet clients' needs, and 46% do not. 8% of responses were undecided. This is a significant finding and may be of interest to service managers.

Regarding whether or not staff believe older adults have a choice in the type of therapy they receive, 46% said ‘yes’, and (40%) responded ‘no’; 14% did not know. Given the current emphasis on ‘choice’ in the government modernisation programme for the health service (DoH, 2004), the observation that 40% of cases do not believe older service users have a choice about receiving psychological therapy, is another significant finding.

51% of staff routinely considered referring older adults for psychological therapies, while 36% did not. Four cases could not answer either way. Of those that did not consider routinely referring, the two most common reasons cited by staff were that the waiting list was too long (17 cases- 24% of cases) and equally that there was limited availability of psychological therapies available for older people (17 cases – 24%). In some respects, this belief is borne out in the results, where very little evidence-based, formal therapy is available. 82% of respondents thought that access to psychological therapies was ‘unreasonably’ restricted by waiting lists. The type of therapy provided for each mental health difficulty by staff is highlighted in Table 3.

**Table 3. Frequency of Types of Therapy provided by Staff for Mental Health Difficulties**

Mental Health Difficulty	Type of therapy provided and number of staff providing that therapy			
	Formal Therapy	Therapies Specific to Older People	Therapeutic conversation	Other type of therapy
Dementia	7	36	51	2
Depression	13	30	54	4
Anxiety	14*	26	52	2
Bereavement	10	18	44	1
OCD	6	11	27	-
PTSD	4	7	19	-
Psychosis	2	21	35	1
Self-harm	5	13	23	1
Personality Disorder	7	18	31	1

Sexual Disorders	3	6	13	2
Other Functional Mental	2	4	17	1

\* NB. More staff provided formal therapy for anxiety than ‘formal therapy’ per se. A possible reason for this is discussed in the study’s Limitations.

For all mental health difficulties, a consistent finding was that ‘therapeutic conversation’ was the type of therapy practiced most frequently. An interesting observation is that therapies specific to older people, which have an evidence base for types of dementia, were also used for many difficulties (e.g., psychosis, OCD) for which there are no guidelines.

Among professional groups, nurses most frequently provide all types of therapy to clients. However, overall numbers providing formal therapy are low, with the exception of psychology staff, all of whom provide formal therapy. In terms of staff training, many have completed ‘short’ courses. Only 17% of the sample reported education at degree level and above. Very few staff however, had training in formal therapy. This suggests that some staff providing formal therapy were not trained to do so. Twelve cases reported not using their skills and qualifications related to psychological therapies: lack of time was the most frequently cited reason for this. On a related issue, twenty-four staff reported a preference to develop additional skills in formal therapies.

Clinical supervision is recognized as a valuable mechanism in the delivery and process of therapy, and was also measured by this audit. The results are summarised in Table 4.

**Table 4. Number of Cases receiving Clinical Supervision for the Therapy they provide.**

<b>Types of Therapy</b>	<b>Number of Cases Providing therapy</b>	<b>Number of Cases receiving clinical supervision</b>
Formal Therapy	13	8
Therapies specific to older people	41	22

Therapeutic conversations	50	30
Other types of therapy	11	3

Of thirteen respondents providing formal therapy, only eight reported receiving supervision. Twenty-two of 41 (54%) respondents reported receiving supervision for providing therapies specific to older people. The highest number of respondents receiving clinical supervision did so for ‘therapeutic conversations’, totalling 30 staff. The length of supervision varied. 22 cases reported receiving supervision once a month, with ‘once a week’ reported by only two staff. Given the importance placed on supervision in monitoring and delivering therapy, the findings are not encouraging.

### **Adult Mental Health and Older People Services – How Do They Compare?**

An accurate comparison between the two services is methodologically problematic, as staff participation in the adult mental health (AMH) audit was far higher, which prevents any firm conclusions being drawn. However, the data does allow some observations between the services. Of the 166 Staff surveyed in the adult mental health audit, 137 (83%) provided psychological therapy, compared to 13/72 (18%) of staff in older people’s services.

A higher number of staff in AMH services spent more time providing formal therapy compared to staff in older people’s services: between 40% - 60% compared to on average 20%, respectively. In older people’s services however, many staff reported spending 50% and above of their time providing therapeutic conversations.

In terms of mode of therapy delivery, similarities between services were observed: staff in both services provided therapy on a mostly individual basis: individual staff in each service often provided different types of therapy in different contexts: nurses were the professional group that provided most types of therapy, and individual nurses appear to provide more than one type of therapy. Another similarity between services was the lack

of supervision: 39% of AMH staff did not receive supervision for the therapies they provided.

The most striking difference is the range and quantity of therapy available to clients in AMH services. The range of formal therapies available to clients in AMH exceeded 17 types. Although the generic term ‘formal’ therapy was used in the present audit to cover many of the therapies listed by the AMH audit, the observation that only 13 cases from 72 respondents reported providing formal therapy with established efficacy in older people’s community settings is cause for concern.

## **DISCUSSION**

### **Summary of Results**

Results indicate that the range of evidence based psychological therapies offered to older people is extremely limited, and that many individual staff provided at least two types of therapy: therapeutic conversations and therapies specific to older people. The most common therapy provided (by 83% of respondents) is ‘therapeutic conversation’, for which there is no evidence base (DoH, 2001). This is a therapy that reflects only the opinion of the practitioner delivering it.

However, therapies specific to older people – including, reality orientation, reminiscence, validation and resolution therapy – were second most frequently practiced. These therapies have been shown to be of particular usefulness with clients presenting some form of dementia, and have a growing evidence base (Woods, 2004). This supports the finding that the second most common mental health difficulty staff reported providing therapy for is dementia. However, many staff were also using therapies specific to older people for clients without dementia (for example, OCD, psychosis) which have no evidence base (Roth and Fonagy, 2004) or guidelines (DoH, 2001).

For staff providing efficacious therapy, there is little supervision, yet supervision is far more evident for staff providing non-efficacious therapy. The length of the waiting list

for psychological therapy deters many staff from referring clients to psychology.

### **Results: how do they compare to the four standards?**

Given a response rate of only 55%, it is difficult to determine how representative the results are of the older people's community workforce population. However, the findings do allow some inferences to be made.

The limited availability of therapy is at odds with Department of Health (2001) guidance about effective interventions. The National Service Framework for Mental Health (DoH, 1999) stipulates that any service user should be offered '...effective treatment...' (p4). While it acknowledged here that 'therapeutic conversation' and its definition is a theoretical construct created solely for the purpose of this audit, its inclusion was based on much anecdotal clinical evidence. This hypothesis has been borne out by the results. It is of great interest that given the emphasis on 'person-centered' care, the most popular therapeutic intervention is that which is perceived by the *mental health practitioner* to be of benefit to the service user's mental health.

Yet, 'effective treatments' with established efficacy (e.g., CBT, brief psychodynamic therapy: DoH, 2001) do exist but are virtually unavailable for service users. It seems that very few Staff were trained in and delivered formal psychological therapies (as defined by DoH guidance and standards: 2004: 2001) that have an established and growing evidence base.

Given Standard 3 of Everybody's Business (2004, p50) stipulates that, 'All staff involved in psychological therapies should have formal clinical supervision...programmed into their work', the number of staff receiving clinical supervision for therapy they provide should be a concern for managers. For most types of therapy, little more than half of staff received supervision.

Over one third (38%) of staff did not routinely consider referring clients for psychological therapy. These findings are contrary to guidance of Standard 1 of

Everybody's Business (2005, p50) which stipulates that 'psychological therapies should routinely be considered as a treatment option when assessing mental health problems.' There was, however, also some evidence of a lack of awareness among staff of how to refer, and a perception that some referrals would not be accepted.

The perception among staff that the waiting list is too long, and that access to the waiting list is 'unreasonably restricted' by the waiting list concords with the length of the waiting list, currently approximately seven months. None the less, this finding is contrary to guidance detailed in Everybody's business, particularly Standard 2: 'Access to psychological therapies should not be unreasonably restricted by waiting lists' (p50), as well as Department of Health and Trust pressure to meet 13 week waiting targets. A number of respondents also expressed the opinion that there is limited availability of psychological therapies. This belief is largely corroborated by the results, where very little evidence-based therapy is available.

42% of respondents stated they did not believe clients have a choice in the types of therapy they receive. The reasons for this were not clear (as no opportunity was provided for explanations on the audit tool) but at the time of the audit (summer, 2006) a major government initiative emphasising the importance of choice - which is at the heart of the government's modernisations agenda for public services - for service users in accessing psychological therapies was being implemented in two pilot sites. Within the initiatives of Improving Access to Psychological Services and Choices in Mental Health, as part of the Care Services Improvement Partnership (CSIP), 'choice' is seen as central as it is 'about the power to make decisions', and is beginning to redefine the relationship between providers and users of services. Given the importance of the choice agenda, it would be interesting to see if the results obtained here differ in a future re-audit.

### **Older people's services in comparison to adult services**

Accurate inferences from the available data are limited, because of the difference in measures, sample size and response rate between the two surveys. However, it appears that in adult services, clients have a far greater choice of psychological therapy in terms

of range and quantity, and many therapies on offer in AMH services are of established efficacy, as defined and graded by DoH (2004: 2001) guidance. Moreover, Staff in AMH services spent more of their time providing therapy than did staff in older people's services. Given the value of clinical supervision, it should be of concern to managers that only about half of staff in both services received supervision for the therapy they provide.

## **CONCLUSION**

Given the response rate, conclusions are tentative. However, the results clearly do not accord with Department of Health (2004) recommendations concerning the organization and delivery of psychological therapies to older people. Conversely, the results do accord with the DoH (2001) finding that 'in many mental health services psychological therapy provision is patchy, uncoordinated, idiosyncratic, potentially unsafe, and not fully integrated into management systems' (p1). This suggests that in relation to standard one of the NSF-OP (DoH, 2001) psychological therapies for older people were *not* comparable to adult services in providing efficacious treatments on the basis of need rather than age.

Moreover, none of the standards to which the results have been compared were met. The main therapy delivered by staff has no evidence base, and those therapies that are evidence based are barely practiced. Supervision is also a major issue, with many staff receiving inadequate levels thereof.

In line with this conclusion, the following recommendations are made.

## **RECOMMENDATIONS**

The Department of Health (2004) states that attention needs to be directed to the psychotherapeutic needs of different groups, including older people, and suggests one way of meeting these needs is by co-ordinating different parts of psychological therapy services and offering clear leadership, both professionally and managerially. This is best achieved through a Psychological Therapies Management Committee, which oversees the

delivery of evidence-based treatments that are coordinated, appropriate to the client's difficulties, regularly audited, safe, supervised, equitable, comprehensive, and delivered by well trained professionals.

To achieve this, Parry (1996) offered a definitional framework to describe clearly the ways in which psychological interventions are offered:

Type A – psychological treatment as an integral component of mental health care (performed by a wide range of health professionals)

Type B – eclectic psychological therapy and counselling

Type C – formal psychotherapies.

Within older people's services, it seems Type A therapies are mostly available, with very little availability of Type C, evidence based therapy, provided by staff qualified to do so

This framework not only reflects the way that psychological therapies are delivered, but also the way that services are organised. Although there is no national template to model, there are now well established pointers to good practice that will help local services be confident they are supporting staff effectively to deliver better treatment outcomes for service users and carers.

Further, while psychological therapies of all types are popular with service users, there is still widespread ignorance and confusion surrounding 'talking therapies'. More and better information are essential pre-requisites for choice and engagement with treatment, and although more information is now available, there is still room for significant improvement at local level.

A waiting list initiative should be devised where referrals are agreed and screened, then monitored for clients' unmet needs. This might include a monthly letter / phone call to clients to inform and update them on their waiting list status and could focus limited resources in specific areas so that 'severe' difficulties are prioritised.

Finally, in line with the principles of audit cycle, a re-audit should be conducted when the above recommendations are implemented.

### **LIMITATIONS OF THE STUDY**

The most obvious limitation of the study is the response rate. Further, while it was felt the audit tool had face validity, constraints of time prevented establishing content, criterion and construct validity (Barker, *et al.*, 1994). Consequently, the reliability and validity of the audit tool was unknown.

Staff completing questionnaires ‘on the spot’ brought methodological problems, which could be interpreted as confounding variables. Despite clear requests to respondents to complete the forms without consulting colleagues (thus eliciting ‘uncontaminated’ answers) I observed that several staff at most team meetings did consult their colleagues on answering some items. Whether this reflected ambiguity in the questionnaire where staff felt compelled to seek clarity from co-workers, or whether there was an element of social comparison (Festinger, 1954) operating as part of a group process, where some staff sought validation of their abilities and attitudes by comparing themselves with colleagues in the answers they gave, is difficult to ascertain.

It was also observed that some staff groups found the audit tool quite difficult to complete in relation to their particular working practices. This may suggest that in future audits of this kind, consultation with staff groups may benefit the development of an audit tool that is more universally user-friendly. A future audit tool may benefit from being shorter and simpler.

Staff may have found the different types of therapy difficult to distinguish. This hypothesis is supported by the Department of Health (2004) which notes that a wide range of interventions can be classified as ‘psychological therapy’ and that psychological care forms a component of the work of a wide range of health professionals. Parry (1996) notes that there is ‘...a degree of confusion surrounding the meaning of the term ‘psychotherapy’’, and this may have been reflected in responses, which relates to the

audit questionnaire's reliability and validity. For example, 14 staff reported using 'formal' therapy for anxiety, but only 13 staff reported using 'formal' therapy on Question 1

Only two forms were completed by medical staff from a pool of fifteen consultant psychiatrists, staff grade doctors, and senior house officers. This was disappointing, given that their training involves both education in psychological therapies and contribution to audit (Royal College of Psychiatrists, 2007). A higher response rate from this group may have illuminated further the extent to which therapies of established efficacy were delivered (or not) to older clients.

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## **APPENDIX**

**FRONT PAGE**

**Main Project Literature Review:**

**An Investigation in to the Experience of Parents whose child  
has sustained Traumatic Brain Injury: A Qualitative  
Perspective.**

**Year 3**

**University of Hertfordshire  
Doctor of Clinical Psychology Training Programme**

Graham Williams

Word Count: 5022

## INTRODUCTION

Children who have sustained traumatic brain injury (TBI) represent an under resourced clinical problem in the United Kingdom (British Psychological Society, 2006).

Until the mid-1990s, the majority of research into the effects of children with traumatic brain injury had focused on neuropsychological and academic deficits (Fletcher *et al.*, 1987; Jaffe *et al.*, 1993). Partly because a consistent relationship between severity of injury and behavioural outcome has not been established (Kinsella *et al.*, 1999) more recent research into paediatric TBI (e.g., Taylor *et al.*, 2004; Yeates *et al.*, 2001) has highlighted the importance of several factors found to moderate positive and negative outcomes in childhood TBI (Taylor *et al.*, 1999). Of these, family influences only will be discussed here.

Several studies have shown the adverse effect of childhood TBI on families (eg. Gan and Schuller 2002; Max *et al.*, 1998; Rivara *et al.*, 1996; Wade *et al.*, 1996) which can vary between the acute and rehabilitation phases of the injury (Wade *et al.*, 1995). These studies suggest that families of children with severe TBI experience greater stress and dysfunction than do families of children who have sustained mild TBI or other traumatic injuries. Negative consequences for the family in turn, make it more difficult for the family to support the child's recovery. For example, Taylor *et al.*, (1999) measured three dimensions of family adversity in post-acute outcomes (family dysfunction, parental psychological distress and injury-related family burden) in a study using a one-year follow up design. This was one of the first studies to suggest that measures of post-injury family environment predicted child outcomes. They concluded that more favourable family circumstances were associated with better child outcomes.

Both published and unpublished research indicates that the experience of parents whose child sustains TBI is generally negative, and may be vulnerable to psychological morbidity (Wade *et al.*, 1997). However, not all families are adversely affected. Some families appear to draw closer together as a result of the crisis (Wade *et al.*, 1995). For those families that do experience difficulty, there is a need for a greater understanding of

the nature of these difficulties in order to inform the provision of rehabilitation services, and enhance the understanding of professionals working with such clients.

This paper will present a brief overview of the issues associated with children with severe TBI before summarising the research on the impact on the family.

## **TRAUMATIC BRAIN INJURY IN CHILDREN**

### **What is traumatic brain injury?**

The Division of Clinical Neuropsychology (British Psychological Society, 2006) defines head injury as ‘...understood to mean either intracranial injury or fracture of the skull’ (p5). Few studies actually define TBI. A rare exception is Rivara *et al.*, (1993) who define brain injury as ‘blunt trauma to the head resulting in documented loss of consciousness’ (p1048). There appears to be no ‘benchmarking’ of measuring TBI, and Middleton (2001) notes that the description of ‘severe’ brain injury can vary between studies, with some investigators simply using a Glasgow Coma Score (Teasdale and Jennett, 1974) of 8 or less (e.g., Kinsella *et al.*, 1999; Rivara *et al.*, 1993; Taylor *et al.*, 2001) as defining criteria.

### **Measurement of traumatic brain injury**

Fletcher *et al.*, (1995) analysed the various factors that need to be taken into account when measuring TBI and have found that many indices are poor, and may obscure the sometimes sensitive changes that follow TBI. However, in her review of the literature on psychological sequelae after brain injury in children and adolescents, Middleton (2001) identifies as a ‘rough guide, children with a GCS of 12 or below...have lost consciousness for more than 20-30 minutes...or those who have post traumatic amnesia of longer than 7 days are more likely to have psychological sequelae’ (p 168). It is also difficult to gauge the severity of injury because many hospitals do not specifically record the GCS or the length of post traumatic amnesia, and it is not easy to extrapolate these from medical notes (British Psychological Society, 2006).

## **Epidemiology**

Traumatic brain injury represents one of the most common causes of acquired disability in childhood (Anderson *et al.*, 2001) and the incidence is increasing. Research indicates that the immature brain is more susceptible to injury than the fully mature brain (Kolb and Withshaw, 1996) because the child's skull is more flexible and incompletely fused. Thus, the pathology of head injury in children is different to that of adults (Oddy, 1993). Current evidence suggests that the outcome for children is worse than for adults with TBI (Taylor, 2004).

As many as one child in every 30 will have received a head injury before the age of 16 (Anderson *et al.*, 2001). However, the statistics for Accident and Emergency (A&E) attendance, hospital admissions and mortality for head injury are not unified nationally (Middleton, 2001). Department of Health (1997) figures for the UK suggest that for children aged 0-15 years, at a minimum 14,000 were admitted to hospital. In general, about 1% of children admitted will have a severe head injury.

Overall, boys outnumber girls 2:1, although this is partly age-dependent (Krauss, 1995). For the under 5 year-olds, the ratio is 1.3:1 boys: girls (Hays and Jackson, 1989), but between 5 and 14 years the ratio swings 2.2:1 boys: girls (Krauss, 1995). Higher incidences of head injury are observed in children of lower socio-economic status, as assessed by parental earnings (Appleton, 1998; Kraus *et al.*, 1990).

Causes of injury vary enormously, although age-related patterns are observable; infants under 2 years most likely suffering non-accidental injury (such as shaking); younger children sustaining injuries from falls, and middle to older children being injured as a result of pedestrian or bicycle accidents, or from sport. At all ages, children may also be injured as passengers in cars involved in accidents.

## **Sequelae of Severe Traumatic Brain Injury**

The literature indicates that in the case of children with severe TBI, without exception the findings confirm chronic sequelae and may include physical, neuropsychological, behavioural, emotional, and cognitive difficulties (Taylor, 2004). Children with severe brain injury (compared to those with less severe injuries) have the lowest potential for full recovery (Montgomery *et al.*, 2001).

Children who have sustained severe TBI exhibit more behaviour problems, greater rates of psychiatric disorders, and lower levels of adaptive behaviour than do children with milder forms of TBI, other injuries not involving the head, or siblings (Brown *et al.*, 1981; Fletcher *et al.*, 1990; Max *et al.*, 1997, 1998a; Perrott *et al.*, 1991; Taylor *et al.*, 1999; Yeates *et al.*, 2001). Specific post-injury problems include attention deficits, irritability, agitation, confusion, lack of spontaneity or insight, affective disturbances, and decreased social, adaptive and school functioning (Fletcher and Levin, 1988; Levin *et al.*, 1982; Max *et al.*, 1997). Physical complaints can include impaired mobility, headaches, fatigue, dizziness and disturbances in sleep or sensation (Levin *et al.*, 1982).

Younger children are at greater risk for residual impairments and poorer recovery than older children or adolescents (Anderson *et al.*, 2000). Outcome is complicated by symptoms that are in part related to TBI severity, age and developmental level at injury, and time post-injury (Taylor and Alden, 1997). For those that develop behavioural dysfunction as part of the sequelae, these are especially problematic for families and schools (Taylor *et al.*, 2001).

Outcome in paediatric TBI appear highly variable, even among children with more serious injuries (Fletcher *et al.*, 1995; Wade *et al.*, 1995). Taylor *et al.*, (2004) note that heterogeneity of outcomes of TBI is unexplained, even after grouping children into traditional severity classifications. While injury severity has been shown to be the most consistent predictor of sequelae in the injured child, it is not a reliable predictor of outcome.

## **FAMILY INFLUENCES AS MODERATORS OF OUTCOME**

The importance of the family environment has been demonstrated in numerous studies linking child behaviour problems to family stress, negative life events, and parental psychological symptoms (e.g., Egeland *et al.*, 1990). Social and family factors also account for variability in the outcomes of neurological disorders other than TBI, even after taking disease severity into account (Taylor *et al.*, 1992). It is not surprising therefore that the same relationship would hold for TBI (Taylor *et al.*, 1996).

In one of the earliest studies to consider family outcomes following paediatric TBI, Rutter *et al.*, (1983) reported their clinical observations of families followed prospectively from the time of the child's injury. They noted a range of family changes, including parental anxiety, changes in the parent-child relationship and increased marital strain. However, standardised measures were not used to assess family sequelae and a small sample size prevented statistical analysis.

A groundbreaking study by Rivara and colleagues (1992) using standardised measures and follow up produced data that indicated TBI has significant impact on families. Their data also pointed to the potential moderating role of family resources and coping on TBI outcome. This was observed even after controlling for injury severity. In addition to the study's many strengths, it has limitations which caution the interpretation of findings. For example, parent ratings of family functioning were administered, but changes in these measures over the follow up interval were not reported, which may have biased the analysis.

### **Why study childhood TBI from a psychological perspective?**

It was Lezak (1988) who originally described TBI as a 'family affair' because of its often all encompassing impact on the family. She described the 'burden of demands' (p. 114) that the caretaker of the child – usually the mother – faces as a result of the injury. Lezak (1986) is one of the few authors who have attempted to detail the psychological implications of TBI upon the family in terms of their expectations and beliefs. A comment from a mother recorded in a qualitative study illustrates this:

*My child is not what she was, nor will she be what she was to become. Neither am I. Neither is anyone else in the family. I never knew that a brain injury could be so devastating or so contagious – everyone in the family has been stricken...even though it's been 5 years since her injury.*

(Savage and Morales, 1994: 66)

Based on her extensive clinical experience, Lezak (1986) theorized that family reactions to TBI evolve through a series of stages (although these are not specific to childhood TBI). A family's response to TBI is conceptualised as an unfolding progression of reactions and adjustment defined by perceptions of the patient, expectations for recovery and family attitudes.

Because of the sequelae following traumatic brain injury in individuals, and the impact on the family, there is a significant role for applied psychologists (British Psychological Society, 2006). For example, both child neuropsychologists and clinical psychologists have an important role in the assessment and rehabilitation of injured individuals and their families. Child neuropsychologists provide specialist diagnostic assessment and treatment to children and adolescents presenting with cognitive, behavioural or educational change in the context of injury. Because parents can become distressed following their child's injury, clinical psychologists can provide for example, psychological therapy with family and siblings, who may need counselling or specific interventions for their own difficulties.

## **OUTCOMES OF TRAUMATIC BRAIN INJURY IN CHILDREN FOR FAMILIES**

### **Traumatic brain injury and the family: Conceptual and methodological issues**

Drawing conclusions about the impact of childhood TBI on parents is difficult, as studies have produced conflicting findings (e.g., Rivara *et al.*, 1996; Wade *et al.*, 2002). This may be due in part to different methodologies used by investigators. Early research was criticised on a number of methodological grounds, including the use of unreliable

measures of child behaviour (Oddy, 1993), the lack of adequate long-term follow up (Fletcher and Ewing-Cobbs, 1991; Oddy, 1993) and problems of internal validity (Orme, 1998). Sample attrition is a concern among prospective studies, particularly among minority families (Yeates *et al.*, 2006) and measures of injury severity are currently not precise and need to be improved (Taylor *et al.*, 1999). With the exception of Wade *et al.*, (1995), a coherent conceptual framework of analysis is lacking – even among more recent research.

In an attempt to address some of the methodological weaknesses identified in previous research, a major contribution to our understanding of the role of the family as an outcome moderator in TBI has come from the research group of Yeates and colleagues in the United States (e.g., Wade *et al.*, 2006). Strengths of their research programme include analyses of long-term follow-up and consistent use the same measures which add reliability to their findings.

Using prospective designs, Yeates and colleagues have studied a number of variables and interactions hypothesised as influential in TBI family outcome; initial impact on the family of childhood TBI (Wade *et al.*, 1997); family burden and adaptation during the first year of injury (Wade *et al.*, 1998); the relationship of caregiver coping to family outcomes in the first year post-injury (Wade *et al.*, 2001); influences on first year recovery from childhood TBI (Taylor *et al.*, 1999); interpersonal stressors and resources as predictors of parental adaptation following childhood TBI (Wade *et al.*, 2004); the interaction of the injured child and their parents as an influence of outcome (Taylor *et al.*, 2001); long-term caregiver and family adaptation following childhood TBI (Wade *et al.*, 2001); the impact of cultural differences on families as a variable in outcome (Yeates *et al.*, 2002), and long-term parental and family adaptation following TBI, which measured a variety of variables at 6 time points over 6 years (Wade *et al.*, 2006).

While valuable, Yeates and colleagues' methods have limitations. One such limitation is that, as is a common feature of TBI family outcome research, the mother is usually the sole respondent. This presents at least two problems in interpreting results. First, mothers' reporting of the family environment is inferred to represent that of the family as

a whole. This is at odds with Lezak's (1986) clinical observations who observed that fathers react to the injury differently to mothers. Second, mothers, as sole respondents, completed all measures at all time intervals which may inflate correlations through shared method variance leading to inaccurate associations (Yeates *et al.*, 1999).

Several review papers (Middleton, 2001; Savage *et al.*, 2005; Taylor, 2004; Verhaeghe *et al.*, 2007; Wade *et al.*, 1995) and the comparatively few qualitative studies (e.g., Prentiss, 1999; Prigatano and Grey, 2007) in the field broadly concur with the findings of Yeates and colleagues. Indeed, different methodologies indicate consistent and similar themes associated with parents of the brain injured child. A growing number of investigations have documented parental psychological morbidity (in the form of clinical levels of anxiety and depression) associated with injury-related stress and burden, and family dysfunction during the initial year following a child's injury, and beyond (Rivara *et al.*, 1992; Wade *et al.*, 1998). For some families, this continues for many years after the injury.

### **Burden and Stress**

Because the onset of TBI is sudden and catastrophic, the principal morbidity and source of burden for parents often arises from long-term cognitive, behavioural, and academic deficits rather than from physical impairments. Cognitive and behavioural dysfunctions, such as emotional disinhibition, impulsivity and failure to learn from experience place significant demands on parents to alter expectations, rules and disciplinary practices (Lezak, 1987). Burden is conceptualised as an outcome in the form of 'demands' that the injury brings. Demands specific to TBI have been identified as obtaining rehabilitation services, school re-entry, and ongoing behavioural and intellectual changes in the child (Wade *et al.*, 1995). However, there is little indication in the literature as to the psychological mechanisms and processes that might make such demands more or less burdensome.

Also, while parenting 'stress' is often reported, like burden, it seems poorly defined conceptually and theoretically and the mechanisms by which it operates and manifests are

not identified. As is the case for burden, it is operationalised as an outcome in the form of organisational difficulties, impaired family communication and supportiveness, adjustment problems in siblings, and restrictions in social activities and interactions with friends (Wade *et al.*, 1995).

Lezak's (1986) framework suggests that families may experience little stress following hospital discharge in light of the child's initial dramatic recovery. A family may be initially 'happy' and expect 'full recovery' when their loved one survives the injury, as this extract from a qualitative study illustrates:

*Walina was hit by a truck walking home from school. After almost 15 days in a coma she started to respond... In the next few weeks I was amazed at how fast she was progressing. But when she started to walk I was ecstatic.*

(Savage and Morales, 1994: 71)

However, the family is confronted with different demands over the course of the recovery process (Rivara, 1994: Rolland, 1987). For example, generic tasks of the acute or crisis phase include learning to deal with the injury, learning to deal with the hospital environment and medical treatments, and establishing relationships with healthcare professionals (Rolland, 1987).

Further stress may arise from the disruption in family routines associated with prolonged hospitalisation. Rolland (1987) argues that families seek to preserve a sense of mastery and competence in the face of a largely uncontrollable trauma. Tasks during the chronic or 'long-haul' phase include maintaining or trying to return to normal life and promoting autonomy for all family members despite the inclination to be over protective or overly involved in caretaking (Rolland, 1987). Such aims are not always possible, however.

A qualitative study by Savage *et al.*, (2005) notes that 'parental guilt is among the most agonising reactions experienced by these families' (p93). Reactions of self-blame, guilt and regret are very common and can prolong the mourning process. This concurs with

Lezak's (1988) observations which sees families' affective reactions change to 'anxiety', 'guilt' and 'mourning' as families realise their loved one has been changed irreversibly as a result of the injury.

### **Appraisal**

Appraisal may be an important mediator of how the stress, demands and changes that the injury brings are met. An individual's or family's appraisal of the child's injury may predict long-term adaptation more than the severity of the injury itself (Boss, 1992). Appraisal may involve perceptions of the injury event, assessment of the child's current status, and expectations for the future. The appraisal of these factors will change over the course of the child's recovery, determining how the family responds and what resources it can bring to the event (Wade *et al.*, 1995). Appraisal can be critical in making judgements about the preventability of the injury event and assessment of guilt and blame. Such judgements may impede coping and successful transition from the crisis phase (Rolland, 1987). Discrepancies between the parents' perceptions – or appraisals – of the child's recovery and those of other family members may create an additional source of family stress.

As the recovery process slows, the family may become confused and anxious. If a family then perceives the child's lack of recovery is a result of poor motivation, it responds differently than if the same poor progress is perceived as a function of psychological or neuropsychological factors (Lezak, 1988). Here, there may be another important role for psychologists in providing psycho-education about the relationship between brain and behaviour to the family - and possibly non-psychologically trained rehabilitation staff – to prevent attribution of inaccurate appraisals about a child's slow recovery.

### **Social support and relationships**

Social support has also been indicated as an important variable in moderating outcome. It either increase or decrease caregiver vulnerability to stress related to a child's TBI, depending on the quality of the relationship (Masten *et al.*, 1988). The source of the

support or strain is another important consideration (Rook, 1990). Research has suggested that interpersonal strain with a spouse or other close family members' results in greater distress than strained relationships with friends (Pagel *et al.*, 1987). Thus it may be necessary to consider both the quality (supportive or strained) and the nature (extended family, spouse, or friend) of the relationship (Wade *et al.*, 2004).

The relationship between the mother and father of the injured child may also be affected by the injury (Lezak, 1988). Clinical reports and focus group discussions suggest that mothers and fathers may cope in different ways with the effects of the injury. Wade *et al.*, (1995) found that mothers report that their spouses 'shut down' and avoid confronting their feelings about the injury, thereby preventing communication between the parents about their concerns and anxieties. The clinical impressions of Wade *et al.*, suggest further that the marital relationship may be strained as one partner assumes a disproportionate burden of care giving and discipline (Waaland and Raines, 1991). Excessive negative maternal affect arising from anxiety and strain may then flood the marital relationship, which may lead to further paternal disengagement, possibly leading to marital distress and dissolution (Gosling and Oddy, 1999: Gottman, 1993:). The relationship between parents and non-injured siblings may also change as siblings are asked to assume increased responsibility for caring for the injured child (Waaland and Kreutzer, 1988: Waaland and Raines, 1991).

In the first empirical study of the impact of relationships on TBI outcome, Wade *et al.* (2004) found that positive social relationships can make parents more resilient when facing the significant challenges of paediatric TBI. Through general linear mixed model analysis, Wade *et al.*, (2004) found that between both follow up points (6 and 12 months), family supports buffered care givers (mothers) against the injury-related stress and burden associated with severe TBI (Rivara *et al.*, 1992, 1996: Wade *et al.*, 2002). Their findings suggest that, depending on the source, both interpersonal stressors and resources are associated with parental distress. This is all the more important given that clinical observations (e.g., Taylor *et al.*, 2001) and research suggest that families of children with TBI are susceptible to role strain, lack of support or communication within

the family, and restriction of social support outside of the family (e.g., Conolay and Sheridan, 1996).

### **The Role of Interpersonal Resources for Parents**

Parent and family outcomes after paediatric brain injury appear also to be moderated by psychosocial factors.

In an innovative study examining the relationship of caregiver coping to family outcomes in the first year following injury, Wade *et al.*, (2001) found that emotion-focused coping strategies (such as support seeking and acceptance) in response to a traumatic injury were associated with more favourable care giver and family outcomes. By contrast, avoidance strategies such as denial and disengagement were associated with more adverse outcomes. An interesting finding from this study was that care givers relied ‘heavily on religion...and acceptance’ (p409) as ways to deal with their child’s injury, followed by active coping and planning. On a speculative level, this may reflect a cultural difference in coping strategies between a study sample the United States and a study sample in the United Kingdom (if such a study were undertaken) which is a comparatively more secular society.

Another interesting finding was the use of humour at baseline was associated with significantly lower levels of psychological symptoms at 12 months post injury. Wade *et al.*’s., (2001) study is also exceptional in that it is among the first to examine clinical significance (in addition to the routine analysis of statistical significance between groups) of coping, which they found accounted for between 8% and 10% of the variance in outcome at 6 months.

### **Loss: The ‘ghost’ of parental experience?**

‘Loss’ appears to be a theme identified in the qualitative literature, but almost totally absent from the quantitative literature. On a speculative level, loss could be an additional

factor associated with stress and burden leading to psychological morbidity, particularly anxiety and depression.

For example, Lezak's model (1988) suggests that over time, the family acknowledge the child's deficits and mourns the loss of the person as he or she was before the injury. This is illustrated in the following extract:

*... She couldn't remember anything, not even the name of the show we had watched just 5 minutes before. I cried, but I realised then... that her life was never going to be the same. With three other kids at home, all younger than Walina, I felt overwhelmed. She's only 13 years old. Will she still have friends? Will she ever marry?...On one hand, I was so happy with all her progress, she looked so good. But she wasn't herself. Would she ever be herself again? I grieved for the Walina I had lost.*

(Savage and Morales, 1994: 71)

Another qualitative study provides some clues as to the extent of loss experienced by parents. The following is a mother's reactions to her child's injuries:

*You're waiting for them to come out of the coma. You're so thankful they're alive. Then they come out of the coma and (you say to yourself), 'This is not the same kid that went into the coma. Where is that...that used to be mine? He's not there, he's gone.'* And the bottom line is that you almost treat it like a death. That child is no more. Is no more. You have to go through a grieving process. You had to let go of what you had because he's not the same child. His name is the same, he may look the same, he may not look the same. That's what really happens, is this huge sense of loss, just sometime overwhelming sense of loss.

(Guerriere and McKeever, 1997: 109)

Boss (1991) has suggested that when a child's behaviour and personality change after the injury, caregivers face an 'ambiguous' loss because the person has not died. Such losses

are especially difficult because they are not ritualised (as in burial) or given public validation. Guerrie and McKeever (1997) found that as a result of their child's injury, not only were mothers coping with loss of the pre-injury child, but their experience had forced them to reconstruct their identities as mothers and that of their child.

### **Culture and Diversity as a family influence**

Notably absent from the literature are studies evaluating (any) extent that ethnic minorities and culture differences influence outcome of TBI. A singular and notable exception is Yeates *et al.*, (2002). They evaluated whether parent and family outcomes of paediatric TBI were moderated by race in an attempt to understand better how socio-cultural differences among ethnic groups affect family responses to TBI.

This was examined in the context of coping strategies found in previous research (Wade *et al.*, 2001). Yeates *et al.*, (2002) conducted a prospective study of child and family outcomes following TBI by ethnic minorities and Caucasians. They concluded that race was a significant moderator of parent and family outcome. Analysis suggested that differences in coping strategies may be a cultural factor. For example, minority parents relied more on religion, mental disengagement and denial in coping with traumatic injuries. By contrast, white families relied more on acceptance. These results are consistent with previous research that suggests racial differences in coping exist independently of SES (Neighbors *et al.*, 1983). Yeates *et al.*, (2002) caution that coping strategies may themselves be subject to moderating variables. For example, the health care system in the United States requires health insurance to receive treatment - which itself may represent a significant outcome variable and a possible cultural difference between the US and UK (Yeates *et al.*, 2002).

However, cautions need to be highlighted with reference to the findings. The authors acknowledge that limited information is available regarding ethnic differences in previous studies using these measures. The Brief Symptom Inventory (Derogatis and Spencer, 1982) normative samples included about 87% 'whites' and 12% 'blacks' (indicating a significant bias in reference population towards whites). In addition, the

number of black participants was small, particularly in the TBI group. As Orme (1998) argued in his review of TBI studies, this may have affected power calculations. Moreover, attrition rates in the TBI group varied by race, and participants of lower SES were underrepresented in the study.

## **CONCLUSIONS AND DIRECTIONS FOR FUTURE RESEARCH**

The family appears to be a powerful moderator in childhood TBI outcome. A number of factors have shown that how the family responds to their child's injury will play a part in how the family – and child - adapts over time. These include the family's initial response, how it copes over time, the type of coping styles it adopts, how it appraises the injury, the quality and sources of social support, and ethnicity characteristics of the family. Taken together, the above review implies that both protective and risk factors are operating in the outcome of paediatric traumatic brain injury for parents.

Quantitative methodologies are valuable in constructing linear models that identify predictors and indicators of TBI outcome (Kinsella *et al.*, 1999). However, group averages – the principle explanatory mechanism of quantitative methods - tell us nothing about individual differences, or the richness of peoples' experiences. Research may thus benefit from examination of more subjective variables that may not operate in a linear, causative way.

Narrative methodologies that investigate the meaning and constructions that parents attach to their experiences could compliment our knowledge of how parents respond to childhood TBI, and add new areas of investigation. Indeed, comparatively little is known about the non-measurable and subjective experience of family care giving in the context of childhood TBI (Guerriere and McKinnon, 1997). This has research and clinical relevance. For example, Lezak's (1986) model, although stage-like, is non-linear: some families may experience all of the stages, although at different rates and in different order. Other families may miss one or other stages completely or get stuck at a particular stage for many years. These stages may also overlap or shift back and forth according to how families are able to cope at any given point.

An area that all investigators agree on is that given the adverse effects of TBI on families and current evidence for familial influences on the child's recovery, there is a clear need for rehabilitation efforts aimed at the family system (Lezak, 1987; Wade *et al.*, 1998). Research suggests that very few families receive psychological or supportive services for themselves or their injured child (Wade *et al.*, 1995). A first step to providing services following TBI is identifying the specific material and emotional needs of families during the acute period and subsequently as the child returns home and re-enters school. Taylor *et al.*, (1999) assert that it is crucial that we learn how to intervene effectively to prevent or reduce family morbidity.

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## APPENDIX 1

### LITERATURE REVIEW SEARCH STRATEGY

#### **Search process**

##### *Initial ideas and broad search*

The search process began with an initial interest in brain injury and its impact on the family, based on literature previously read by the author. This led to a search for review papers on head injury in children. Reading of the review papers by, for example, Middleton (2001) and Taylor (2004) Wade *et al.*, 1995) led to the development of a list of key terms that would form the basis of later search strategies.

Then, a search of the PsychInfo database was conducted using key words, such as ‘brain injury’, ‘childhood’ and ‘paediatric’. This enabled more information to be gained about further key terms, concepts, and issues. I was also liaising with people in the field of traumatic brain injury in children, and I was given key names and references.

From this, key authors and their original theoretical and empirical papers and books were identified and read. Ideas for potential focus of the literature review were then discussed with supervisors and clinicians.

##### *Focus of ideas and systematic search*

In trying to identify literature related to the impact of traumatic brain injury in children on their parents, it was clear that a specific set of search terms was required. For example, the terms ‘traumatic’ and ‘paediatric’, and ‘families’ appeared central to this literature. These were added to the list of key terms.

Following this, the search became considerably more focused and electronic databases were searched (see below) with an emphasis on unpublished as well as published original

work. It appeared from the initial search that there was comparatively little research on the impact of childhood traumatic brain injury on the family. I was then told by a clinician in London of a group of clinicians and researchers in the United States, particularly Keith Yeates and colleagues who have published extensively in the area of paediatric brain injury and its impact on the family. I found his email address on the University of Ohio web page, and emailed him. He and I then exchanged several emails and he sent me several empirical articles his group has published. Among them was a review article by Wade *et al.*, (1995) which detailed methodological and conceptual issues in the area. This enabled identification of relevant research and theoretical (and lack of) developments since original papers had been published. Through this process, gaps in both theoretical and empirical literature were identified, and impetus for a more 'concentrated' search was found.

#### *Gaps in the knowledge base*

Several searches were conducted between over a three month period. As time elapsed between searches, to check that gaps in knowledge still existed, a second systematic search took place that restricted the search to the previous year.

#### Databases searched

Below is a list of all the databases searched for this literature review:

- PsychINFO (a database of psychological literature)
- Pubmed (which provides access to citations from MEDLINE (a health database) and other life science journals)
- Cinahl (Cumulative Index to Nursing and Allied Health Literature, which allows access to nursing, allied health, biomedicine and healthcare literature).
- Cochrane Library

- Applied Social Sciences Index and Abstracts (an index and abstracting tool covering, among other areas, health and psychology).
- International Bibliography of the Social Sciences (a database covering the core social science disciplines).
- ProQuest Digital Dissertations (which provides access to dissertations in the Dissertation Abstracts Database)

### *Search terms*

Below is a list of search terms used, grouped into categories for description purposes.

- Brain, head, injury, damage.
- Review
- Impact, effect, outcome, transition, adaptation, adjustment
- Positive, negative, symptoms, post traumatic stress, reaction, second order factor, psychological impact, psychological distress, emotional distress, emotional impact, health, secondary trauma,
- Traumatic, trauma, severe
- Children, child, childhood, adolescent, paediatric, pediatric (American spelling)
- Parent\*, caretaker\*, father\*, family\*, relationships\*
- Experience\*, exploration\*
- Stress, stresses, stressor, burden, demands

- Coping, resilience, mastery, control,
- Methodology\*, quantitative, longitudinal, qualitative, questionnaire, phenomenology, narrative, analysis,
- Definitions, defined\*, measured\*
- Risk factor\*, protective, predictor\*, indicator\*

### *Specific searching procedures*

As several databases were used, each search term was entered in to the database in turn.

The following editing/expansion procedures were used for this further review:

- 1) Key terms/words/concepts and major descriptors: those identified from the most relevant articles were used as search terms.
- 2) Boolean operators: The Boolean operators (AND, NOT, OR) tell search engines which keywords to include or exclude from searches.
- 3) The truncation technique: An asterisk placed at the end of a key term ensures that all terms that began with that word are found. For example, parent\* should find all terms that begin with the root *parent*; parents, parental, etc. This can be particularly helpful when there are plurals (e.g., parent vs. parents) and for alternative spellings, as is in the case of *paediatric* which in the American literature is spelt *pediatric*.
- 4) MeSH terminology: this provides a consistent way to retrieve information that may use different terminology for the same concept (e.g., head vs. brain injury).
- 5) Search dates: due to the paucity in the literature, the search included material from the early 1980s, which saw the first publication of the impact of brain injury on

individuals and their family's (e.g., Rutter, et al, 1983) and was up to the present day.

- 6) English language publications: Publications in other language were excluded.

#### *Website searches*

Search engines on the internet were used, including Google ([www.google.com](http://www.google.com)) and Google Scholar ([www.scholar.google.com](http://www.scholar.google.com)). Service user websites were also searched. The University of Ohio website was searched for information on Keith Yeates and his research group.

The British Psychological Society website was also searched ([www.bps.org.uk](http://www.bps.org.uk)) and the Division of Neuropsychology website. Finally, the Department of Health website ([www.doh.gov.uk](http://www.doh.gov.uk)) was searched.

#### *Author relevant searches*

The names of the most relevant authors were searched within the above databases. In addition, their names were searched on the internet s above, which enabled some personal web pages to be found that showed research interests and publication lists. These publication lists were cross-referenced with literature already obtained to ensure no key references were missing.

#### *Reference searches*

Using the reference lists of the obtained articles proved useful in identifying further relevant papers. Reference lists were also checked in the latter stage of the search to ensure all relevant literature had been identified.

#### *Citation searches*

Web of science ISI Citation Indexes were used to find all publications by key authors and enabled the identification of other journal articles and authors that had cited the literature already obtained. The citation search was very useful in the 'checking' stage of the search to ensure all relevant literature had been found.

### *Problems in obtaining literature*

Two key references are absent from the review. These were unpublished research dissertations by researchers at American universities. Prentiss (1999) conducted a phenomenological study of the experiences of four mothers whose children underwent traumatic brain injury. I ordered these through the University of Hertfordshire system, and they were due to arrive electronically on microfilm. At the time of writing, they had not arrived. I consequently relied on their abstracts.

### *Search output*

The search produced many relevant pieces of literature. The Review consequently includes only those considered most relevant to the proposed study. Where possible, articles and books were obtained electronically or in hard copy from the University of Hertfordshire Learning Resource Centre, or from the British Library.

**Shattered Narratives and the Search for Meaning: The  
Experience of Parents who's Child Sustained Traumatic  
Brain Injury**

**Graham Ross Williams**

Submitted in partial fulfilment of the requirements of the  
University of Hertfordshire for the degree of DClInPsy

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## ABSTRACT

This study looked in detail at the parental experience of having a child sustain traumatic brain injury (TBI); beginning with the child sustaining the injury, through the acute and chronic stages of rehabilitation, to the child's return home. Mother and father dyads were interviewed in their own homes using a semi-structured interview schedule. A narrative analysis highlighted important findings through the identification and construction of several plots and subplots within parent narratives. These include that parents themselves appear to undergo trauma as a consequence of their child sustaining TBI; that parents made - and wanted to make - a major contribution throughout their child's rehabilitation, and that all parents went - and are continuing to go - through a number of transitions in this process.

Given that fathers have historically been neglected from research into child health issues, the finding here that mothers *and* fathers made a substantial contribution throughout the rehabilitation process is timely and important. For most parents, this event led to profound and long-lasting changes in their lives and life stories where their previous, hitherto narratives were 'shattered'. On the child's return home, these changes appear neither recognised nor supported by services. There seemed little if anything in service provision and coordination to meet the needs of children and parents, which resulted in parents continually fighting for services. Clinical implications are discussed as well as directions for future research.

## CONTENTS

Abstract .....	98
INTRODUCTION .....	105
Traumatic brain injury.....	106
Epidemiology.....	106
Sequelae of Severe Traumatic Brain Injury.....	107
Methodological problems investigating TBI.....	109
Assessing Injury Severity.....	109
Operationalising outcome.....	110
Factors influencing outcome .....	110
‘Plasticity’ and ‘early vulnerability’ .....	110
Childhood Traumatic Brain Injury: The importance of Parents.....	111
Injury-related stress and burden .....	112
Contributions and Limitations of Quantitative Methodologies .....	114
Qualitative studies .....	115
Clinical relevance: National Service Frameworks & extant literature .....	116
Summary.....	117
Research Question .....	119
METHODOLOGY .....	120
The Case for Narrative Inquiry.....	120
Settings .....	122
Researcher .....	123
Power Relations.....	123
Researcher Position.....	123
Context.....	125
Age and Gender.....	125
DESIGN .....	125
Sampling Strategy .....	125
Participant recruitment .....	126
Participants .....	126

Selected Families.....	126
Narrative Interview Schedule.....	127
Procedure .....	128
Interview Procedure .....	128
Transcription.....	128
Ethical Considerations.....	129
Confidentiality .....	129
Consent .....	130
Information .....	130
Avoidance of Harm .....	130
THE PROCESS OF ANALYSIS.....	131
Definitions.....	131
Narrative.....	131
Core story creation.....	131
Plots.....	132
Tacking.....	133
Emplotment.....	133
RESULTS.....	135
Plots and subplots.....	136
Plot 1. The early stages: disbelief and disintegration.....	137
Plot 2. The role of parents.....	142
Plot 3. Fighting for services.....	145
Plot 4. Transition phases: Emotional, temporal and action.....	150
Plot 5. After-care and long term impact.....	156
DISCUSSION.....	163
Plot 1. The early stages: disbelief and disintegration.....	163
Plot 2. The role of parents.....	164
Plot 3. Fighting for services.....	166
Plot 4. Transition phases: Emotional, temporal and action... ..	168
Plot 5. After-care and long term impact.....	170
Clinic Implications.....	173
Strengths and limitations of this study.....	175

Strengths.....	175
Limitations .....	176
Future Research .....	177
CONCLUSIONS .....	178
REFERENCES .....	180
Appendix I.....	193
Methodological Rigour: Issues and Procedures.....	193
Appendix II .....	195
A flyer .....	195
Appendix III.....	196
Invitation letter.....	196
Appendix IV.....	197
Information sheet.....	197
Appendix V .....	200
Consent form .....	200
Appendix VI.....	201
Interview Schedule: Parents' Experiences following their Child's Traumatic Brain Injury.....	201
Appendix VII .....	203
Introduction to interview in the home.....	203
Appendix VIII.....	204
Debriefing information.....	204
Appendix IX.....	206
Ethical approval.....	206
Appendix X.....	207
Example of completed member checking questionnaire.....	207
Appendix X1.....	208
CD ROM containing all raw data .....	208

## FIGURES

Number	Page
Table 1 Family constellations.....	135
Table 2 Plots and Subplots .....	136

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## INTRODUCTION

Children sustaining severe traumatic brain injury (TBI) have been shown to have slower recovery and poorer outcome than adults with similar insults (e.g., Anderson and Taylor, 1999; Taylor and Alden, 1997). Literature and clinical evidence (Anderson *et al.*, 2001) indicates that recovery processes for the child are long-term and complex, beginning with acute phases and medical issues through to sub-acute and long-term outcomes with respect to physical, cognitive and psychosocial factors.

Compared to studies of adult traumatic brain injury, studies of childhood TBI are limited, and in relation to developmental parameters, psychosocial context and outcome, many unanswered questions remain (Anderson *et al.*, 2001). While severity of injury is of prime importance immediately post insult, environmental factors become more relevant in the long term. Anderson *et al.*, (2001) note that in studying childhood TBI, a number of parameters specific to children require consideration including, for example, age at injury, time since injury, and family environment. Studies suggest that psychosocial factors (such as family function, socioeconomic status, access to rehabilitation and response to disability) play a role in recovery and become more important with time (Anderson and Taylor, 1999).

It is the stories of parents of children sustaining TBI that this study is concerned, as little seems to be known about the experience of parents from a qualitative perspective following their child's injury.

The introduction provides first some background information regarding the frequency with which childhood TBI occurs. It then considers briefly the impact, or sequelae, of traumatic brain injury on children and adolescents by highlighting general research findings to date. Consideration of important mediating factors highlighted in the literature known to influence impact and outcome then follows. The literature presented highlights the importance of the family when considering both the impact and outcome of childhood TBI. The chapter concludes by arguing the clinical relevance of this study in relation to the needs of people with long-term conditions.

## **Traumatic brain injury**

Traumatic brain injury refers to a general or localised insult to the brain capable of producing brain damage and associated functional impairment. These traumatic insults are usually caused by a physical blow to the head that is sufficient to result in altered consciousness and may lead to neurological or neurobehavioural sequelae. It is this alteration in conscious state that is mostly used to distinguish true TBI from minor insults (Anderson *et al.*, 2001). Consequences and severity of TBI will depend on a number of risk factors. In collision with an object, for example, the greater the force applied to the brain, the more severe the associated damage.

## **Epidemiology**

Traumatic brain injury represents one of the most common causes of acquired disability in childhood. In the UK, the statistics for Accident and Emergency (A&E) attendance, hospital admissions and mortality for head injury are not unified nationally (Middleton, 2001). Department of Health (1997) figures for the UK suggest that for children aged 0-15 years, 1% of A&E attendees had a severe injury. Such incidence levels establish childhood TBI as a significant problem for the community (Anderson *et al.*, 2001; Hayes and Jackson, 1989). Little epidemiological evidence exists for the incidence of stroke in children, although De Scheyver *et al.*, (2000) note it is 'rare'.

Overall, boys outnumber girls, 2:1, although this is partly age-dependent (Krauss, 1995). Boys tend to sustain more severe trauma. Krauss *et al.*, (1986) note that incidence of TBI increases in males throughout childhood and adolescence, whereas incidence for females shows a relative decline through childhood. Lehr (1990) suggests such a consistently identified gender-related trend may reflect higher levels of activity and exploratory behaviour in boys. Epidemiological research indicates that childhood TBI occurs most frequently on weekends, holidays and afternoons, when children are most likely to be involved in leisure activities (Anderson *et al.*, 2001). Middle to older children sustain injuries as a result of bicycle accidents or from sport. There is also a relatively high incidence of pedestrian accidents, in keeping with the

greater mobility of this age group and their lack of awareness of danger (Lehr, 1990). Chadwick (1985) reports that road traffic accidents account for the majority of severe, closed head injury (except in children under one year) in the paediatric population. In closed head injury, damage results from compression and deformation of the skull on impact, leading to complex primary and secondary injuries as a result of high velocity deceleration forces (Anderson *et al.*, 2001). Primary injuries are produced when the brain is shaken around within the skull cavity resulting in multiple injury sites as well as diffuse axonal damage. Such shaking can cause neural tearing throughout deep cerebral structures, particularly at junctions between grey and white matter in areas of the basal ganglia, hypothalamus, cerebellum, and frontal and temporal lobes. Secondary injuries, such as raised intracranial pressure are common after TBI, and have been found to be predictive of outcome. The effects of TBI in the child can cover many domains, and are discussed briefly in the next section.

### **Sequelae of severe traumatic brain injury**

Research on the effects of childhood severe TBI has yielded important information on sequelae, outcomes and risk factors (Taylor, 2004). While a proportion of children make substantial recoveries, for a significant number in this population sequelae are chronic, long term and persisting (Klonoff 1971: Klonoff *et al.*, 1995). Compared to those with mild to moderate injuries, children with severe TBI have the lowest potential for full recovery (Montgomery *et al.*, 2002). Sequelae have been found to be long-term. The studies of Klonoff (1971) and his associates (Klonoff *et al.*, 1995) were the first systematic attempts to evaluate the effects of TBI in children. These studies followed a prospective sample of 231 children with a diagnosis of closed head injury from the time of the injury through to adulthood. Telephone follow-up in adulthood found that 31% of the sample reported persisting sequelae.

Such children exhibit more behaviour problems, greater rates of psychiatric disorders, and lower levels of adaptive behaviour than do children with milder forms of TBI, or other injuries not involving the head (Brown *et al.*, 1981: Fletcher *et al.*, 1990: Max *et al.*, 1997a: Max *et al.*, 1998: Perrott *et al.*, 1991: Taylor *et al.*, 1999: Yeates *et al.*, 2001). When the injury includes damage to the frontal lobes, which are particularly

vulnerable in TBI (Ylvisaker *et al.*, 2003) the resulting impairment of executive functions can intensify over time and manifest as irritability, impatience, frequent loss of temper, emotional volatility, egocentrism, impulsiveness, anger, depression, and lack of interests. Such poor regulation can cause the loss of relationships, increase the burden of daily care and support on families, and compromise the safety to the injured person and others.

Cognitive problems associated with impaired executive control often worsen over the child's developmental stages (Ylvisaker *et al.*, 2005). Cognitive and behavioural problems bringing residual impairment in a number of skills (particularly information processing, attention, memory and learning) affect the child's capacity to interact with their environment effectively, resulting in lags in skill acquisition and increasing gaps between injured children and their age peers.

Ylvisaker *et al.*, (2005) note that the past 20 years of research has shown convincingly that social and behavioural disorders after childhood TBI are simultaneously common and extremely troubling for parents, teachers, peers and others. Estimates of persisting behavioural problems not evident before the injury among children with severe TBI range from around 35% to 70%. Most studies suggest that a large percentage of this population experiences new and persisting problems after the injury. Such sequelae have been labelled 'primary deficits' (Anderson *et al.*, 2001) because of their impact on the child.

While sequelae are well documented, outcome is highly variable. Taylor (2004) noted that heterogeneity of outcomes of TBI is unexplained, even after grouping children into traditional severity classifications, and appears highly variable even among children with more serious injuries (Fletcher *et al.*, 1995: Fletcher & Levin, 1988). This is complicated by the interaction of a number of complex variables and may be compounded by a number of methodological problems inherent in the investigation of childhood TBI.

## **Methodological problems investigating TBI**

A full review of methodological limitations in the TBI literature is beyond the scope of this chapter. By way of examples, Wade *et al.*, (1995) note that the range of assessment approaches and plethora of self-report measures of family functioning pose a dilemma for researchers. This makes comparison between studies and drawing conclusions difficult. Further, few investigators have considered the possibility that TBI has multifaceted effects on family members and relationships (for example, through particular relationship dyads within the system (Boss, 1992)) and that family consequences may vary with the method in which outcome is assessed. Two further examples are discussed in detail below; assessing injury severity and operationalising 'outcome'.

### **Assessing injury severity**

Taylor (2004) noted that the assessment of injury characteristics relies on traditional classifications of mild, moderate and severe TBI. These are determined by lowest post-resuscitation Glasgow Coma Scale (GCS: Teasdale and Jennett, 1974) scores, duration of unconsciousness, and presence-absence of neurological abnormalities.

Fletcher *et al.*, (1995) analysed the various factors that need to be taken into account and found that many indices are poor and may obscure the sometimes sensitive changes that follow TBI. For example, while the adapted paediatric version of the GCS provides a universal benchmark for classifying injury severity, it is often too crude a measure to detect sensitive changes following trauma. Anderson *et al.*, (2001) highlight other limitations. For example, reliability of measures varies depending on the experience of the rater, with results from inexperienced raters less consistent than those recorded on or after hospital admission. Second, where patients require sedation or undergo surgery, GCS monitoring is interrupted. There is also no clear agreement about the optimal time to measure Glasgow Coma Score. So, despite its popularity there remains some debate about the prognostic value of the GCS. It is also difficult to gauge the severity of injury because many hospitals do not specifically record the GCS or the length of post-traumatic amnesia (which is a more reliable predictor of

sequelae) and it is not easy to extrapolate GCS scores from medical notes (Division of Neuropsychology, 2006).

### **Operationalising outcome**

Where injury severity has been shown to be the most consistent predictor of *sequelae* in the injured child, it is not a reliable predictor of *outcome*. It seems implicit in the TBI literature that ‘outcome’ is a more beneficial and accurate description than ‘recovery’, as those sustaining severe TBI – regardless of age at injury – do not follow a ‘recovery’ trajectory in the traditional sense, as might be expected in cases of, for example, orthopaedic injuries not involving the central nervous system. Outcome depends on the interaction of a number of dynamic and complex influences including, sequelae, developmental parameters, environmental factors, psychosocial context, and pre-injury behaviour characteristics of the child (Anderson *et al.*, 2001).

### **Factors influencing outcome**

#### *‘Plasticity’ and ‘early vulnerability’*

One factor influencing outcome that has generated much research and debate is the extent to which the child’s brain is able to recover from early insults, because of its relative immaturity. Investigators have proposed two models: ‘plasticity’ and ‘early vulnerability’ (Anderson *et al.*, 2001: Hebb, 1949: Kennard 1936: 1940: Kolb, 1995: Schneider, 1979). The Plasticity hypothesis postulates that the immature brain is able to recover and reorganise function following insult, and promote relatively positive outcome (Kennard, 1940). Early vulnerability hypothesis, by contrast, holds that the developing brain is less able to reorganise function, due to timing and critical periods of cognitive and architectural development (Kolb, 1995).

Contemporary evidence suggests the plasticity hypothesis is out of date (Anderson *et al.*, 2001: 2006: Middleton, 2001) and that outcome for children with severe TBI is worse than for adults with TBI (Taylor, 2004). In their prospective study of functional recovery 30 months following injury, for example, Anderson *et al.*, (2006) concluded that children sustaining injuries in early childhood exhibit deficits similar to, if not more persistent than those observed in older children and adolescents, ‘providing little

support for the presence of functional plasticity in the developing brain.’ (p55). Indeed, in the context of more severe injuries there is evidence of decline or lack of development across cognitive and behavioural domains by 30 months post-injury.

As important a debate as plasticity/early vulnerability theories are, neither is able to explain the range of outcomes observed. The outcome for the child (and, to an extent, the family) appears determined by a range of complex and dynamic factors; lesion variables (such as size, severity and nature, percentage of damage), developmental parameters (such as stage of development, age of child at injury, and timing of insult), environmental factors, psychosocial context, and family parameters (Anderson *et al.*, 2001).

For those outcomes that are poor, the impact on some families can be profound. Injury-related sequelae for the injured child account for a significant proportion of the variance in child outcomes after TBI (Fletcher and Levin, 1988) and have been described as ‘primary’ deficits. The impact on the family has been described as ‘secondary deficits’ (Anderson *et al.*, 2001). For those that develop behavioural dysfunction as part of the sequelae, these are especially problematic for families and schools (Taylor *et al.*, 2001).

### **Childhood traumatic brain injury: The importance of parents**

In one of the earliest studies to consider family outcomes following childhood TBI, Rutter *et al.*, (1983) reported their clinical observations of families followed prospectively from the time of the child’s injury. They noted a range of family changes, including parental anxiety, changes in the parent-child relationship and increased marital strain. A limitation of this study was that it had a small sample and did not use standardised measures.

Subsequent research has supported Rutter *et al.’s* (1983) findings and established reliably the impact of TBI on families, and similarly the role of parents in childhood TBI outcome. For example, following severe TBI in children, developmental accomplishments and symptoms evolve in relatively unpredictable ways. Children and

especially adolescents face the daunting task of integrating their evolving pre-injury sense of self with the new realities imposed on them by their injury. Parents and teachers can therefore play a crucial role in the difficult process of constructing a positive and organised sense of identity for the child (Ylvisaker *et al.*, 2005).

Using prospective and longitudinal designs, three research groups have made a substantial contribution to our understanding of the importance of the child's parents in TBI outcome: Keith Yeates and colleagues in the United States; Mark Ylvisaker and Tim Feeney and colleagues, also in the United States, and Vicki Anderson and colleagues in Australia. While the impact of childhood TBI on both the child and family is well established (Anderson *et al.*, 2006, 2001; Wade *et al.*, 1996; Ylvisaker *et al.*, 2003) it is only recently that the reciprocal role of family/injured child has been demonstrated in the literature (Taylor *et al.*, 2001; Anderson *et al.*, 2006; 2001; Ylvisaker *et al.*, 2005).

The importance of this relationship is, however, not new. Experienced clinicians have recognised for two decades that long-term family and child outcomes are reciprocally inter-related. It was Lezak (1988) who originally described brain injury as 'a family affair'. The research literature has demonstrated that positive/negative child outcomes increase the likelihood of positive/negative family adjustment, and similarly, positive/negative family adjustment increases the likelihood of positive/negative child outcomes (Taylor *et al.*, 2001).

Best outcomes have been associated with good social support and family cohesion. Rivara *et al.*, (1993) showed that in school-aged children, high levels of family cohesion and low levels of parental control were predictive of good child adaptive functioning, social competence and global functioning at one-year post injury. Conversely, Wade *et al.*, (1996) found that the degree of perceived family burden and parental problems post-injury was greater in families who reported chronic life stress and maladaptive coping styles.

### **Injury-related stress and burden**

Because the onset of TBI is sudden and catastrophic, the principal morbidity and source of burden for parents often arises from long-term cognitive, behavioural, and academic deficits rather than from physical impairments (Taylor, 2004). Researchers have operationalised this as injury-related stress and burden for parents.

Feeney *et al.*, (2001) note that two decades of research have documented negative effects on support people as a result of living with and caring for a person with behavioural disability after TBI. Lezak (1986) was one of the first clinicians to observe that cognitive and behavioural dysfunctions, such as emotional disinhibition, impulsivity and failure to learn from experience placed significant demands on parents to alter expectations, rules and disciplinary practices for their children.

'Demands' and 'burden' specific to TBI have been identified as obtaining rehabilitation services, school re-entry, and ongoing behavioural and intellectual changes in the child (Wade *et al.*, 1995). However, long-term follow up of many injured children and their families suggest that even with access to excellent rehabilitation services these problems persist, although the nature of stressors change with time since injury and developmental level of the child (Anderson *et al.*, 2001). The family is also confronted with different demands over the course of the outcome process (Rivara, 1994: Rolland, 1987). For example, generic tasks of the acute or crisis phase include learning to deal with the injury, learning to deal with the hospital environment and medical treatments, and establishing relationships with healthcare professionals (Rolland, 1987). Rolland's (1987) work highlights the transition from the crisis phase to the chronic phase as a critical period for families. Evidence is emerging in the literature that the event of the injury to their child for many parents is itself traumatic (Colville and Gracey, 2006).

Because stress and burden have such an emphasis on day-to-day family functioning, it could be argued that they are poorly defined conceptually and theoretically and the psychological mechanisms and processes by which stress and burden operate and manifests are not identified. Further, to confine stress and burden to 'functional' aspects of parents' daily living is to potentially limit our understanding of the

consequences of the event, particularly around any deeper meanings it has for parents of injured children.

### **Contributions and limitations of quantitative methodologies**

Quantitative methodologies have yielded much valuable information about the familial impact of childhood TBI. Strengths of research programmes from the United States and Australia include analyses of long-term follow-up, the use of aged-matched control groups, and consistent use of the same measures, which add reliability to their findings.

While standardised measures and generic instruments yield reliable and valid data they may conversely obscure the presence of and be insensitive to the stresses and changes in family experiences that are unique to TBI (Wade *et al.*, 1995). Another limitation is that means calculated through group comparisons tell us nothing about 1) individual differences and commonalities among parents, and 2) the nature of parental experience from a qualitative perspective.

A further limitation highlighted by Yeates *et al.*, (2001) (and a common feature of TBI family outcome research) is that the mother is usually the sole respondent. The omitting of fathers from child health research is recognised in the literature as a serious limitation to understanding parental responses and contributions to family adaptation in a range of child health conditions (Kazac *et al.*, 2003; Phares *et al.*, 2005): an observation that can be extended to childhood TBI research.

Moreover, mothers' only reporting presents at least two problems in interpreting results. First, mothers' reporting of the family environment is inferred to represent that of the family as a whole. This is at odds with Lezak's (1988) clinical observations that fathers react differently to the injury than mothers. Given the importance of the family in TBI outcome as demonstrated in the research literature, on a speculative level it is reasonable to hypothesise that fathers' reactions may influence recovery. The inclusion of mothers' only reporting in much of the literature therefore highlights a limitation of these studies. Second, mothers, as sole respondents, often complete all

measures at all time intervals which may inflate correlations through shared method variance leading to (potential) inaccurate associations.

Kazac (2003) argues that there is much to be learned from the broader inclusion of families in our conceptualisation of children and health. In a review of clinical child and family research published between 1984 and 1991, Phares (1992) found that fathers were significantly underrepresented in child and family research that focused on clinical issues. In their recent review of the 1992 article, Phares *et al.*, (2005) note that this pattern had not changed in 13 years. They argue that there is a clear need to increase the inclusion of fathers in research related to child well-being. In the context of TBI, this is all the more relevant given that significant relationships exist between fathers and normative developmental issues (Lamb, 2004) and the bi-directional relationship between the injured child and the family in the TBI literature (Taylor *et al.*, 2001; Taylor *et al.*, 1995).

### **Qualitative studies**

The comparatively few qualitative studies (e.g., Prentiss, 1999; Prigatano and Grey, 2007) in the field broadly concur with the findings of Anderson, Yeates, Ylvisaker, and their respective collaborators. Examples of qualitative inquiries have included exploring childhood TBI and its impact on mothers using symbolic interactionist principles (Guerrie and McKeever, 1997) and using phenomenological approaches to gain a deeper understanding of the parental experience of raising a school-aged child with brain injury (Prentiss, 1999). Different methodologies have found similarities and differences associated with parents of the brain injured child (for example, that injury brings with it severe distress (Prigatano and Grey, 2007)) while Smucker (1997), in her exploratory study using grounded theory, found that parents became empowered through managing their child's care.

Experiences associated with childhood TBI investigated through qualitative methodologies have also complimented quantitative approaches in bringing to our attention omissions in the standard literature. An example of this is loss; a theme identified in the qualitative literature, but almost totally absent from the quantitative

literature. However, such (clinical) observations were made over 20 years ago. Based on her clinical experience with adult TBI patients and their families, Lezak (1986) formulated a model of TBI which highlights affective responses of families that evolve through a series of stages, each representing different emotional responses of family members over time in response to the 'recovery' of their loved one. For example, over time, the family acknowledges their loved one's deficits as persistent and mourns the loss of the person as he or she existed before the injury. On a speculative level, it could be hypothesised that parents of injured children also experience such loss. In the case of children, it is possible that such feelings are exacerbated because parental hopes and expectations now have to be re-evaluated as a result of the injury. With little if any reference in the quantitative literature, loss has been highlighted in the qualitative literature:

*... She couldn't remember anything, not even the name of the show we had watched just 5 minutes before. I cried, but I realised then... that her life was never going to be the same. With three other kids at home, all younger than Walina, I felt overwhelmed. She's only 13 years old. Will she still have friends? Will she ever marry?... On one hand, I was so happy with all her progress, she looked so good. But she wasn't herself. Would she ever be herself again? I grieved for the Walina I had lost.*

(Savage and Morales, 1994: 71)

Boss (1991) has suggested that when a child's behaviour and personality change after the injury, caregivers face an 'ambiguous' loss because the person has not died. Such losses are especially difficult because they are not ritualised (as in burial) or given public validation. Guerrie and McKeever (1997) found that as a result of their child's injury, not only were mothers coping with loss of the pre-injury child but their experience had forced them to reconstruct their identities as mothers and that of their child, which echoes the findings of Ylvisaker and colleagues (2005: 2003).

### **Clinical relevance: National Service Frameworks & extant literature**

Children who have sustained traumatic brain injury represent an under resourced clinical problem in the United Kingdom (Division of Neuropsychology, 2006). It seems the well-documented need for intensive family supports is often unmet in the UK as it is in other countries. For example, families continue to report the need for a

central point of contact providing case management, information, networking, advocacy, and other support (Armstrong and Kearns, 2003). This critical support is often not available to them. This is clinically relevant, as families continue to report a sense of isolation in relation to their TBI-related needs. The needs of families where a child sustains TBI have recently been recognised in Department of Health initiatives such as Every Child Matters and guidance in the National Service Framework for Long-term Conditions (Department of Health, 2005). Although not specifically focused on head injury in children, the NSF identifies this group and acknowledges the clinical need due to the changes and difficulties that the injury brings for children and their families.

Alarmingly, these needs were identified twenty years ago (Lezak, 1988) and despite advances in formulating conceptual frameworks (Ylvisaker *et al.*, 2003) that attempt to overcome the fragmentation in many service delivery systems, these needs remain unmet today in many parts of the world (Ylvisaker *et al.*, 2005) including the UK (Division of Neuropsychology, 2006).

### **Summary**

The majority of literature about parents' experiences after their child sustains TBI is quantitative in nature and adopts a positivist approach in which data are manipulated, sorted, labelled, counted, and weighted (Fairbairn and Carson, 2002). No narrative studies within the field were identified.

'Stress' and 'burden' emerge as consistent findings among parents, particularly around the impact of the child's injury on the family, disruption in family routines, access to rehabilitation services and the long-term cognitive, behavioural, and academic deficits rather than from physical impairments (Taylor, 2004). Despite the number of studies documenting TBI-related stress and burden, it remains poorly conceptualised and lacking theoretical substance (Keith Yeates; personal communication: June, 2007). The conceptualisations of stress and burden seem to be 'functionally' based; where the injury impacts on family routines and necessitates changes in behaviour that involve care giving to the child. Several issues of

methodology, conceptualisation and definition have been highlighted, as well as the broader and politically relevant issue of quality of life for both parents and injured children and siblings.

The comparatively few qualitative studies generally support the findings from the quantitative literature. They also draw our attention to aspects of parental experience barely acknowledged in the standard literature such as loss and the phenomenology of the experience. The dominance of quantitative studies – although valuable – conversely limits the context and meaning of parents' experiences of their child's injury, and even more so of the injured child.

In order to put parents at the centre of this study, and to literally promote their voices, a narrative analysis was chosen to investigate the parental experience of their child sustaining TBI. This suited the investigation for several reasons. One aim was to get behind the 'dominant voice' of positivist, quantitative approaches. In this vein, there is very little information in the literature about what the injury might *mean* for parents on levels other than day-to-day functioning; alternative discourses are lacking. Novel approaches such as ethnographic interviews hold promise as additional windows into family functioning post-TBI. An interview schedule combining open ended and structured probes facilitates greater sensitivity to actual rather than theorised family experience and is consistent with a 'consumer oriented' approach to research (Wade *et al.*, 1995).

As a qualitative investigator, a major assumption I have about this project is that traumatic brain injury of a child could be understood as a major life transition for parents. This conceptualisation has particular relevance and poignancy for the change in parents' - and families - lives that such an injury brings; their child appears to be following a 'normal' developmental trajectory, and parents' narratives too are normal in this context, with normal hopes and aspirations for their developing child. The child then sustains severe injury to the central nervous system. Parents' existing narratives are then thrown into chaos - shattered - and a process of forced narrative reconstruction is thrust upon them (and the rest of the family) on a previously

unimagined and unparalleled level.

By giving parents a voice, a channel through which to tell their own stories, I sought to empower them and enable them to be heard.

### **Research Question**

- How do parents experience the traumatic brain injury of their child, and what does it mean to them?

## METHODOLOGY

One school of thought about research is at the philosophical and epistemological heart of this thesis; social constructionism. Based on ideas of for example, Berger and Luckman (1967), social constructionism has assumptions that individuals seek understanding of the world in which they live. They develop subjective meanings of their experiences – meanings directed towards certain objects or things. These meanings are varied and multiple, leading the researcher to look for the complexity of and subjective differences and similarities of views rather than narrowing meanings into a few ‘objective’ categories or ideas. Research from the perspective of social constructionism relies as much as possible on participants’ views of the situation being studied. The questions become broad and general so that the participants can construct their own meaning of a situation, a meaning typically forged in interactions with other people (Creswell, 2003). Often, these subjective meanings are negotiated socially and historically; they are not simply imprinted on individuals but are formed through interactions with others, through historical and cultural norms that operate in individuals’ lives. Constructionist researchers also focus on the specific contexts in which people live and work in order to understand the historical and cultural settings of the participants. In conjunction with the theoretical position of the study, the researcher assumes that “meaning” is constructed socially, historically, and dynamically (Grbich, 1999).

Researchers also recognise that their own background shapes their interpretation, and that they ‘position themselves’ in the research to acknowledge how their interpretation flows from their own personal, cultural and historical experiences. The researcher’s intent then, is to interpret the meanings others have about the world, as well as to acknowledge their own perspective in that interpretation.

### **The case for narrative inquiry**

One aim of this study was to place parents at the centre of the investigation; to make them the experts of their own experience, to elicit their meanings and constructions. Another aim was to make as few assumptions about their experience as possible, and

most importantly of all, to hear (and listen) to their voices. Such an approach, it could be argued, concurs with the philosophy of various Department of Health documents published in the last decade (e.g., DoH, 2005: 1999) which espouse ‘person centred care’ where the needs of service users are recognised, understood, and attempts made to address them in service delivery.

Given such aims it was decided that a narrative account from parents could provide an alternative but complimentary lens to existing literature through which to gain further understanding of their experience. That no narrative analysis could be found in this area of clinical research only strengthened the argument for narrative inquiry.

Chase (2005, p.651) presents narrative *inquiry* as a particular type – a subtype – of qualitative research, arguing that contemporary narrative methods revolve around an interest in biographical particulars as narrated by the one who lives them. For this study, the empirical material to be studied is an interview with parents focusing on an extended story about a significant aspect of their lives – their child sustaining severe brain injury.

Mishler (1986), a pioneer of the use of narratives in research, regards this particular approach as a principle means of making sense of an experience, a view reflected by Stanley and Wise (1990). They maintain it is arguably the most successful way of eliciting a personal description of people’s perceptions of life experiences and according to Lieblich *et al.*, (1998), adopting such methodology provides rich and unique data.

A central tenet of the narrative turn is that speakers *construct* events through narrative rather than simply referring to events (Chase, 2005). Narrative is retrospective meaning making – the shaping or ordering of past experience. It is a way of understanding one’s own and others’ actions, of organising events and objects into a meaningful whole, and of connecting and seeing the consequences of actions and events over time (Bruner, 1986: Polkinghorne, 1995). Unlike a chronology, which reports events over time, a narrative communicates the narrator’s point of view,

including why the narrative is worth telling in the first place. So, in addition to telling what happened, narratives also express emotions, interpretations and thoughts – the focus and emphasis being the narrator’s voice. Essentially, the narrator makes the self the protagonist. Through this, versions of the narrator’s self, reality and experience are highlighted. Reissman (1994) speaks of narratives as the means for us to create who we are and how we define situations in our daily lives. Narratives also allow us to order our worlds and make connections (meanings) between our past and present, and between ourselves and the worlds we live in. Ricoeur (1984) points to the temporal nature of the world, and that by using narratives we are able to construct meanings within a time frame that has a beginning, middle, and end.

It is important to note that a narrative is a socially situated interactive performance (Chase, 2005). That is, it is produced in a particular setting, for a particular audience, for a particular purpose. As narrators too, researchers develop meaning out of and some sense of order in the material they study. They develop their own voices, as they construct the reality and voices of others. They narrate ‘results’ in ways that are both embedded and constrained by the social resources and circumstances embedded in their disciplines, cultures, and historical moments, and they write (or perform) their work for particular audiences. Unlike ‘standard’ scientific discourse, which also explains or presents an understanding of actions and events, narrative discourse highlights the uniqueness of each human action and event rather than their common properties (Bruner, 1986; Polkinghorne, 1995). Despite this uniqueness, similarities between accounts allow also for the identification of themes across the narratives. Chase (2005) asserts that narrative researchers, by contrast, listen to narrator’s voices – to the subjective positions, interpretive practices, ambiguities and complexities – within each narrator’s story. Such a process usually includes attention to the narrative linkages that a storyteller develops between the biographical particulars of their life, on one hand, and the resources and constraints in their environment for self and reality construction, on the other (Holstein and Gubrium, 2000, p.108).

### **Settings**

Given that a person’s subjective experience is constructed socially, historically, and

dynamically through interactions with others (Rosenthal, 2004) the setting of the research plays an influential role in the construction of parents' experience and meaning. It was decided to collect parent narratives via interviews in their homes. The interviews provided a setting in which social, historical, and dynamic processes could operate and narratives could be constructed, expressed and interpreted using a specific type of narrative analysis.

### **Researcher**

When considering the research setting, and its role in constructing narratives and providing data, it can be helpful to consider the interaction between the researcher and participants. Aspects of this relationship that can be important include power relations, gender, and age (Oakley, 1981; Brodsky, 2001).

### **Power Relations**

Within a research setting it is common that the researcher holds a dominant position within the relationship as the interactions are primarily guided by the researcher. Within this study the power relationship enabled the researcher to guide parents' narratives towards areas of interest highlighted as important in the paediatric TBI literature. Nevertheless, it is also necessary to allow the participants to narrate as freely as possible within these areas and reduce the researcher's element of the co-construction of the narratives; that is not to dictate the type of narratives produced. To reduce the potential power differential between researcher and participants, I emphasised that I was interested in hearing and learning from them, in their role as parents of an injured child, trying to emphasise that they were experts on their own lives and of their own experience. My sense is also in conducting interviews in parents' homes, I was an invited 'guest' in their lives, albeit for a short period of time. I believe this reduced the power differential between us, and enabled and promoted a more 'free-flowing' narrative than would have been possible or achieved at a different location.

### **Researcher Position**

As qualitative research is underpinned by subjective concepts (Grbich, 1999), the

researcher is an integral part of the research process and will impact on the design, analysis and findings (Stiles, 1993). It is therefore helpful to illuminate the researcher's subjective position to help the reader understand the process of the research, and the decisions made. The aim here is to help the reader share the perspective of the researcher throughout the study.

Regarding the injury, the researcher assumes that the meaning of the event is constructed and maintained through the narratives that are held and conveyed (Reissman, 1994). Additionally, these narratives are co-constructed depending on the individual's context. Another example creates further context; stories told within the family about a child born with a developmental disability might be subject to more emotional 'openness' about this event between parents compared to how these stories are expressed external to the family where the emotional details are played down. Consequently, narratives may alter depending on the context; the alterations may be dependent on the meaning of the narrative within the given context.

In terms of my position as researcher, I was born into a relatively developed, affluent, liberal western country and culture, characterised by a class system. I am from a working class background, in Wales. This time, location and contemporary society has bestowed upon me certain discourses, attitudes, values, assumptions, biases, prejudices, privileges and inequalities.

I began the research with some assumptions, based in part based on my reading of the literature and clinical experience from working in a brain injury service about how the experience may have been for parents. One assumption, for example, was that the experience would have been a significant life event for parents which altered their children's and their own life trajectories in a negative way. These assumptions, I reasoned, inevitably played a part in my approach and interactions with parents. However, as discussed above, a critical feature of this study is that narrative inquiry enabled parents through their stories to disrupt any assumptions I held as researcher.

## **Context**

As highlighted above, when using a qualitative approach to answer exploration type questions, one needs to consider the context of the research as it influences the subject matter under investigation. Therefore, to help understand the meanings, narrative processes, and experiences of parents, the context in which the narratives were produced needs to be made explicit (Potter & Weatherell, 1987). However, it is only feasible to express some of the contextual issues due to the enormity, complexity and diversity of the factors that are influencing us at any one time e.g. social history, gender, personal memories, emotions, level of education, employment, etc. The point being that the personal history of this person could influence how they perceive their child's injury. Contextual details that the researcher was aware of, that may have had an influence on the narratives produced, are detailed below.

## **Age and Gender**

To what extent my age and gender influenced the narratives produced is not clear. My sense is that my age was within a decade of the ages of all parents I spoke to. Such an observation implies that any generational influences (for example, parents relating to me as son, brother, uncle, father, etc.) on narratives would have been at least limited, if not totally absent. I certainly was a stranger in their home. I wondered how this impacted on the way parents related to me. As the interviews progressed, it was clear that the conversations took on a 'natural' style, characterised by openness and a willingness to talk which provided the material for narrative analysis through Emden's (1998) method.

## **DESIGN**

### **Sampling Strategy**

When using qualitative methods it is appropriate to use a small number of participants (Silverman, 1997) owing to the large quantity of verbal data requiring analysis (LoBiondo-Wood and Haber 2002). This enables the researcher to study meanings, experiences, and to gain an "insiders" perspective by collecting a lot of individual data (Chamberlain *et al.*, 1997). It was also felt this would provide a manageable amount of

rich and detailed data given the constraints of the research timetable but the number would be sufficiently large enough to examine similarities and differences between participants. For this reason, a number of eight dyads were decided upon.

The need for a small number of participants who have had experiences of a specific event required the need for purposeful sampling (Mays & Pope, 1995). That is, parents who have a child that sustained TBI would be selected purposefully to describe their experiences regarding the research question. Generalisability is not an aim of the study, and I do not claim that my own sample will be representative of all parents that have a child who sustains severe brain injury. However, given the various processes and mechanisms to ensure methodological rigour (see Appendix I) through, for example, trustworthiness, narratives may resonate with the wider group of parents who have had this experience. The approach to purposeful sampling was conducted through the following recruitment strategy.

### **Participant recruitment**

#### *Participants*

The study was conducted in collaboration with the Children's Trust, Tadworth. This is an organisation which specialises in the rehabilitation of children with multiple disabilities, including traumatic and acquired brain injury. Following an invitation from Sue Walker, Educational Psychologist, I first visited the trust in August 2006. This was in response to my telephone enquiry to conduct research in July the same year.

#### *Selected families*

Potential participants who met the inclusion criteria were identified by staff at the Trust. The parents selected were homogenous in the following way. Parents had a child (under the age of 16) who has sustained 'severe' TBI as the literature indicates this will make the greatest demands on the family in adjusting to the event. Perlesz *et al.*, (1999) note that the greatest functional recovery from TBI is within 6 months after trauma. Second, to obtain rich and deep experience from parents, the child needed to have been discharged from residential rehabilitation services, and be living at home.

This would have enabled parents to experience the range of situations and events which the research question was designed to investigate.

Also important was that mothers and fathers were still living together. This was to address some of the weaknesses in previous studies. That fathers were included here constitutes a methodological advance (Phares *et al.*, 2005).

Equally, parents of children who had certain pre-injury characteristics were excluded. These included non-accidental brain injury, and history of previous closed head injury (disequilibrating one head injury from another would be methodologically difficult). Parents whose injured children include such characteristics were not invited to take part because another key focus of this study is that the injury was sudden and unexpected in that parents had no 'warning' and thus were unable to 'prepare' emotionally or psychologically for the event.

A list of potential parents was then made. Invitation 'packs' were posted to selected parents. Each pack contained a 'flyer' (Appendix II), an invitation letter (Appendix III), an information sheet about the research (Appendix IV), and three consent forms (Appendix V). Two consent forms were for participation consent (one to be retained by parents, the other posted back to me) and the other consent form was to include parent's telephone numbers so that interviews could be arranged. On receipt of consent forms respondents were contacted by phone and dates and times for interviews arranged.

### **Narrative Interview Schedule**

A lightly structured interview schedule was specifically designed for this study (Appendix VI). This was discussed with my external supervisor, who added constructive comments and further questions to it. It used generative questions to encourage parents to 'tell their story' around the child's injury and included several types of prompts to invite parents to expand on responses.

The structure and contents of the schedule was based on areas identified by the

literature as important in childhood TBI and its impact on parents. These included the child before the injury, the accident that led to brain injury, services received by the child and family, how the family has coped since the accident, the reaction of family and friends, social networks, parent's hopes and fears for the child's future, and advice they would give to other parents in a similar position. The interview contained 'planned' probes (such as elaboration, descriptive, examples, and spontaneous probes). However, a key feature of the schedule was flexibility, which allowed spontaneous exploration where I could respond to comments and pursue areas of interest that occurred 'in the moment'.

## **Procedure**

### *Interview Procedure*

On arrival at parent's homes, an introduction to the interview was given (Appendix VII). This highlighted confidentiality (and its limits) and what parents could expect. Ongoing consent was a constant theme of the study. All interviews were tape recorded for accuracy of narratives and the transcribed copies were kept at the researcher's home on a pass-word protected personal computer. Notes were taken during the interview so that I could return to important points made by parents without interrupting their accounts.

After the interview, parents were given de-briefing information about why the study was being conducted (Appendix VIII). They were again reminded of confidentiality and assured of no personal identification.

### *Transcription*

All interviews were transcribed by a professional typist. The typist and I have worked together previously. She was familiar with confidentiality protocols. Nonetheless, these were reiterated prior to the first interview being transcribed. To be able to represent participants' experiences only major conversational characteristics were necessary. These included the lengths of pauses, and the noting of non-speech sounds (e.g. laughter, crying, sighs etc.). As the typist did not conduct the interviews it could be considered that aspects of the narratives could have been misrepresented once in

text format. Therefore, I read all of the transcripts whilst listening to the interviews and amended them as necessary.

### **Ethical considerations**

Participants were made aware that participation in the study was voluntary, and that the interviews concerned a formal piece of academic research. This was made explicit from the outset. As with most voluntary activities the research may have attracted participants with a helping nature, or who had an ‘axe to grind’. Indeed, all parents were asked why they decided to participate; all stated that they didn’t mind contributing if others in their situation benefited. In addition, participants’ awareness that this was a piece of research for a formal academic qualification may have shaped some of the narratives produced; considering that aspects of the interviews may be published, resulting in parents selecting what to say and what not to say.

On July 17, 2007, I presented my proposal to the Research Governance Committee at the Children’s Trust. The Committee approved the study, subject to University of Hertfordshire ethical clearance. Following advice from John Kerslake at the Surrey Ethics Board, NHS ethical clearance was not sought, as I was intending to interview *parents* of injured children who are funded by local Primary Care Trusts (see email from John Kerslake, Surrey Ethics Coordinator in Appendix IX).

### **Confidentiality**

Participants were informed via the information sheet (appendix IV) that all data would be kept in a locked unit and only the primary researcher and other bona fide researchers (including the research supervisors) would have access to this information. Those who look at the data understand, and are bound by the ethical procedures of the study to keep data confidential. Furthermore, no personally identifying information would be published. However, excerpts from their interviews may be published to illustrate the findings. Providing participants with this information enabled them to make an informed decision regarding their participation in the research.

## **Consent**

Participants were interviewed after they had read the information sheet, had the opportunity to ask questions regarding the study and signed the consent form. Participants were reminded that they could withdraw from the study at any time despite having consented to participate in the study.

## **Information**

Each participant was forwarded a copy of the information sheet which made up the invitation pack. This detailed the study in sufficient depth to allow the participants to make an informed decision regarding their participation. This included the purpose of the study, the requirement to talk about their experience of their child's brain injury and how the data was going to be used, and who would have access to the data.

## **Avoidance of Harm**

In my quest as a researcher for parent narratives through a very sensitive and painful subject, I needed to be attentive to and mindful of any possible exploitation of the participants. Towards this aim, I was guided by the British Psychological Society's guidance on ethics in research.

In addition, continually obtaining consent throughout the study (e.g. "is it okay to continue/or not?") reduced the possibility of participants becoming distressed. However, it was still expected that some individuals would become distressed by this emotive topic. It was therefore made clear that they could stop the interview at any point and withdraw from the study if they wished. If a participant became distressed, I listened, empathised and provided support to that individual until they felt able to continue, or else decided to stop. No participants withdrew from the study. Participants were also given details of helping agencies (as detailed in the information sheet, Appendix IV) and reminded that the researcher could provide ways of contacting these agencies, or their own general practitioners, if necessary.

## THE PROCESS OF ANALYSIS

The method of Emden (1998) was chosen for several reasons. Emden's (1998) approach is a 'descriptive' one (as opposed to an explanatory one) whereby an accurate description is produced of the interpretive narrative accounts individuals use to make sequences of events in their lives meaningful. Second, in producing core stories, Emden's (1998) method uses entirely the words of the speaker, which suits the philosophical spirit of this study in putting parents and their experience at the heart of this investigation. On this theme, Emden also stipulates 'member checking' where transcripts were returned to parents for their comments and the opportunity to make amendments.

### Definitions

#### *Narrative*

Polkinghorne (1988), cited in Emden (1998) defines narrative as '...a scheme by means of which human beings give meaning to their experiences of temporality and personal actions' (p.11). Here, narrative is 'a meaning structure that organises events and human actions into a whole' (p.18). Polkinghorne's definition sees narratives as involving stories – that is, it is more than a single story – the term therefore embraces the collective 'stored wisdom' of peoples' individual stories. Denzin (1989, p.37) defines narrative as '*a story that tells a sequence of events that are significant for the narrator and his or her audience*'.

#### *Core story creation*

Core story creation is a means of reducing full length stories to shorter stories to aid the narrative analysis process, and is the end-point of Emden's method in ascribing meaning to participant narratives. Emden (1998) devised the following method, comprising eight distinct stages:

- 1) Reading the full interview text several times over several weeks to grasp its content. This was done in conjunction with listening to the tapes for accurate representation. I felt that the process of analysis had begun at this point as I

noted and reflected upon the emotions, pauses and emphasis contained in the tapes

- 2) Deleting all interviewer questions and comments from the full interview text.
- 3) Deleting all words that detract from the key idea of each sentence uttered by the respondent
- 4) Reading the remaining text for sense
- 5) Repeating steps 3 and 4 several times, until satisfied that all key ideas were retained and extraneous content eliminated, returning to the full text as often as necessary for rechecking
- 6) Identifying fragments of constituent themes
- 7) Moving fragments of themes together to create one coherent core story, or series of core stories (as narrators do not neatly package their stories into logical timeframes)
- 8) Returning the core story to the respondent and asking, 'Do you wish to develop/correct/delete any part?'

Steps 1-5 above constitute 'combing the data'. It is this initial method that enables identification and construction of plots and subplots within the narratives (that is, identification of fragments of constituent themes, as per stage 6, above).

### *Plot*

Plot is described by Emden (1998) as 'the logic or syntax of narrative discourse...a linguistic expression that produces meaning through temporal sequence and progression' (p.35). This is an attempt to capture the powerful potential of stories to give meaning to people's lives. A story therefore has parts to it, it is constructed, and it conveys meaning. The plot of a story captures the importance of and could be considered the heart of the story. It is able to weave together complex events to make a single story, or several stories, that become the larger core story. It is able to take account of the historical and social context in which the events took place and to recognize the significance of unique and novel occurrences. A plot has the capacity to articulate and consolidate complex threads of multiple activities by means of the

overlay of subplots, put events in the sequence in which they occurred (not necessarily in which they are *told* - hence the need for techniques of combing, tacking and plot construction) and so give continuity to the main narrative – or core story.

Emden (1998) also points out that the plot of a story is not neatly packaged in a logical sequence as such by the narrator: it may take much work on the part of the narrative researcher to identify through tacking and emplotment as highlighted below. Narrative researchers acknowledge that human experience does not match a carefully crafted story, rather it requires that the ‘final story must fit the data while at the same time bringing an order and meaningfulness that is not apparent in the data themselves (Polkinghorne, 1988, p.16).

### *Tacking*

Similar story elements, or subplots, are created through ‘tacking’ (stage 7, above). Tacking is the process of identification of subplots within the stories where a ‘searching back and forth’ (p.37) for what was important about these subplots, or what distinguished them, and then further searching back and forth across stories, comparing and contrasting these distinguishing or important features to see if they were common to more than one story. That is, it is putting together as one sequential element in the narrative plots and subplots that ‘belong together’. An appropriate configuration (or plot) emerges only after the tacking procedure, which compares proposed plot structures with the events and then revises the plot structure according the principle of ‘best fit’

For example, tacking led to the creation of subplots that made up Plot 1 (The early stages: disbelief and disintegration). Several subplots, in the form of events that had a clear sequence were identified within narratives that formed Plot 1. For example, parents first learning about the injury; how they got to hospital; their immediate reactions on physical, emotional and cognitive levels; and their subsequent experience in the ICU, etc.

### *Emplotment*

Where plots and subplots bring order and continuity to a series of events by putting them in the story's chronological 'sequence' through tacking, it is through emplotment that the *meaning* of the event for the individual is created. Emplotment is a process of working with one or more plots of a story in such a way that the significance of the story is disclosed; that is, emplotment ascribes sense and meaning to a story at potential different levels of sophistication and complexity. For example, Plot 1 was made up of the early stages where parents spoke of several aspects of their experience, including learning of the injury and arriving at the ICU. These were the subplots of Plot 1. They then went on to describe their reactions (for example, 'not being able to respond'/ 'being devastated' when being told of their child's injury) where they described the meaning (i.e., emplotment) this particular event had for them.

Emden (1998) asserts that through core story creation, we are dealing with the life meanings of participants; that is, the meanings they create from their experience. Through core story creation, plots and meaning common to all stories were brought together to describe the experience of being a parent of a child that sustained traumatic brain injury. The core stories were about quarter the length of full-length stories and used the participants' own words exclusively. Core stories were then returned to parents for their comments on a simple questionnaire, as per Emden's (1998) method of 'member checking'. An example of a completed form is included as Appendix X.

## RESULTS

Eight parent dyads participated in the study. Parents all lived in their own homes, and lived in geographically dispersed areas of England.

Table 1 summarises family constellations and the nature and dates of injuries sustained by children. To preserve confidentiality, all names used throughout are pseudonyms. Information identifying locations and professionals has been removed. Information is presented in the order that interviews took place.

Table 1 Family constellations

Interview Number	Parents	Name of child & age at injury	Nature of injury	Date injury sustained	Time since injury to interview	No. of siblings
1	Tony & Jacqui	Michael, 13	Infection: Encephalitis	November 2003	4 years	2
2	Neil & Jessica	Lucy, 15	Road Traffic Accident	December 2003	4 years	1
3	Jeff & Angela	Gary, 13	Road Traffic Accident	September, 2005	2 years	2
4	Paul & Judith	Steven, 13	Road Traffic Accident	December 2004	3 ½ years	1
5	Ian and Sally	Chloe, 15	Stroke	December 2004	3 years	2
6	Ahbhass & Zulehka	Badaal, 6	Stroke	April 2006	2 years	2
7	Jonathon & Melanie	David, 13	Stroke	February 2005	2 years	3
8	Colin & Nicki	Sammy, 13	Road traffic accident	June 2006	2 years, 10 months	2

Raw data in the form of interviews is included in Appendix XI, on a CD-Rom. This is for the purpose of space as interviews and subsequent core stories were of considerable length. They are presented in the order in which parents responded to the invitation to participate, and are numbered N1 – N8. For the purpose of consistency, within these interviews, speakers are identified by the initial of their pseudonym. Identification of speakers is a departure from Emden (1998). But as there were two speakers, it was felt necessary to indicate the speaker, be it mother or father.

Table 2 summarises the plots and corresponding subplots derived from parents' narratives. Plots and subplots vary in length. This is a reflection of the emphasis placed on each by parents.

### Plots and subplots

Table 2 Plots and Subplots

<b>Plots</b>	<b>Subplots</b>
1. The early stages: disbelief and disintegration	<ul style="list-style-type: none"> <li>i) The shock of it</li> <li>ii) Arousal and survival</li> <li>iii) Dates and times</li> <li>iv) Uncertainty</li> <li>v) Intensive Care Unit: Realisation and Dissociation</li> </ul>
2. The role of parents	<ul style="list-style-type: none"> <li>i) Part of a team</li> <li>ii) Organisational Skills</li> <li>iii) Online learning</li> </ul>
3. Fighting for services	<ul style="list-style-type: none"> <li>i) New relationships</li> <li>ii) Knowing what's needed</li> <li>iii) Knowing what's needed – and fighting for it</li> </ul>
4 Transition phases: Emotional, temporal and action	<ul style="list-style-type: none"> <li>i) Loss</li> <li>ii) Hope</li> <li>iii) Coping, resilience, and support</li> <li>iv) Turning points</li> <li>v) Time</li> </ul>
5. After-care and long-term impact	<ul style="list-style-type: none"> <li>i) Shattered narratives</li> <li>ii) Lack of joined-up services</li> <li>iii) House modifications</li> <li>iv) School reintegration</li> <li>v) Acceptance and closure</li> <li>vi) The future</li> </ul>

One mother (N4) used the analogy of their family going on a 'journey' following their child's injury. Analysis shows the story of a 'journey' these parents take, that starts with the moment they learn their child has sustained brain injury. It was a journey that was unplanned and un-welcomed. It has no specific, clean-cut end and there is no guidebook. By allowing these parents to tell their stories, shared themes have emerged. The analysis has allowed me to identify common plots and associated

subplots. The journey begins with parents learning of their child's injury and the accompanying shock and disbelief felt by parents. This results in sleep disturbances and physiological reactions such as adrenalin 'rushes'. The clarity of parents' memories were still painfully clear. There is also much uncertainty and stress at this time. Then, the journey takes on a new dimension and meaning, as the realisation of the seriousness of the injury emerges, and parents find themselves in unfamiliar terrain that has no end-point. The time in PICU reinforces this as acute recovery begins. The long-term recovery begins with the move to rehabilitation and then discharge home, followed by questions and concerns over the child's future. That some plots are longer than others signified the emphasis placed on these by parents.

From narratives, the following plots and subplots were created by me. First, plots common to all or most narratives are highlighted and then subplots are illustrated through personal extracts from dyad narratives.

Connecting all narratives is the 'suddenness' with which the event was experienced. Narrative 5, where Chloe had for many years an undetected anterior vascular malformation (AVM) is included as an 'atypical' narrative. However, it is also similar to other narratives in that the bursting of the AVM in 2004 which led to a brain haemorrhage was sudden and unexpected. .

**Plot 1: The early stages: Disbelief and disintegration.**

*'I was devastated, knowing that we might not see him tomorrow, or we might not see him in an hour' (N1: 658-660).*

The first plot to emerge was parents' learning about the event. All parents gave varying descriptions of 'shock' to the event, and recalled in detail their reaction.

i) The 'shock' of it.

Jessica recalled her reaction when being informed of her daughter's injuries from a car crash:

*'But I just – didn't respond to him at all, because I couldn't respond, I just went sort of numb.'* (N2:145-147).

On discovering his son fitting with as yet undiagnosed encephalitis, Tony commented;

*'We weren't really taking in what was going on. Oh (sighs), I just saw a boy just lying there (sobs), just fitting, and we didn't know what was going on' (N1: 59-61).*

Angela:

*'...it was like we'd been transported into this world and you just couldn't believe it was happening, happening to him. (N3: 249-250)*

*'...it's like everything's like in slow motion.'* (N3:78).

Judith sums up the magnitude of the event, three years after Steven's road accident:

*'I don't think it's even sunk in now. No we still – we say that he will get out and walk, don't we?' (N4: 232-233).*

Jonathon and Melanie had been given a 5% chance of the operation to remove a benign tumour from their son David's brain stem going 'wrong'. On finding out that the operation had gone wrong, Jonathon said, *'Our world did fall apart when he had his operation.'* (N7: 21).

For some parents, there was a period of time when the seriousness of the accident was not fully appreciated. Jeff describes his reaction on learning that his son's accident was more serious than he originally thought:

*'He'd been conking that morning. "Oh he's fell out of a tree or..." "Well what, is it a broken leg, what?" And he (older son) just wouldn't tell me. And then he just said, "He's been hit by... a half ton lorry," and as soon as he told me that, I just went numb. I had to sit down, I can remember sitting down. I'd got that going through me head and I just didn't know what to do.'* (N3: 46-53).

For many parents in the acute phase (e.g., N2, N3) they believed that when the drugs were no longer necessary, their child automatically would wake up. Angela articulates the impact when Gary did not wake up immediately after the drugs were discontinued:

*'He was unconscious for nearly three weeks. We naturally thought once all the drugs – the drips, saline and all that were still in, he had an (NG) tube feeding him. Once they stopped we'd think, "Oh Gary, that's it, he'll wake up." But he didn't. That was devastating'* (N3: 140-144)

ii) Arousal and survival.

Some parents also described physiological reactions to the event. This lasted a considerable time, as Neil explains:

*'I think, for a year after her accident, I'm sure I was just pumping twice as much adrenalin around as – as – as normal, and that just carried me through the whole thing. And in fact I can remember the exact (laughs) moment it ran out, I was half way back from \* and I suddenly realised that there was no way I was fit to be driving a car. And I went back to \* and I had to sleep...'* (N2: 834-840).

Judith had a similar experience of physiological reaction:

*'...I think you're just running on adrenaline. In fact I'd say I was running on adrenaline till we actually got home with him from \*...'* (N4: 237-239).

iii) Dates and Times.

Parents remembered dates and times of the event with great clarity. All remembered the specific date of the event, and often the precise time, as Paul illustrates:

*'14<sup>th</sup> December, just before Christmas...And we just – so we were back home for – well at 3 o'clock in the afternoon (N4: 69-70)''*

Commenting on their ability for remembering specifics, Sally said, *'It's embedded in there.'* (N5: 461). Angela corroborates Sally's view:

*'9<sup>th</sup> June was the day we left \*...they are etched on our minds aren't they?''* (N3:412-413)

This seems to be the same for all parents; such was the significance of the event and its ramifications. On recalling the moment her daughter, Sammy, was involved in a collision with a car that failed to stop at a red light, Joanne described to the minute when it happened:

*'June 21<sup>st</sup>, twenty to eight in the morning, Wednesday morning, midsummer's day, walking to school'. (N8: 65-66)*

One father, who considers his son to be making a good recovery from a stroke, gave the subject of times and dates an altogether different meaning. He reflected that his son having a stroke on a weekday may have resulted in a more positive outcome that it might have been had it occurred at a weekend:

*'...it was lucky it was weekday, Thursday, and not night time. If it's weekend, we don't know, they might keep him here, we don't know if there would be doctor available. You know, always problem, evening and weekend doctors, it is not right surgeon...The right time.'* (N5: 71-76).

iv) Uncertainty

The journey to the hospital for most parents, which involved a period of 'not knowing' caused immense anxiety:

*'The worst thing really was not knowing I suppose. we didn't know if he was going to live, we didn't know if he was going to die, we didn't know what was wrong with him, we didn't know what they were going to do.'* (N1: 666-669).

Such feeling was echoed by Sally after her daughter Chloe was rushed to hospital following the bursting of an anterior vascular malformation:

*'Well it was very hard. Because first we had to deal with: would she survive and get to London for the operation? Then it was: would she survive the operation? Then it was: would she come round after the operation? And then it's: would she be left with any disability?'* (N5:236-240)

Neil and Jessica's daughter had been taken to a hospital after being found in a field after a car crash. They were taken to hospital by police escort after getting a phone call from a friend. Neil described their anxiety:

*'That was terrible, because we didn't – I mean she was obviously so bad we – we didn't know until we got there that she'd be still alive when we got there''.* (N3: 131-133).

v) Arrival at Paediatric Intensive Care Unit (PICU): Realisation and Depersonalisation.

Parents then went on to describe their experiences of first arriving in the PICU and seeing their child. Without exception, all parents were shocked to see their children in intensive care. For two pairs of parents, chaplains had been called to the bedside of their injured children. This may have been a highly significant time for parents because arguably, it was here that the realisation of the seriousness of the event began to take hold, leading to parents themselves undergoing trauma.

Ian described standing in the accident and emergency room of the local hospital relaying his daughter's history to a doctor, fully aware of the gravity of the situation facing his daughter, and his family:

*'Outwardly I was calm, not inside I wasn't calm. I was very distressed, because I knew that I was looking at a life and death situation basically. You know, you've got a youngster whose life has hardly started... And now we're faced with that she might be fighting for her life, and she's your eldest daughter. You saw her come into the world, you've known her every minute of every day since she came into the world and suddenly there she is on a trolley, fighting for her life. Unless you've been through it, I can't explain it.'* (N5: 145-155).

On arriving at hospital to be told of the seriousness of her daughter's car accident, Jessica describes the traumatic process of depersonalisation:

*'...before we saw her they took us into a little room and, you know, explained what had happened. But I felt like I was in a film. Well I just – it wasn't real, just didn't feel real at all, peculiar. It felt like I was watching the telly. It was odd, I didn't feel involved'* (N2: 87-91).

Continuing,

*'...I was aware...I couldn't articulate anything. I can't articulate it now. I was aware of the fact that I wasn't doing the polite nods and yes's and no's, I wasn't responding, I was just staring. I just couldn't – couldn't respond at all.'* (N2: 138-141).

Angela and Jeff recalled being let in to see their son Gary, after a period of spent in the waiting room:

*'So eventually they did let us in, and they (staff) just said, "Prepare yourself." and there was just drips and needles everywhere, all these drips. And he just looked asleep.'* (N3:90-92)

This period also led to disturbed sleep patterns for most parents: Tony, *'I don't think I slept for 10 or 11 days.'* (N1: 702-703).

Angela:

*'It was like we eventually fell asleep, but you couldn't remember. And then you'd wake up and think, 'Where am I?' Oh it was horrendous.'* (N3:108-110)

Paul recounted his reaction to his son not waking up, despite the administration of

nine different drugs over three weeks in the PICU:

*'Once they'd started to wean him off those, they said he could become conscious. That's when they had to take us to one side and tell us the seriousness of...Well that was when it was devastating to us.'* (N4: 165-169).

Sally:

*'...you're absolutely devastated. You're not really functioning or thinking properly.'* (N5:770-771)

Judith recalled being told what was wrong by medical staff, but being unable to take it 'in':

*'I mean even for the nurses and doctors telling us what was wrong...it just goes over your head. It's not till after that you think, "Well who said that? And what does that mean?" and you try and piece it together...it's just impossible.'* (N4: 826-830).

Melanie spoke wanting to make contact with her friends while she as in hospital with her son, David, but felt unable to:

*'I felt like I was in a bubble...a bit like being under water...you can't – you can't quite make contact with them'* (N7:417-418)

Jacqui:

*'That was horrific, oh that was the worst week of my whole life... I could have quite easily just, honest to God, died.'* (N1: 687-693).

Continuing,

*'bearing in mind your mind's not there when your child's – you think your child's going to die'* (N1:835-836).

**Plot 2: The role of parents.** *'...with my skills I'll persevere and do anything.'* (N4: 1194)

Throughout the journey, mothers and fathers played a reportedly consistent, proactive and positive role in the care of their children. This is an important finding as historically fathers in particular have been excluded from research into child health issues (Phares *et al.*, 2005). Mothers and fathers considered themselves skilled in many areas, such as organising much of their children's care.

i) Part of a team

For many parents, teamwork between seemed to be intrinsic in coping, as Sally describes:

*'I think the relationship between us as well... you're very good at doing those things you've just said then, but I'm very good... in the home. So I think a combination of you perhaps being the driving force in getting things done...'* (N5:725-728).

Jessica describes a 'teamwork' aspect to her partnership with Neil, which she clearly valued and believes has served them well as parents of a child with brain injury:

*'I suppose we tend to take turns, when one of us is collapsed in a heap the other one kind of takes over... We've been lucky that we've not both collapsed at the same time.'* (N2: 594-597).

## ii) Organisation skills

Narratives consistently indicated that fathers and mothers contributed greatly in many areas, including organising care for their children from the beginning of the acute recovery phase to the child's return home, and the fight for services discussed below that has characterised parents' experiences. Paul and Judith stayed with their son, Steven, in hospital for six months. Paul took a very proactive part in his son's care, learning some of the medical maintenance tasks:

*'I didn't leave Steven when he was at the Children's Hospital'* (N4:312)

Continuing,

*'I had to learn how to maintain his trachi, give his feed. Yeah I did all that from day one.'* (N4: 318-319).

Jonathon gives a broad overview of how he tries to get the best care for David:

*'I'm using a lot of my life experience to understand what's happening and to work out what the best way of getting what we want is.'* (N7:116-118).

Angela describes how she 'modelled' aspects of Gary's physiotherapy to encourage him to participate:

*'You've just got to keep encouraging all the time. And sometimes I even had to do the things that they had him doing. Once he saw me do it, then, you know, he followed on like.'* (N3:712-714)

### iii) Online Learning

For fathers in particular, the internet emerged as a powerful resource. Most fathers used it to find out about their children's condition and as a tool to educate themselves about their child's prognosis. Colin and Joanne give an example of this, and the reason they turned to the internet for information:

*'there were Internet access PCs on the wards. So 10 o'clock at night, you can't go to sleep...so you're on the Internet looking up. Every time they mentioned something, temple bone fracture, right where is the temple bone? (N8: 619-622).*

Supporting Colin's quest for online information, Nicki adds:

*'If you don't get the information from the doctors or the nurses at the hospital, you will go to the – especially nowadays you will go to the Internet.'* (N8: 658-660).

Tony:

*'My lifeline was...I was on the computer 24/7, finding out whatever I could'* (N1:826-827).

This however, was not without its pitfalls. Parents quickly learned that the quality of the information available, particularly on topics around brain injury was highly variable:

*'we were on the Internet a lot. if you've never been on the Internet before anyway from the brain tumour point of view, having... is a dangerous thing to do. We took that into account, stupid, we didn't.'* (N7: 52-56).

Nicki made a similar evaluation: *'Some information was good; some was pretty bad.'* (N8: 623).

For Tony and Jacqui, that encephalitis and its effects had not been explained to them meant turning to the internet for information:

*'We didn't even know the name encephalitis. Never even – I was looking it up on the computer, the reason I know so much about it is 'cos I looked it up on the computer just to see what it was. We've done a lot of research.'* (N1:88-92).

Ian:

*'...it's that initial process of finding out...because no one tells you, you've got to find out for yourself. I mean the Internet is a fantastic*

*thing.’ (N5:775-777)*

### **Plot 3: Fighting for services.**

*‘It’s worth fighting. Because we have got a reasonable level of support as a result.’ (N7:916-917).*

Within the ‘fighting for services’ plot several subplots emerged that characterized parents’ experiences.

#### **i) New relationships.**

For all parents, their child’s injury meant the formation of new relationships with a variety of healthcare professionals. This was variable in terms of quality and satisfaction on the part of parents. Some told of very positive relationships, and identified the qualities that made such interactions and relationships positive. For others such interactions were highly stressful and anxiety-provoking.

Talking about the relationship between a medical team and Chloe, Ian said:

*‘They treated (Chloe) properly, they listened to what she said, and they spoke to us as parents properly, and they listened to what we said and they took onboard what we said. It was a proper two-way relationship I would say. Very important.’ (N5:521-524)*

Ian also spoke about the importance of having faith and trust in the people that were providing the care for Chloe, a view echoed by Melanie:

Melanie:

*‘The people that did like um have more credibility with you are the ones that acknowledge that they don’t know what it’s like for you.’ (N7:612-614).*

Paul provides another example of the importance of personal qualities in professionals:

*‘...I can remember the one...he was one of these guys who – a real understanding doctor / consultant...one who would never give up.’ (N4:213-215).*

Equally, however, it emerged that experiences for some parents had also been quite negative, with parents questioning the role of some professionals in specific contexts,

particularly in the chronic phase (i.e., discharge from ICU). For example, Angela's mood was quite low as she tried to adjust to the immense changes that Gary's RTA had brought, and then had to cope with the insensitivity of one professional:

*'She just said to me, "Well cheer up, you could have been planning a funeral." And I just couldn't believe it.'* (N3:228-229)

Such insensitivity towards parents was not an isolated example. Tony was similarly on the receiving end when Michael was diagnosed with encephalitis: *'All we was told, "Encephalitis," and that's it.'* (N1: 146)

Talking about wanting to learn about encephalitis and its effects, Jacqui:

*'I would have liked someone to sit me down and explain to me how that affects the brain, because we didn't even know he was brain damaged.'*  
(N1: 344-346)

ii) Knowing what's needed.

Narratives suggest that as the transition progressed, parents became more adept and skilled in recognizing their child's needs and what would benefit their children. Parents regarded themselves as 'experts' on their own children. In addition to their growing knowledge of the rehabilitation process, they valued and wanted to promote their own contribution to any decisions made regarding the services provided. As Ian illustrates:

*'...how do you want us to help in this? It's trying to work with them more rather than be sort of done to. Yeah, trying to sort of have a role in it, and be seen to have a role in it, rather than just be recipients of a service.'* (N5:876-879).

For other parents, the relationship with professionals was a source of frustration and conflict, as Melanie illustrates:

*'So they think they're the experts...they're not experts about David. I'm the expert on David. I had a valid opinion and felt that it should be listened to, um and it wasn't always.'* (N7:485-488).

A similar view was expressed by Judith, in explaining that as parents, they wanted to bring their knowledge, understanding and 'knowing' of their own child to maximize his chances for optimal recovery:

*'...because nobody knows him like we do.'* (N4:663).

However, being experts on their children was a double-edged sword, as Paul describes:

*'...like our own doctor said, "The problem is," he said, "you're now the experts on Steven," and that, as silly as it seems, is a bit of a worrying thing sometimes when we're clutching at straws some days. You feel you want somebody to come in and say, "No, you do that."' (N4: 1238-1243).*

This recognition of what their children needed sometimes led to disagreement and conflict between some parents and professionals. In addition to the challenges parents faced in response to the dramatic change in their circumstances and lifestyle as a result of their child's injury, conflict with professionals was added source of distress. Most parents' spoke of 'fighting', 'battling', and that it was a 'constant struggle'.

iii) Knowing what's needed – and fighting for it.

For Angela and Jeff, their fight began with trying to secure funding for Gary's rehabilitation programme. Although the 'lady from the PCT was on our side', to paraphrase Angela, she put the funding issue in stark contrast before funding was secured. It was going to cost the PCT £63,000 to send Gary to rehabilitation for 12 weeks. He was there for six months.

*'And she said, "Don't take it personally if they turn you down." And it's like how can you not take it personally? It's your child. And it's, "Well, you know, the trust have got to decide whether to do 90 hip operations or send one child off to rehab."' (N3: 322-326).*

An extreme example of a fight is provided by Ian, who was trying to secure a statement of special educational needs for Chloe:

*'... in the end we had to go to the high court in London, against \* County Council, who spent £50,000 fighting the case to stop Chloe getting a statement, which they lost. So we don't hold the process in much regard really.'* (N5:587-590)

Ian and Sally were not alone in their struggle and experience of fighting for school provision. Although they did not face the struggle and legal complexities of the situation faced by Ian and Sally, Jeff and Angela explain:

*'Even getting back into mainstream school, that was just another...*

*nightmare.*' (N3:507-509).

While the above examples of fighting services may be considered 'extreme' in this sample, all but one pairs of parents none the less gave vivid examples of the fights they faced, with various professionals and services. In some cases, they explained how they have been changed by this process:

Neil said:

*'It's turned us into people who, you know, push to the front of the queue, and that's not, that's not our natures.'* (N2: 409-411).

Through this process, it seems parents learnt and developed new skills to secure the necessary support for their children. In describing their application for child tax credit, Neil commented:

*'I had some very, useful notes from Cerebra, the charity. "This is how to fill in the form for a brain injured child," and it just told you exactly what, how. It was phraseology and make comparisons with a normal child of that age, and how to do it. I mean I don't think I could have done it without those notes.'* (N2: 386-391).

After completing a form for a child tax credit application with guidance notes from a charity, Neil concluded:

*'Those who can fill in a form and write a good letter get; the poor devils who can't don't. That just frightens me, people who can't take on the system just don't, just don't get it.'* (N2: 401-404).

Jonathon's experience supports the need to remain proactive in the process, describing his role thus:

*'I'm the one that's been sorting out all the council, all the bureaucratic stuff, that I mean it just gets to me, and it gets to Melanie even more I think.'* (N7: 260-262).

Jeff:

*'If you don't push, and we're still pushing now, I just don't think you get the right results.'* (N3:707-709).

However, for Tony and Jacqui, their efforts at attempting to secure services for Michael came to nothing:

*'We've fought tooth and nail to get help for him, and nobody cares. They chucked him out of school basically.'* (N1: 64-65).

Tony and Jacqui felt they had been let down (N1:359) by services. A sentiment they were not alone in. Although in very different circumstances, Colin and Nicki felt that in not being given the opportunity to present their case against the driver who knocked over their daughter, they too had been let down, as Nicki says:

*'We both feel extremely let down by the whole – the way the whole system works.'* (N8: 328-329).

The fight for services in the chronic phase also required some parents to attend various meetings with numerous professionals - another source of distress. Ian recounts numbers of meetings at an important time in Chloe's education:

*'Well that was another part of the trauma. We had loads of professionals' meetings. We had meetings at \*, meetings at \* first of all, round table meetings, hospital. Then a number at \*, some back at Chloe's school. Because that's the other thing, she was doing GCSEs and that all went by the by....'* (N5:371-376).

Melanie reflects on the experience of no longer being the principle decision-maker for her own child's welfare:

*'and then suddenly there's 15 people, strangers in a room, making decisions about what's happening with your child, rather than you making the decisions. And that was really hard.'* (N7: 476-478).

Judith adds another dimension to this new and alien experience, and gives some indication of how disempowering this new experience was to begin with:

*'That's very intimidating as well. You have to go to these meetings with all these professional people...And they go around the room and introduce themselves, and they all speak clearly, and it comes to me and I'm thinking, "Oh what do I say now – 'I'm Mum'?" I used to get so worked up and I hated it. I've got better now because...it's a personality change.'* (N4:1054-1067).

A point of contention within several narratives and clearly important for parents was that the people often making decisions for their children had never actually met their children. Judith:

*'Life changing decisions...And some of the decisions they've had to make and not know our child is just unbelievable.'* (N4:1100-1101)

Melanie's experience was similar, and recounts a specific episode when David was in ICU:

*'And most of whom we'd never met, and most of them had never met David. And it really did feel like sometimes you were sort of having to fight all of them on the NG tube' (N7:461-463).*

Some parents found the process of decision making in meetings with professionals difficult and frustrating, to the point where they felt their own roles and responsibilities as parents was devolved from them, as they experienced a loss of control and autonomy. They found meetings disempowering and invalidating. It seems not being listened to emerged as a feature for some; arguing that as parents, they know and understand their children in a way that professionals simply do not.

*But that whole meeting was 15 people in a room saying, "Well no, we know better than you." (N7: 469-470)*

When attending a meeting for a school place, Melanie was deeply upset by the long-term prognosis relayed to representatives from the school by one particular professional. Despite being involved with this particular service for several months, it was the first time Melanie heard the prognosis described in this way:

*'...this whole business with \* and the meeting. I can talk about it now, but um at the time it was one of the most distressing times I've ever had.'* (N7:705-707)

Not all interactions with professionals were difficult. In terms of service provision, Jonathon and Melanie considered luck in the process of their relationships with professionals:

*'I think it's not so much the services, it's just the luck of the draw with the people that are assigned.'* (N7: 547-548)

Melanie continued,

*'Because it really is the people and their approach that makes all the difference.'* (N7: 549-550).

Jeff summarised his experience of Gary's rehabilitation:

*'...they do a cracking job.'* (N3:286-287)

#### **Plot 4: Transition phases: Emotional, temporal and action**

*'..it is a very, very lonely place being the parents of someone with a brain injury when other people don't appreciate what's going on.'* (N8: 951-953).

Parents spoke about their experiences in a way that I inferred as distinct phases, or transitions, as they responded to events over time. The first was loss.

i) Loss

Some mothers spoke of losing their children, and losing themselves as a consequence of the event.

*'And then you find yourself thinking of before the accident, and that used to get me down. I used to think, "Why – why Gary, why has this happened to Gary?" (N3: 250-253).*

They also spoke of losing the future relationships with their children that they thought they would share, as Jessica explains:

*'I still feel quite resentful about the fact that I was looking forward to having an adult female companion, and I haven't got that now. Yeah we started to get on really well...' (N2: 613-615).*

Angela reflects on her experience thus far and she is slowly regaining her sense of self as time progresses:

*'And I feel more like myself as time is going on. But at first I just – you just feel lost don't you? You feel like you're ploughing through blancmange.' (N3: 639-641).*

Melanie offers a comprehensive description of the loss of David, and the subsequent impact on her own sense of self:

*'when he first had his stroke obviously we lost the David that we had before, but I also felt like I lost myself...my personality which had been very happy, optimistic, sort of very positive person...that went away and I just sort of felt like I was – literally I wasn't myself any more. And that was quite strange to come to terms with...' (N7: 375-380).*

*'And I didn't know if that was going to come back either.' (N7: 396-397).*

For Nicki, the loss had different meaning. She reappraised her expectations of what defined 'happy' and 'healthy' as an outcome, a part of her personality which possibly afforded her the resilience she needed to cope:

*'OK, you're not going to have the high flying career that we all hope our children are going to have before the accident. But, you know, at the end of the day I'll be happy if you're happy and healthy.' (N8: 847-851).*

Jonathon's experience of losing the David he knew:

*'It was David went into the operation David, and he didn't come out, so um yeah it was horrendous.'* (N7: 248-249).

## ii) Hope

Hope was spoken about by mothers and fathers and referred to throughout narratives, possibly signifying the importance of it for parents. Jacqui describes the meaning of hope for her and Tony thusly:

*'I'd probably crack up if I didn't hope...But we like to live in our little world where he probably will get better.'* (N1: 734-737).

Judith expresses similar conviction:

*'...if you give up on hope, I don't know... what you'd do.'* (N4:610-611).

Collin, too, is clear about hope and its role for people in their situation:

*'...I think everyone in that situation is always looking for hope.'* (N8: 669-670).

Jeff is equally clear in the type of hope that he and Angela don't want:

*"Don't give us false hope; just tell us how it is."* (N3: 438).

For a minority of parents, hope was sought through prayer. Parents of Badaal highlighted their faith in the process of his recovery when Badaal suffered a stroke, aged 6 years.

*'And we took him to India, because we believe in one of the (Slaminarine), you know, Hindu like temple. So we took him in India last year (to prey) everywhere. Because er we believe in that part of, you know. Yes very good, we believe a lot and they help. Doctor also said, "You believe in God, and it's something...they help a lot." A miracle.'* (N6: 253-260).

This was echoed by Melanie, who described herself as Christian:

*And for me, because I'm Christian I was wanting to know what to pray for. I wanted to pray for something that was achievable.* (N7: 589-590).

A powerful feature to emerge from narratives is the way parents coped with the injuries of their children over time. Participants appeared to be psychologically healthy individuals faced with a devastating and life-changing event. This is the subject of the first subplot within the Transition plot.

### iii) Coping, resilience and support

For Melanie, the early stages of David's stroke, was only about survival:

*'...you have to, to survive. Especially in the early stages when everything is so desperate' (N7: 574-575).*

Paul describes his strategy in slightly more detail:

*'You take each day as it comes with head-injuries...that's how I get through.'* (N4:818-819).

For Jonathon and Melanie, belief that David understood them was crucial:

*'as parents, we have to believe that he knows what's going on...Partly for our own benefit, if you like, partly for us to really believe there is a purpose, there is still David there. Partly – partly we have to do it for his benefit, because we have to look for the best for him, that's what we've been continually fighting to.'* (N7:97-105).

Jacqui continues to worry about the effects of fits on Michael:

*'I still worry that he's going to die of having a fit, it worries me sick. I've only just been able to be on my own with him. After four years.'* (N1:261-263)

Neil highlights his strategies for coping:

*'I've consciously tried not to look at the big picture overall, because I think that would probably be far too depressing. You just – you just deal with bits of it here and there and as they arise.'* (N2: 656-658).

Neil also highlighted another important resource in the long-term:

*'I think having a sense of humour... has probably helped us get through it.'* (N2: 610-612).

He also suggests that he and Jessica have coped 'successfully', and articulated a sentiment expressed by other parents:

*'we've had to face things almost on a daily basis that most people will never have to confront in their lives, and we've just dealt with them and got on with it. So I think we, well yeah, we ought to give each other a pat on the back for that.'* (N2: 636-639).

Colin and Nicki attributed their ability to cope to a number of inter-related possibilities:

*'I don't know if it's because we're both managers, I don't know if it's because of our upbringing, I don't know if it's just because we was a strong family unit before it happened, or what.'* (N8: 860-863).

Despite the upheaval and dramatic change to parents' and families' lives that the injury brought, a minority of parents highlighted some positive aspects to the event in terms of their relationships with each other:

*'I mean it's really I suppose it's brought us closer. Whereas before I wouldn't voice my opinion as much as what I do now. I will say what I say. You know, and so I think that's brought us closer, because before we never used to sit and talk about things...'* (N1: 504-511).

Jessica reflects that despite the trauma and changes of the event, her relationship with Lucy changed positively:

*'I think she has changed for the better in a way, I think she's more open with us now than she ever was before.'* (N2: 762-764).

Reference was made by several parents to the presence of other families in the PICU in the context of support. Other parents in the PICU gave comfort to the parents here. It seems they were seen as being in the 'same position', and therefore understood what was happening and what parents here were going through. This also seemed to give parents a sense of hope for their child.

For some parents who wanted to seek support from others, they were quite specific that they did not want to talk to counsellors, but other parents in the same position.

*'I wasn't offered counselling because...the way you feel then, it would be, "What the hell do you know about it? Have you been through this? No, well how the hell can you offer me advice?"'* (N4: 244-248).

Reflecting on their journey with Gary, Angela recounted:

*'I just wish that there was somebody that we could have, not counsellor-wise, people who had probably been through the same thing as us. Because there wasn't anybody, we were just thrown into it weren't we? And we just had to find our own way.'* (N3:642-645).

Judith:

*'To me, nobody can understand how I felt, and I couldn't talk to a stranger about it.'* (N4: 281-282).

Ian and Sally did not have the opportunity to talk to other parents, and would have valued doing so:

*'But what would have been useful would have been if we could have spoken to other parents, and that never was an option. It seems to me that the rights of parents to deal with these horrendous health issues are very, very limited. Because parents do need a lot of support, not just financial support, just understanding and time are two of the biggest things - I mean money comes into it somewhere, but giving parents space and time to deal with these issues.'* (N5:748-754).

A view echoed by Paul:

*'it's almost as if once you share all those experiences you think, "Well perhaps it isn't so bad, and tomorrow's a new day, and we're going to go forward."* (N4: 484-486).

By contrast, Jonathon's view of support from other parents in the same position:

*'We haven't gone in for any of that meeting other families in the same position. I think we've got to get on with life. We've got to enjoy the time we've got. We've got other kids that really help - you're our therapy. But I think, just trying to be normal as possible.'* (N7: 596-601).

However, two mothers spoke positively about professional counselling. Jacqui (N1) stated she wanted counselling and information about encephalitis. Nicki (N8) described how she and Colin had received counselling, and that she had been diagnosed with post traumatic stress disorder after seeing her daughter on the road after the car crash.

#### v) Turning points

As the following extracts illustrate, it could be hypothesized that 'turning points' are functional in that on an emotional level they give parents hope that improvements were possible and achievable, and on a cognitive level serve to help parents reappraise and thus redefine stressful events to make them more meaningful, and thus contribute to adaptive coping (Benn and McColl, 2004). When Michael regained consciousness after a week in a coma, despite him then not knowing that Tony and Jacqui were his parents:

*'I was so pleased that he was awake, but he was like in a cage because he was like a wild animal. We went up to him and I give him a kiss and he went, "Are you my Mum?" And I went, "Yeah." And he said to Stuart, "Are you my Dad?" And he went, "Yeah," oh and that was it really weren't it?'* (N1: 128-132)

The turning point for Colin and Nicki came relatively early in the transition phase,

when a doctor informed them that Sammy *would*, rather than *might*, wake up:

*'It was always 'if'. And I think it wasn't until about the Saturday or the Sunday...Dr. \* was the first one that said, "When she wakes up." And of course you were... with that because it was a 'when' and not an 'if'. So, "Yeah she is going to wake up." (N8: 207-210)*

Jeff and Angela describe the first time Gary started to talk after his accident, some three months after his accident:

*'...at teatime he had a bit of mash...Because it must have – the food and eating started working his larynx and he began to... 'Just saying to me, "Mum (.)" Oh crickey, I'm filling up now thinking. It was just unbelievable because I never – I never expected... We didn't think he'd ever speak again. (N3: 274-281).*

In showing me the diary that she had kept of David's journey, the following dialogue from father, mother and sister reveals a similar experience and their clear joy the first time David smiled after his operation:

*'And this is the first time he smiled.'*

*'Yeeaaaah.'*

*'I remember.'*

*'Brilliant.' (N7: 647-650).*

v) Time

The importance of time also emerged for many parents as significant in their ability to relate their narratives:

*'I can talk about it more now than when - like months, you know, when it first happened I couldn't string a sentence together.' (N3: 729-731).*

*'I mean there have been times where it was too painful even to sort of talk about things.' (N7: 774-775).*

For some parents, it has taken a number of years to progress to get where they are 'now': and for some there is still no sense of normality.

*'It's been four years and we're still not there.' (N1: 767-768).*

*'We have come to terms, we know what the score is. You go through different sort of phases.' (N7: 139-140).*

**Plot 5: After care and long-term impact.**

i) Shattered Narratives.

Most parents commented on the extent to which their lives had changed since their children's injury. The following extracts from mothers and fathers illustrate this:

Jessica,

*'It's like somebody's just hit you over the head with a mallet. Because your life – our life was so full then. We were planning things. (N3:630-632).*

Angela,

*'...it's like you've got a head in – your head in a bucket...'* (N4:822-823)

Ian:

*'And it's terrible, it's awful, and this doesn't figure in anything you read, that people's lives are torn apart by this.'* (N5:604-606)

Tony:

*'It's turned us upside down. Turned the whole family upside down.'* (N1:606-607).

As a result of his daughter's accident, Neil concluded that his engineering job was 'futile' and made a significant career change as a result:

*'I changed from engineering to social care and my salary just plummeted.'* (N2: 540-541).

The long term impact of children's injuries is without exception highly significant and includes many issues, one of which is the extent to which parents' lives have changed as a result of their experiences since their child sustained injury.

Jonathon observes:

*'And it's still horrendously hard work.'* (N7: 60).

Jacquie and Tony had no idea what to expect when Michael was discharged from hospital:

*'No one explained, we didn't know what we were going to face when we came home. Oh that was a nightmare.'* (N1:146-147).

Nicki and Colin both received counselling after Sammy was knocked down by a car. Through this process, Nicki had come to understand her reaction to the event. She was clear in the formulation of her experience following the accident:

*'I suffered quite a bit from post-traumatic stress after, about a year after the accident. ...we had counselling... the pair of us' (N8:106-108).*

Jacqui, reflecting on the way things have changed for her:

*'I would never ever imagined my life how it's panned out.'* (N1: 628-629).

ii) Lack of joined-up services

Many parents spoke about a lack of 'joined-up' services where after their child had returned from rehabilitation when parents were forced to take on responsibility for organising and providing for their children's needs.

Jessica:

*'When she came home from \*, we needed somebody to turn up on the doorstep and say, "This is what's available, what you need, this is what she's entitled to...because we wouldn't have felt so alone then.'* (N2:858-865).

Sally:

*'It's a real eye opener. Once you are in the situation you automatically think things will be put in place for your child, to meet your child's needs, and it's not the case at all.'* (N5:342-345)

Neil:

*'...some things are so difficult to I mean it's so hard finding the people who are there to help you, it's just not very joined up at all, the sort of – the care that's available after the event. You largely stumble across things by accident' (N2: 816-820).*

For some parents whose child had been involved in a road traffic accident, a case manager was involved, which parents valued greatly. This seems to have alleviated the issues faced by other parents around 'joined-up care'.

Jessica:

*' And they have actually provided us with a case manager now, which is a great relief to me. Because she will take over a lot of the stuff that I've been doing. You know, I've had to organise Lucy's learning support at college, just about every aspect of Lucy's life I've organised. But luckily, wonderful woman here is now going to... the insurance company is going to pay for it.'* (N2: 436-443).

Colin:

*'Sammy's solicitor engaged (\*) Case Management to manage Sammy's case. (N8: 687-688).*

*'...and there's absolutely no way we would have known who to contact if we didn't get this case manager in.'* (N8: 705-706).

iii) House modifications.

Several parents were also forced to make significant modifications to their house prior to the arrival home of their children from rehabilitation. Many described this as a frustrating and expensive ordeal:

Paul:

*'now we're back here and now the house is modified. I mean we struggled to get the house modified, it was a lot of red tape. Our friend up the road, like I say, had to get our MP involved...'* (N4: 1002-1006).

*'I think it was £60,000 to modify.'* (N4: 1025).

Jonathon:

*'...there's always people in your house looking at assessing your environment, assessing how he is now...Intrusive, really intrusive. I don't like it. Because Melanie just gets torn apart by it, she really can't stand it, just hates the intrusiveness in the house...'* (N7: 134-138)

Ian:

*'Chloe was coming back to the home environment and there was nothing. I mean she couldn't do the stairs, we needed a stair lift. She couldn't bathe, wash at home, so we needed a special bathroom for her. Um and all those things were a huge battle to get put in place for her. Various visits, lots and lots of talking, lots of paper shuffling, but it took so long to get these things put in place.'* (N4:)

Jeff alludes to the politics and safety issues that house modifications may entail:

*'...you've got to have, and you've got to be seen to have, the right things in place.'* (N3: 545-546).

Where parents lived appeared to be a factor in funding issues for house modifications, as well as equipment that their children needed for their continued rehabilitation.

Judith:

*'We pay our poll tax to \*, which our doctor's is in, because he is in \* we have got funding from \* PCT. So in actual fact it's helped us, because \* apparently are very poor, and you wouldn't get half the stuff. But we've been backed from \*. And the Complex Care team come from \*. And so things have developed quicker, things that we've wanted that they can get, and they approve, comes from there.'* (N4: 396-403).

Jonathon considers himself lucky to live where he does in terms of funding for Gary's

needs:

*'again we were lucky, new legislation had come in such that anything wasn't means tested. The extension was going to cost about £60,000 and that has been 100% funded by \*.'* (N7: 167-169).

iv) School reintegration

School reintegration was another big issue, where parents not only had to organise their child's educational provision but again had to fight for it.

Sally:

*'It was "You need to find a school," and we (laughs) thought, "Where do we go? What do we do?"* (N5:655-656)

Jeff:

*'... it was like the fight we had to get him into mainstream school, it just scared them, totally scared them.'* (N3:683-684).

Melanie:

*'the horrible educational meeting that I had to fight through, um secured him a place at \* until he's 16, and he's already 14. I can see that we're going to have another fight ahead.'* (N7; 823-827).

v) Acceptance and closure.

Where some parents felt there have been positive aspects to the event, some parents spoke of the need for closure, which seemed to be important issue them. Feeling they had been let down by the judicial system after Sammy's accident, Nicki said:

*'I think it was the closure, that we just didn't get the closure we needed.'* (N8:364-365)

In discussing a conversation with a professional where she had been told she 'had to accept the injury', Judith stated:

*'And I don't think he'd got that right to say to me that I – I'd got to accept it. Because I don't think I ever will accept it because it's – it's not a closure.'* (N4:575-578)

Continuing,

*'But like his bedroom, he's got all his toys, his books, his clothes, and now what do I do with them? You know, he's not dead, so I can't feel as though I can get rid of them. And it's that, and you haven't – whereas if it is a death you have got that closure, you know, where eventually I will sort out his room because I know he*

*will never use those things again. But I've always got this hope that maybe, yeah, he might use his remote control car...' (N4:580-587)*

For Neil and Jessica, with the help of a case manager, (relative) closure was in sight.

*'The next couple of years, are all down to assessing how much help Lucy is going to need for the rest of her life.'* (N2: 417-418)

Jeff and Angela were also looking forward to closure and some form of resolution through a court case. They too, like Neil and Jessica, were expecting to wait another two years for proceedings to conclude, and highlighted the financial implications of losing the case:

*'If you want to pursue, and it goes our way, then we'll hold you liable for the costs.' And that's scary'.* (N3:435-436)

Judith:

*'if we win (the court case) it'll be great because we'll be able to set Steven up in a future where hopefully he will be comfortable when we're not around...we don't really think about that, but we have to.'* (N4:915-917)

vi) The future

With children again living at home, all parents had concerns for the future about their children.

Sally:

*'...will she ever have a job, will she ever have a husband, will she ever have children, will she ever live independently? You know, all these things that, when you have a child, you assume they will reach those stages.'* (N5:818-822)

Jessica:

*'it's just it's uncertainty about the future.'* (N2: 501).

Nicki:

*'Independent living, it really is. My meaning is will she be able to handle a budget, will she be able to maintain a job?'* (N8: 888-890).

Melanie:

*'What's going to happen to him after school? That's the big issue. Such a big thing at the back of our minds, and we don't really know. And I've no idea what to expect, as we've never done this before. We need to start asking some things soon, but I'm almost dreading doing it. (N7: 821-829).*

Tony:

*'...encephalitis – not enough aftercare...no one will help us. Ridiculous isn't it?' (N1:881-883).*

This inquiry was conducted through the lens of social construction. Having spoken at considerable length to all parents about their experiences since their child sustained traumatic brain injury, perhaps Melanie and Paul poignantly sum up the 'feeling' about the journey these families were forced to embark on:

Melanie:

*'...nobody knows what – what's going to be ahead for you ...so never give up hope, because things can change, and they do change. Because your experiences are, in reality, different.' (N7:956-961).*

Paul:

*'There is no finite finish, it's continuous. And it will continue.' (N4: 1344-1345).*

## DISCUSSION

Through a specific research question, the purpose of this study was to put parents at the centre of this thesis by enabling them to tell their stories about their experiences since their child sustained traumatic brain injury. As the majority of research within this area has used quantitative methods which have tested specific research hypotheses, this study aimed instead to use a qualitative approach in order to gain a contextual “insider’s perspective” (Chamberlain *et al.*, 1997). The length of parent interviews suggests that parents – mothers *and* fathers - had much to say. The relevance of these findings are now discussed and then considered in relation to implications for clinical practice. Finally, the strengths and limitations of the study are considered, as are suggestions for future research.

As Table 2 highlights, I was able to identify five main plots using Emden’s (1998) method: 1) The early stages: disbelief and disintegration: 2) The Role of parents: 3) Fighting for services, 4) Transition phases: Emotional, temporal and action, and 5) After-care and long term impact. From each main plot, I derived several subplots. Their implications are discussed next.

### **Plot 1: The early stages: Disbelief and disintegration**

Subplots corresponding to Plot 1 suggest that many parents reported difficulty in processing many aspects of their experiences – and used powerful metaphors (for example, ‘Being hit over the head with a mallet’ (N3:630) / ‘everything went into slow motion (N3:78)) and other descriptions of their reactions. Description from parents experiencing this event (such as ‘running on adrenaline’) suggest they may themselves have undergone trauma as a second-order, or vicarious, factor. That the outcome of retrieval of the children from the scene of the event to hospital was so uncertain and anxiety-provoking for parents only contributed to this.

There is an emerging literature where some investigators liken the experience of having a child sustain TBI as traumatic, with symptomatology comparable to those of posttraumatic stress disorder (Taylor, 2001). Colville and Gracey (2006) note that

there has been increasing recognition in the recent literature of the impact of trauma on witnesses, where the threat to life or integrity of a loved one is itself sufficient to qualify as a traumatic event. Colville and Gracey (2006) found that 18% of mothers scored above threshold for diagnostic criteria for PTSD. However, conclusions from their study are difficult due to two main limitations of the study; a small sample size which limited the statistical power of the study and a low response rate.

Shudy *et al.*, (2006) conducted a systematic literature review of the impact of paediatric critical illness and injury on families. Their review notes that most reports of parental stress after paediatric intensive care (PICU) admission indicate that anxiety levels are elevated to near panic. In addition, investigators have reported that parents who experienced an unplanned PICU admission had higher mean scores on all stress dimensions than those whose children were electively admitted to PICU. One feature of such unplanned admission is that critical illness and critical trauma are not anticipated. Therefore unlike elective admission, advance preparation is not an option. Unplanned admission is a key feature for children sustaining TBI, and was part of the operationalising of the event in this study. Most parents recalled events as though ‘they happened yesterday’, with dates and times still very clear in their memories, possibly indicating the magnitude of the event.

## **Plot 2: The role of parents**

Mothers and fathers played – and wanted to play - a major role in the rehabilitation of their child. From nursing their child in ICU, contributing to care in the chronic rehabilitation phase through to caring for their child on their return home from rehabilitation and often wrestling with bureaucratic processes at every point in the process, their role was instrumental. Mothers and fathers appeared to occupy general and specific roles, although this varied according to the stage of rehabilitation their child was at. Narratives suggest that roles were also characterised by flexibility and ‘turn-taking’, where parents took turns to perform tasks when necessary. While mothers and fathers experienced and expressed similarly disturbing reactions, fears and emotions in response to the event (particularly in the early stages), narratives indicate that parents functioned as ‘a team’ in taking on tasks. These tasks have varied

in nature at different points and places throughout the process – and continue to do so. My sense from the interviews also was that parents communicated with each other, and listened to one another, and talked openly about the situation. It is possible that styles of communication within parent dyads were also an important source of support for parents but was barely acknowledged by them in our meeting. Perhaps this was an implicit aspect of their relationship.

On a speculative level, this may also represent a broader issue of communication between parents where they negotiated their different roles in the process. Individual parents may have been aware of their skills in certain areas and utilized them accordingly – at times in the face of what was reported to be on the one hand great uncertainty about the outcome for their child, and on the other, what was perceived by parents to be resistance from service providers. Narratives suggest that parents themselves learned and developed new skills as a consequence of the event. This learning appeared to take place according to the context in which they found themselves at certain times in the process. For example, several parents became adept at changing their child's tracheotomy and other tasks, and came to understand the role and function on the medial equipment in the ICU. In moving to residential rehabilitation, most parents continued to take part in this process (such as physiotherapy and speech and language sessions). Learning continued when the child was discharged home. Such learning resulted in an increased skills-mix of parents through their participation and contribution to their child's care. On a speculative level, it is perhaps the child's return home where parents learned the most, as the lack of coordinated services and their feelings of 'aloneness' necessitated 'action' from them in securing the help and support they needed for their child.

From the time of the injury, for mothers and fathers, the internet was a powerful and informative resource. Information that was not provided by professionals was sought online. This varied for parent dyads; from understanding the implications of a diagnosis (N1) to finding out about brain anatomy and possible outcomes (N6), for example. But parents quickly learned that the quality of this information was highly

variable. One father (N8) spoke of a ‘hunger’ for information which was not available from professionals.

The majority of quantitative literature has elicited responses about family functioning in response to childhood brain injury from mothers (e.g., Yeates *et al.*, 2001). The finding here that fathers were so instrumental in their children’s rehabilitation contrasts with previous research. Wade *et al.*, (1995) suggest from their focus group research that the emotional reaction of fathers is different to that of mothers. They found that fathers ‘shut down’ emotionally, and consequently the mother is left with the burden of looking after the injured child

Kazac *et al.*, (2003) argue that there is much to be learned from the broader inclusion of families in our conceptualisation of children and health. They note that historically, families of ill children tend to be viewed as disrupted, complicated, or even pathological. Perhaps the paediatric TBI literature is ahead of the ‘standard’ paediatric literature in this respect, as it is well documented that the way parents – mothers *and* fathers – respond to the event is a significant determinant in outcome (Taylor *et al.*, 2001: Taylor *et al.*, 1995: Wade *et al.*, 2006). The findings obtained here support the argument of Kazac *et al.*, (2003).

As the rehabilitation process progressed, one of the tasks that emerged for mothers and fathers – and narratives indicates this came as an unwelcome surprise – was fighting for services. This is the next plot.

### **Plot 3: Fighting for services**

Their children sustaining TBI brought parents into contact with a number of services and health care professionals. At different times and in different contexts, these ‘new’ relationships were found to be helpful for some parents, but a source of conflict and disagreement for others. Several parents reported that during the acute and chronic phases of rehabilitation, they knew what their child ‘needed’. It was this ‘knowing’ that led many parents to fight for services to (as they saw it) maximise the chances of a positive outcome for their child. However, there was also a need to fight for basic

service provision. The greatest 'fight' faced by parents was on their child's return home from rehabilitation. Here, parents faced coordinating access to services, re-integration to education and in some cases, modifying their homes to accommodate the needs of their child. Parents used powerful adjectives to describe their search for and access to services ('fighting' / 'struggle' / 'battle'). In some cases they were forced to threaten tribunal proceedings and in one instance a court case for a statement of special educational needs ensued (which the parents won against their local authority).

Given that supporting parents' mental health is one of the underpinning assumptions of this study, and the emphasis on patient-centred care espoused in Department of Health documentation (e.g., DoH, 1999: 2005), the finding that most parents were left to fend for themselves and had to fight for services when they returned home after rehabilitation is a finding of great concern. The challenges faced by parents suggest they did not know what to expect in terms of what services they were entitled to, how to access them, where they could find them, and what they could expect from professionals. Narratives indicate that parents were certainly not expecting to have to 'fight' for a range of support; from information about what to expect from their child's behaviour changes following the injury, to services such as school reintegration and statements of special educational needs, and in some cases the battle through 'red tape' in order to make the required modifications to their homes, etc.

This suggests that unlike Armstrong and Kearns's (2002) findings, parents' experiences of being forced (in two cases) to access services through legal proceedings are beyond 'unmet needs'. Parent narratives are more akin to the findings of Savage *et al.*, (2005). In their review of issues related to TBI, Savage *et al.*, (2005) note that in the United States, children with TBI returning to school, for example, is a complex scenario. As has been found here, many children in the US are sent home directly from rehabilitation centres with no referrals to schools and inexperienced parents are often perplexed and overwhelmed by the array of assessments, meetings, formal planning and documentation involved.

#### **Plot 4: Transition phases: Emotional, temporal and action**

There were a number of transition points in the process that I constructed through Emden's (1998) method. I identified these as emotional, temporal, and action transition phases.

An example of an emotional transition (and related to all plots) is the early stages where parents had difficulty processing their experiences at various points after the event; from learning that their child had been injured, to realising the seriousness of the injury. Another example would be parents learning to cope with the injury and consequent uncertainty of outcome for the child. Such coping may have been mediated by parents' resilience, hope and support received from various sources at different stages of the process.

An example of an 'action' transition would be situations that required specific action at certain points. For example, nursing their child in the ICU and learning to change the tracheotomy. On a broader level, an example of an action transition is the important, proactive, organisational role that parents played throughout the process, and the fight parents faced. Narratives suggest this came only as a further shock to an already alien and deeply distressing experience. This culminated in problems with after care emphasizing the long-term familial impact of their child's traumatic brain injury. It could be argued that these transition phases were not discrete, exclusive periods, but overlapped with each other where parents 'prepared' for the 'next stage' of the journey, where time, to a degree, was a determinant. For example, children spent a certain period in ICU which invoked certain emotional resources and action skills from parents: they spent a certain period in residential rehabilitation, which necessitated possibly different types of emotional resources and action skills from parents. In short, the time spent in different places was a time when parents had specific tasks to engage in, and required specific emotional resources and skills to do so. Nothing was 'static' and parents' roles, behaviour, emotional states and appraisals were dynamic and constantly evolving to accommodate the improvements made by their child and the contexts in which these improvements were made.

Narratives suggest that parents coped by focusing on their injured child and taking a highly proactive role in their child's rehabilitation which included nursing their child and learning as much about the injury (from professionals and the internet) and possible outcome as they could. Bregman, cited in Benn and McColl (2004) identified various coping strategies used by parents, the majority of which were problem focused. These included taking each day as it comes (N4); maintaining a lifestyle as normal as possible (N8); keeping well informed (N2); seeking out the best treatment options for their child; trouble shooting and monitoring the standard of services received by their child (all narratives). These are consistent with comments made by most parents here.

Reference was made by several parents to the presence of other families in the PICU in the context of support. Other parents of sick children in the PICU gave comfort to the parents here, because they were seen by parents as being in the 'same position', and therefore perceived to understand what was happening and what they were going through. This also seemed to give parents a sense of hope for their child.

Another subplot construction from narratives is that parents showed great resilience in the face of a hugely adverse event. Future research might investigate this, and how parents are able to draw on their personal and systemic resources to negotiate the unique challenges brought through childhood TBI. Even for those parents that appeared to cope well with their child's injury, emotionally it was 'a nightmare' for them, even several years post-injury.

Some parents also spoke about loss and different types of loss (e.g., Tony, N1: Jessica, N2: Melanie, N7). Tony spoke in quite black and white terms of Steven almost dying whilst in hospital. Jessica said that prior to Lucy's car crash she was looking forward to having a 'female companion' in Lucy as she matured. This, she reflected, had now been taken away from her. Melanie sense of loss encompassed several dimensions. She felt that she had lost her son, David, to the stroke. But she also felt she had lost herself, and did not know if this would ever return. If it did return, she was not sure of the extent to which it would be the same or different as her sense of self compared to

before David's stroke.

Hope was a consistent and strong feature of narratives. In all narratives, parents were clear that hope should not be given up on. As was the case for loss, distinctions were made by some parents between 'types' of hope: the one type parent's did not want was 'false' hope (e.g., N3). Hope for some parents was reinforced and made visible through 'turning points', as discussed above. These turning points were where the child made what was perceived by parents to be a small but highly meaningful improvement. This could have been when the child woke up from a coma (e.g., N1) or a moment of laughter from the child when it was least expected (e.g., N4) when the child had until that time given no indication of understanding their external environment. Time was also an important influence in parental narratives. This was discussed both in terms of how long it had taken their child to get to the position of rehabilitation they were currently at (e.g., N7) and how long it had taken parents to be able to talk about their experiences (e.g., N3). It was while talking about these often subtle changes in their child's behaviour that parents spoke with great warmth, positivity, affection and passion (the spontaneity of which was not conveyed in translation from interview to analysis).

### **Plot 5: After-care and long-term impact**

Interviews suggest that compared to pre-injury experiences, where for parents in the sample their children were following what can confidently be described as 'normal' developmental trajectories, parents' (and families) lives and narratives had been 'shattered' when their child sustained severe traumatic brain injury. This 'shattering' in some senses appears to be temporary, as the parents here appeared – eventually - to respond and adapt positively to the event. None the less, the changes to family life are long-lasting, requiring changes on individual levels and systemic levels in family routine and lifestyles – and even approach and attitude to life (as suggested by most narratives) - and continue to do so.

The final plot I constructed from parental narratives through Emden's (1998) method concerned the child's return home from rehabilitation. It seems the return home of the

child from long-term rehabilitation is poorly recognised by services and is an area of clinical importance and service provision that represents urgent need of development. The fact that head injury was described as the '*...foremost cause of death and disability in young people...*' by the Parliamentary Health Select Committee as early as 2001 (United Kingdom Acquired Brain Injury Forum, 2006) makes this all the more alarming. Parents consistently spoke of a lack of joined up services, when on the return home of their child, they did not know what to expect in terms of service provision, who to contact for advice and support and what they were entitled to. For some parents, extensive house modifications (for example, building a new bathroom (N5)) were necessary to accommodate their child's needs. This often entailed 'fights for services' (N3: N4: N5) which parents were not expecting.

The finding that support is not routinely available over the long-term can only add to an extremely stressful event and its long-term consequences, and add to parents' perceptions of being 'alone'. It raises many questions as to the lack of – and a major gap in - provision of services. There are however, exceptions to this. Where a case manager became involved, the role of this person appeared to be one of organisation and co-ordination of services - a role which for those parents who had a case manager appeared to be a great relief to relinquish - especially after the acute and early rehabilitation phases. This seems only to happen where insurance companies are involved (from road traffic accidents). As one parent informed me, it would have been a different story had their child sustained injury by, for example, falling out of a tree.

In their study investigating the needs of parents during the latter stages of a child's recovery, Armstrong and Kearns (2002) found that only 36% of parents reported their needs as being met – from one to three years post-injury. Unmet needs were identified in several areas. Parents highlighted the desire to have teachers and peers understand their child's problems. Of considerable concern was the need to have available professionals, and for gaining a clear understanding of their child's problems and needed medical care. Interestingly, Armstrong and Kearns (2002) also found that parents had not yet been able to discuss their feelings with others who had gone through similar experiences. The findings in the current study add to this from a

qualitative perspective.

In their review of rehabilitation and ongoing support after paediatric TBI, Ylvisaker *et al.*, (2005) note family and child outcomes are reciprocally inter-related. However, in over twenty years since this was observed by experienced clinicians (e.g., Lezak, 1986) families continue to report the need for a central point of contact providing case management, information, networking, advocacy and other support. However, this critical support is frequently unavailable to them. In addition, families continue to report a sense of isolation in relation to their TBI-related needs.

One way to initiate such development is to have local and national consultation. This could be conducted in negotiation with the All Party Parliamentary Group (APPG) on Acquired Brain Injury. This acts as a forum for discussion and awareness-raising about TBI and has attracted interest from over forty MPs. At their meeting in 2006, members reflected on the National Service Framework for Long-term Conditions and raised concerns about the lack of progress since its publication in 2005 (Department of Health, 2005).

The return home also meant for some children reintegration into school – often another source of conflict between parents and local authorities. Often parents were left to organize access to school themselves (N5), or when even supported by services found themselves, again, having to fight for their child's right of access to education (N7). One parent dyad was forced to take their local authority to court to secure a statement of special educational needs, and another family threatened, but did not need to start similar proceedings.

Acceptance and closure was another important subplot in Plot 5. Variation existed among dyads in the extent to which they were able to move on from the event, for a variety of reasons. Some parents felt let down by services (e.g., N1: N8) which stopped them being able to 'close' the event. Other parents (N2) were able to move on through the involvement of a case manager, whose role was to organise care, housing, and college for their daughter– and thus devolve responsibility from parents.

The future was the last subplot to be identified. All parents clearly expressed concern and anxiety about the future of their injured child; from the child's ability to form and maintain relationships to securing employment and independent living. 'Uncertainty' was a consistent comment within narratives. Parents were particularly concerned about what would happen to their child, for example, 'when we are not around' (N3).

### **Clinical implications**

There is much that clinicians – and researchers - working with parents who have a child that has sustained TBI can learn from this study. My sense is that this sample of eight parent dyads was quite resilient. In response to an event that changed their lives, they demonstrated what can be reasonably described as great resourcefulness and adaptation despite the emotional and practical impact of the event.

From this sample - and despite their resilience - it seems that what parents need from professionals depends on the stage of the process they happen to be at. For example, in the early stages, the need for honest information for many parents here was a clear requisite. However, this is complicated by at least two factors: 1) that TBI outcome is so variable makes predicting outcome problematic, and 2) even when information is given in the early stages, some parents find it difficult to integrate due to their emotional states at this time. Crucially, some parents did and more would have valued talking to other parents who either were or had been in a similar situation. Parents believed their situation was unique and 'unless you've been through it, you don't understand it' (N5:154-155). For some parents then, talking to others they perceive as being in the same position may be beneficial. There may then be an important role for parents that are currently in, or have been in, the same situation. Whether this would mean a support group, or a more individual-based 'buddy' or 'mentor' system depends on the preference of individual parents. Important also may be a similar (group/individual) system for the siblings of injured children, as the children who contributed here clearly showed the extent to which they too had been affected by the event.

In the early acute phases, the role of professionals is a difficult one: should they attempt to alleviate the trauma and shock of the event for parents, or, to paraphrase Ian (N5), just listen when needed and simply give parents the time and space to process what has happened? This is complicated yet further in that parent dyads may differ and individual parents within dyads may differ, as was suggested by Colin (N8). Judith and Paul (N4) were a practical example of this, in that Paul wanted to know ‘everything’, whereas for Judith, ‘no information is good thing’.

When information is sought or not, basic counselling skills and professionals taking a positive approach to children’s care and well being was highlighted as important by parents. Where this happened (e.g., N4, N5, and N7) it seemed to have a reciprocal effect on parents, where it clearly made an important and valuable contribution to parents’ own approaches and their ability to cope. This may well be enough to support parents at this particularly ‘horrendous’ time. Such an approach is in marked contrast to some of the careless and insensitive comments made by some professionals to parents. Further, professionals need also to be mindful and recognise that parents can only ‘move on’ at a time when they are able to, and in no way should attempts be made to force this complex process. Throughout the process parents need to be listened to, have their feelings validated and clearly want – and need – to be active contributors at every level in their children’s care, as all parent narratives indicate. Because their child is so important (e.g., N5, N7) parents do not simply want to be ‘recipients’ of a service but want their own skills and understanding of their children to be recognised and valued by professionals. In terms of the many meetings that parents attended in relation to services for their child’s care, some parents may benefit from preparation and support for such meetings. Such an intervention might help them feel less intimidated by the formality of these meetings, and give them confidence and autonomy in what initially seems for many a strange and alien environment.

Arguably, the biggest issue faced by parents seems to be the return of their child to the family home, and the subsequent fight for services that ensued. This is an area of service development that warrants urgent attention.

A major question raised by this study is of the needs of less-resilient parents experiencing a similar event.

### **Strengths and Limitations of this study**

#### *Strengths*

That this study included fathers *as well as* mothers constitutes a methodological advance (Phares, 2005: 1992: Kazac *et al.*, 2003). On a speculative level, Phares *et al.*, (2005) note, although it is an empirical question that has yet to be asked or answered, it is possible that fathers may be more willing to participate in research if they are contacted by a male researcher, as was the case here.

A qualitative narrative methodology was used which should add to and compliment existing qualitative and quantitative studies. This methodology enabled processes to be explored through a chronological sequence of events since before the injury and enabled the research question to be answered. The method of analysis (Emden, 1998) enabled the researcher to summarise the data in a structured and organised manner, and then expand on this analysis as necessary to accommodate the evolving findings. This process was aided by the support of research supervisors in examining the data. This aided a thorough discussion of the data and analysis, increasing the trustworthiness of the interpretations by reducing the possibility of the findings emerging from only one source (primary researcher). Transcripts were returned to participants for ‘member checking’, which added to the trustworthiness and rigour of the process (Appendix 1). Parents that returned questionnaires agreed with the edited version. One parent requested that a specific piece of information was removed, as this may have compromised anonymity.

The recruitment and sampling of the participants in the study was also considered a relative strength. The likely presence of some biasing in the sample exists in that it may have included ‘helpful’ people. As detailed in the Method chapter, the number of participants required for a qualitative study differs to that of a quantitative study due to the differences in their aims. Eight pairs of parents were included in the study and this was considered appropriate for an in-depth investigation of this type.

Furthermore, conducting interviews, in comparison to other forms of data collection, provided a suitable social context in which the narratives could be constructed.

As described earlier there is a possibility that the findings of the study could be transferred and generalised to other parents experiencing paediatric TBI, even though generalisability of findings is not an aim of qualitative research. Murphy *et al.*, (1998) believe that the findings of qualitative data should move beyond the specific setting in which they were derived.

Finally, the overall findings support the change in paediatric TBI research to include all relevant members of a system (e.g., fathers) and theories (post-traumatic stress as a second order or vicarious factor).

### *Limitations*

As mentioned previously, interviews were chosen to collect the data for the study. One possible limitation is the problem of retrospective data collection, which implies that memory reconstructions can be unreliable. The following description from Lynn and McConkey (1997) however, allows the role of memory a fitting context in the current study,

*'(There is a) virtual consensus among memory researchers today that memory is not a complete static, and accurate record of the past. Rather, it is a dynamic medium of experience – shaped by expectancies, needs, and beliefs, imbued with emotion, and enriched by the inherently human capacity for narrative creation.'* (Lynn & McConkey, 1997, p. xvi).

Part of the interviews required participants to narrate about things that had occurred in the past, for the research to investigate how their narratives had changed over time. It is possible that how parents narrated about these events may have changed since these events actually occurred. The use of probes within the interviews aided participants' recall of their experiences, and most participants appeared to narrate quite freely and openly.

My understanding is that some parents were 'screened out' from invitation to participate because such parents were thought 'too fragile' to contribute. It is possible

that the sample was slightly skewed towards parents who (eventually) did learn to cope and adapt to the event, and whose resilience enabled this. On a speculative level, fragile parents may have provided further information that could help families in future.

Finally, participants were interviewed only once. Narratives were thus obtained at a 'snapshot' point in time. Resources were too limited to look at the possible evolution of parental narratives over time. One final important consideration was whether parents' ideas of rehabilitation led to conflict just between the parents themselves. An interesting question is the extent - if at all - having both parents present may have restricted narratives of parental disagreement emerging?

### **Future research**

Due to the philosophy of qualitative research, the findings generally hold limited potential to be generalised. Yet much of the findings here concur with previous research – and add new findings, too. The current findings have also highlighted potential areas for future research. Examples include:

- What can be done to alleviate the familial impact of the initial trauma?
- Is the role of parents similar to what was found here, both locally and nationally?
- Is the experience of parents when they return home similar to those found here, i.e., where parents feel 'alone' and have to constantly fight for services they assumed would have automatically been put in place for their children and themselves?
- Considering whether deliberately soliciting more 'fragile' families - as screened out here – may reveal similar narrative themes or different process struggles given their relative fragility and perhaps even greater resource poverty?
- The current study aimed to solicit recalled data from several differing time periods (pre-injury, accident, rehabilitation, and discharge home) which suggested to me transitions and journeys throughout parent narratives. It would be beneficial to conduct a longitudinal study collecting data from such actual different time periods and see if the findings here are corroborated. A longitudinal study should highlight how and what parents amend / adjust over time, and how this is accomplished.

- In relation to transitions identified here, a longitudinal study may also highlight how such transitions can be positively facilitated and minimise distress associated with the event.
- A longitudinal narrative approach would also focus on how narratives develop and change over time, in response to varied events and adjustments.

## CONCLUSIONS

Parents' descriptions indicate that they themselves appear to often undergo a significant degree of trauma as a result of their child sustaining severe TBI. Because of this, they may have difficulty processing the event on cognitive and emotional levels, and what it might mean for their children, themselves, and their family. The finding that parents themselves undergo trauma will contribute to the emerging literature. As Colville and Gracey (2006) note, this is not surprising as the event of their child sustaining TBI is a very real threat to the life and integrity of their child, as well as their ongoing survival as a family.

There is a clear need for certain types of interaction from professionals at this critical time, where listening to and validating parents' experiences and reactions are crucial. The giving of information needs to be gauged carefully, and will depend on what individual parent dyads request and are able to absorb at a given time post-injury.

Parents are primary caretakers of their children and face significant change and vicarious trauma when confronted with their child's TBI. Yet the services to support them through this deeply emotional and uncertain transition appear at best disjointed, and at worse, non-existent. This is perhaps the most alarming finding of the study.

As their narratives testify, parents did learn to cope and many make transitions – in terms of their own emotional states and the practical necessities through changes of routine and family life that the event brought. However, this was achieved largely through their own resourcefulness. That fathers *as well as mothers* played (and continue to play) an important and influential role in their child's rehabilitation is a

major finding, and should give impetus to future research about the roles parents play in the rehabilitation of their children with severe traumatic brain injury.

Parents used a variety of psychological and emotional mechanisms and behaviours to facilitate positive transitions. They seemed to work as a team, become committed in achieving the best possible outcome for their child, and where possible involved the whole family in the event. Hope and ‘turning points’ in their child’s rehabilitation trajectory contributed to this, as well as the quality of relationships with professionals and within their own dyads . The stumbling point for some professionals appeared to be their role and attitude in meetings that led to decisions being made about children whom they had never met. This was a source of immense frustration and anger for some parents, who often felt marginalized and undervalued by professionals. Parents reported that they needed professionals to listen to them, validate their feelings and recognize the contribution that parents can, want, and feel the need to make to their child’s rehabilitation.

One of several key plots within this study that unifies parent narratives is that parents go through a series of transitions – where mothers *and* fathers play a vital role – which culminated in fighting for services. It seems that what is needed throughout these transitions is a person or network of people with a broad skills base, who with sensitivity, empathy and warmth can guide parents through the minefield of service provision and logistics. This may help alleviate the shock and turmoil of an experience that so unexpectedly and dramatically changed the lives of parents and their families.

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## APPENDIX I

### **Methodological Rigour: Issues and Procedures**

Reliability and validity both translate into trustworthiness; reliability refers to the trustworthiness of observations, and validity refers to the trustworthiness of interpretations (Stiles, 1993). Practically, there are some overlaps between observations and interpretations, yet it is easier to describe them as separate entities when discussing rigour. Lincoln and Guba (1985) stated that rigour (trustworthiness) came via the establishment of credibility, transferability, dependability, and confirmability.

Credibility concerns the trustworthiness of interpretations and is divided into two further concepts; correspondence and coherence. Therefore, credibility concerned the correspondence between individual accounts and interpretations, and that interpretations are grounded in the raw data. To enhance correspondence I continually referred back to the original transcripts and recordings of the interviews at each stage of the analysis to ensure the developing findings corresponded with the original data. In addition, the correspondence of the interpretations was increased following the discussions of the findings with the participants through member checking (Emden, 1998).

Lincoln and Guba's (1985) transferability concept concerns the trustworthiness of observations. It has been argued that the transferability of qualitative findings is an inherent weakness of this type of research. However, as qualitative research is based on the premise of multiple perspectives of reality, and does not aim to establish an unequivocal truth, transferability has different connotations within a qualitative paradigm. Consequently, to establish transferability the researcher needs to make explicit all the processes involved in the observations, and therefore providing the reader with the opportunity to judge whether the findings are transferable to other settings (Stiles, 1993). Consequently, I have tried to make explicit the theoretical grounding of the study, the procedures and processes of the study, and the decisions made to enable others to evaluate the transferability of the findings to wider settings.

Dependability could be linked to both the trustworthiness of observations and interpretations, as it regards the amendments to the design following an increase in knowledge of the phenomena in question (Marshall & Rossman, 1999). More specifically, it concerns the believability of the findings. Therefore, I provided thorough transcripts, made numerous process recordings regarding my experience of the research through an audio-journal and tried to clearly describe the methods used. By placing my own voice, in form of reflections kept in an audio-journal, within the body of the analysis I am making explicit these concerns as part of the audit trail (Lincoln and Guba, 1985).

Confirmability regards the degree to which another person could confirm the findings of the study.

## APPENDIX II

A flyer



Dear Mr and Mrs

As parents of a child with brain injury, you have unique experience of an increasingly common occurrence.

Would you like to contribute to a research project by sharing your experiences with a researcher in confidence? All information you provide will be anonymous, with no possibility of personal identification.

This is an opportunity to tell 'your story'. It will cost you nothing (apart from a little time).

This is the first research of its kind, and by sharing your experience you could help other families affected by this event by increasing our understanding of what parents go through and how they are affected by this.

I can visit you at home at a day and time convenient to you.

If this sounds of interest, please read the attached information. If you would like to participate, please return the enclosed consent form and your contact details.

Many thanks,  
Graham Williams  
Trainee Clinical Psychologist, University of Hertfordshire

## APPENDIX III

### Invitation letter



University of Hertfordshire

Doctor of Clinical Psychology Training Course  
University of Hertfordshire  
Hatfield  
Herts  
AL10 9AB

Dear Mr and Mrs

My name is Graham Williams. I am undertaking my Doctoral training in Clinical Psychology at the University of Hertfordshire.

As part of this training I am conducting a Research Project and as such I am looking for parents who have a child that sustained a brain injury when under 16 to take part in my study. Following ethical approval by the University of Hertfordshire Ethics Board, I have been given your contact details by John Mulhall, social worker at CFCS. The study is being supported by the Children's Trust, a charity for children with multiple disabilities. The Children's Trust will be made aware of the study's general findings, although no detailed information will be shared. Anything you say during our conversation will remain confidential.

With this letter you will find a research information sheet. I would be grateful if you could read this as it explains the study. If, after reading the information sheet you would like to take part, please sign the (two) attached consent forms. Please keep one of the forms and return the other to me for my records. Please also return the consent form with your phone number.

I can then contact you and a date and time for the interview can be arranged at your convenience.

If you have any questions at any stage, please feel free to contact me:

Email: [G.R.Williams@herts.ac.uk](mailto:G.R.Williams@herts.ac.uk)

Telephone: 01245 610056

Postal address: as above

Thank you for your time.

Yours Sincerely,

Graham Williams

Trainee Clinical Psychologist

## APPENDIX IV

### Information sheet



Title of Project: An investigation into the experience of parents' as a result of their child sustaining traumatic brain injury

### **INFORMATION SHEET FOR PARENTS**

#### **Introduction**

Parents are being invited to take part in a study looking at parental experience after their child has had brain injury from an accident such as a fall or a road traffic accident. Before you decide whether you would like to take part, please read the following information which explains why the research is being carried out and what it will involve.

#### **The researchers**

The study is being carried out by my self. I am a Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology. The study is supervised by Dr Clare Norris, at the University of Hertfordshire

#### **What is the purpose of the study?**

This research is looking at parents' experiences since their child became injured, and any effect the injury had on parents. This is an important area of study, as it can help people providing health care to better understand the experiences parents themselves have, particularly any psychological / emotional difficulties parents may experience related to their child's injury. Brain injury in children sometimes has a significant effect on their families, and an increased understanding of this may help those parents who experience difficulties, as well as future families affected by such an event.

#### **What is involved?**

If you decide you want to take part, I will come to your home – at a time and date convenient to you – and have a 'conversation' with you and your partner by asking lots of questions about your experience since your child's injury. You might find some of the questions quite difficult. However, it is also an opportunity to 'tell your story'. The length of the interview depends on how much information you wish to provide, and because I need to listen to your 'whole' story, the interviews will be tape-recorded so that I can get an accurate account of your experience. When I have studied your story, the tape will be destroyed and no-one will know it was your story.

### **Who is taking part?**

I am hoping that several parents will want to take part.

Title of Project: An investigation into the experience of parents' as a result of their child undergoing traumatic brain injury.

### **Do I have to take part?**

No. If you do not want to take part, or you change your mind *at any time* during the study, you can drop out and you do not need to give a reason. Participation is entirely voluntary and you can withdraw at any time.

### **What do I have to do?**

If after reading this information sheet you would like to take part, you will be given this sheet to keep and you need to sign two consent forms which give your permission to take part. You will keep one copy of the signed consent form and I will keep the other copy.

Please send the consent form (in the envelope provided) to Hayley Williams at the Children's Trust at the address below. You will then be contacted and the interviews will be arranged at your convenience.

### **Will taking part be confidential?**

Yes. All the information you provide will be confidential and anonymous. This means that the tape on which the interview is recorded will have no identification details on it. Tapes will be kept by the researchers at a secure location which will only be accessible by the researchers. Consent forms will be kept separately from the tapes which will be destroyed as soon as your story is analysed.

### **What happens to the information I have provided after the results are analysed?**

The tapes, the transcripts based on those tapes and all relating media/information will be destroyed.

### **What are the benefits of taking part?**

Taking part in this study may or may not benefit you personally. However, it is hoped that this research will help our understanding of parents' experiences if their child becomes brain injured, and may help the types of services available for those families badly affected by this event.

### **What if I have questions or concerns?**

If you have any further questions about the research, please feel free to contact me via email, telephone or post, details of which are below. If participating in this research causes you distress in some way, information about support will be made available.

Title of Project: An investigation into the experience of parents' as a result of their child undergoing traumatic brain injury.

### **Who has reviewed this study?**

This study was reviewed by University of Hertfordshire Research Ethics Committee and approved on the 8<sup>th</sup> October 2007.

Contact details of the researcher: **Graham Williams**

Email address: G.R.Williams@herts.ac.uk

Telephone number: 01245 610056

Postal address: Doctor of Clinical Psychology Training Course  
University of Hertfordshire  
College Lane  
Hatfield, Herts., AL10 9AB

Thank you for taking time to read this.

APPENDIX V

Consent form



p. 1 of 1

**CONSENT FORM**

**Title of Project:** An Investigation into the experience of parents as a result of their child sustaining traumatic brain injury.

**Researcher:** Graham Williams, Trainee Clinical Psychologist

*Please initial box*

1) I confirm that I have read and understand the information sheet dated ( ) for the above study. I have had the opportunity to consider the information and if needed ask questions that were satisfactorily answered.

2) I understand that taking part is voluntary and that I am free to withdraw at any time, without giving any reason, without healthcare or legal rights being affected.

3) I understand that all information I give will be in confidence, with no means of identification during or after the studies completion.

..... Name of parent	..... Date	..... Signature
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..... Name of parent	..... Date	..... Signature
-------------------------	---------------	--------------------

..... Name of researcher	..... Date	..... Signature
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## APPENDIX VI

### Interview Schedule: Parents' Experiences following their Child's Traumatic Brain Injury

Probes	Spontaneous Probes
<p><b>How was * before the accident?</b></p> <ul style="list-style-type: none"> <li>- Did you have any concerns (school, home, friends...)?</li> </ul>	
<p><b>Tell me about the accident...</b></p> <ul style="list-style-type: none"> <li>- Do you remember the day?</li> <li>- What happened? (coma / time off work?)</li> <li>- How did you learn about it?</li> <li>- Where you involved?</li> <li>- Your immediate reaction / what did you feel?</li> <li>- How do you react individually/as a couple?</li> <li>- Have you had any therapy/counselling since the accident?</li> </ul>	
<p><b>Relationship with Professionals</b></p> <ul style="list-style-type: none"> <li>- What services did * receive?</li> <li>- What are your views and experiences regarding how * was looked after by the NHS/?</li> <li>- What has been the most helpful service and why?</li> <li>- What has been the least helpful service and why?</li> <li>X years on, are you getting any support/help?</li> <li>(no) what would you like? Difference would it make?</li> <li>(yes) what is it / is it helping?</li> <li>- Are you involved in any court case?</li> <li>- What sort of an effect has this had on you?</li> <li>- What are the pros and cons of this?</li> </ul>	
<p><b>Family &amp; Friends</b></p> <ul style="list-style-type: none"> <li>- Tell me how things have been for the family since the accident (for you as a couple / loss of intimacy?)</li> <li>- How is your current relationship with *?</li> <li>- How do you think the injury plays out at school/home/friends</li> <li>- How does that affect you?</li> </ul>	

<ul style="list-style-type: none"> <li>- How has the family coped since the accident?</li> <li>- What's the thing (accident) you have coped with best?</li> <li>- What's the thing (accident) you have coped with the worst?</li> <li>- Has your ability to cope/accept/manage changed over time?</li> <li>- Parenting experience of having &gt; 1 child?</li> <li>- Do you talk about things as a family / couple?</li> <li>- Have you accepted the injury? How?</li> <li>- What was the reaction of friends to the accident?</li> </ul>	
<p>Social</p> <ul style="list-style-type: none"> <li>- Have your relationships with family/friends changed since?</li> <li>- Have your social lives changed since the accident?</li> <li>- Have you jobs changed since the accident?</li> </ul>	
<p>Future</p> <ul style="list-style-type: none"> <li>- What do you see as the biggest obstacle to * future?</li> <li>- Do you have any plans for *?</li> <li>- What are your hopes for * future?</li> <li>- What would/do you want from professionals?</li> </ul>	
<p>Advice</p> <ul style="list-style-type: none"> <li>- If I was a parent and my child had just got brain injury, is there any advice you would give me right now?</li> <li>- ...and Why is that important?</li> </ul>	

## Notes

## APPENDIX VII

### Introduction to interview in the home

Confidentiality (with exceptions)

Interview is separated into several main sections, although there is much flexibility around this

I am interested in your views both as a couple and as individuals, so there will be times when I ask both of your views on something and I may alternate between the two of you.

Even though the interview is being recorded, I will need to take a few notes so that I can remind my self if I need to return to an important point that you mention

Some questions I have written down, other will be spontaneous based on what you tell me.

I will be saying very little; questions may be sensitive and possibly distressing. You don't have to tell me anything you don't want to, but at the same time the more you tell me the better picture we can build up of your experience

If you want a break at any time, just say!

There will be an opportunity at the end for you to tell me anything you think important/relevant that I have missed

Do you have any questions before we start?

How many children do you have?.....

Birth order and ages of children?.....

How old was \* when s/he had the accident?.....

## APPENDIX VIII

### Debriefing information



University of Hertfordshire

#### Parent Debriefing Information

Firstly, thank you very much for making this study possible! It is the first of its kind in the UK. By sharing your experience since your child's injury, it is hoped that your story will help our understanding of how parents react to this event.

Research findings suggest that while some parents of a child with brain injury do not experience distress as a result of their child's injury, many parents do: what is not clear is the *nature* of this distress, and this is what is being investigated. It may seem obvious that parents would undergo some sort of distress, but there are other influences too, which complicate the picture.

The aim of this research is to gain a better understanding of any distress that parents' experience. The information you provided may also help other families who have a similar experience

The information you provided will be confidential, and after analysis the tapes will be destroyed. As a participant, you have the right to withdraw the information you have provided at any time.

Below is listed some resources that you may find useful:

*Traumatic Brain Injury in Children – a parents' guide* (available on [amazon.co.uk](http://amazon.co.uk))

Child Brain Injury Trust,  
Unit 1, The Great Barn  
Baynards Green Farm  
Nr Bicester  
Oxon OX27 7SG  
Tel: 0845 601 4939  
Website: <http://www.cbituk.org/>  
Email: [helpline@cbituk.org](mailto:helpline@cbituk.org)

The Children's Trust  
Tadworth Court  
Tadworth, Surrey  
KT20 5RU  
Tel: 01737 365 000  
Website: [www.thechildrenstrust.org.uk](http://www.thechildrenstrust.org.uk)



University of Hertfordshire

Headway  
4 King Edward Court  
King Edward Street  
Nottingham NG1 1EW  
Tel: 0115 924 0800  
Helpline: 0808 800 2244  
<http://www.headway.org.uk/>

Local counselling services (GP surgery).

If you have a complaint to make about your involvement in this research, please contact Dr. Clare Norris whose details are below.

<b>Name of researcher : Graham Williams</b>	<b>Name of supervisor: Dr Clare Norris</b>
Dept. of Clinical psychology	Dept. of Clinical psychology
University of Hertfordshire	University of Hertfordshire
College Lane Campus	College Lane Campus
Hatfield	Hatfield
AL10 9AB	AL10 9AB
Tel: 07738 169 705	Tel:
Email: G.R.Williams@herts.ac.uk	Email: C.Norris@herts.ac.uk

Would you like to know the results of this study?

If so, please write your name together with *either* your email address or postal address in the space below, and the results will be sent to you when the project is completed (around June 2008).

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## APPENDIX IX

### Ethical approval

<b>From:</b>	<a href="mailto:fliegeois@thechildrenstrust.org.uk">Frederique Liegeois &lt;fliegeois@thechildrenstrust.org.uk&gt;</a>
<b>To:</b>	<a href="mailto:G.R.Williams@herts.ac.uk">G.R.Williams@herts.ac.uk</a>
<b>Cc:</b>	<a href="mailto:Sjenkinson@thechildrenstrust.org.uk">Sally Jenkinson &lt;sjenkinson@thechildrenstrust.org.uk&gt;</a> , <a href="mailto:APerkins@thechildrenstrust.org.uk">Alison Perkins &lt;APerkins@thechildrenstrust.org.uk&gt;</a>
<b>Date:</b>	Thu, 9 Aug 2007 15:36:31 +0100
<b>Subject:</b>	FW: Research study at the Children's Trust

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Dear Graham,

As I thought (see email below from the Surrey Ethics coordinator), you are under no obligation to go through the Surrey Committee as your study involves the parents and not the children. Your University Ethics approval will suffice as long as there are procedures of complaint in place. Parents need to have a contact person in case they want to complain about how the study is carried out—this is standard procedure for NHS application and the Trust needs to know who takes responsibility in case things go wrong. Not that it will happen, but we need to be on the safe side! Hopefully your supervisor will be able to clarify this. I hope this helps,

Best wishes,  
Frederique



## **APPENDIX XI**

**CD ROM containing all raw data**

## **Journal Ready Article**

### **Shattered Narratives and the Search for Meaning: The Experience of Parents who's Child Sustained Traumatic Brain Injury.**

**Graham Ross Williams**

The impact on parents of children who have sustained traumatic brain injury can be profound and long-lasting. The role played by parents in the transition from injury to rehabilitation and beyond is known to be important. This study looked in detail at the parental experience of having a child sustain TBI, beginning with the injury, through the rehabilitation process and the child's return home. Mother and father dyads were interviewed in their own homes, using a semi-structured interview schedule. Using a narrative analysis, plots and subplots of parents' experiences emerged and a number of important findings are highlighted. These include that parents themselves appear to undergo trauma as a consequence of their child sustaining TBI; all parents went (and are continuing to go) through a number of transitions in this process. Also, given that fathers have been historically neglected from research into child health issues, the finding here that fathers as well as mothers made a substantial contribution to all aspects of their child's care is timely and important, and should represent a methodological shift towards including fathers in research. This study also found that there seemed to be little if anything in the way services were coordinated when the child was discharged home from rehabilitation. Indeed, parents had to continually fight for services. For most parents, this event led to profound changes in their lives, changes which have not been recognised or supported by services.

Traumatic brain injury represents one of the most common causes of acquired disability in childhood. In the UK, the statistics for accident and emergency (A&E) attendance, hospital admissions and mortality for head injury are not unified nationally (Middleton, 2001). Department of Health (1997) figures for the UK suggest that for children aged 0-15 years, 1% of A&E attendees had a severe injury. Children sustaining severe traumatic brain injury (TBI) have been shown to have slower recovery and poorer outcome than adults with similar insults (e.g., Anderson and

Taylor, 1999; Taylor and Alden, 1997). Literature and clinical evidence (Anderson *et al.*, 2001) indicates that recovery processes for the child are long-term and complex, beginning with acute phases and medical issues through to sub-acute and long-term outcomes, with respect to physical, cognitive and psychosocial factors. Such incidence levels establish childhood TBI as a significant problem for the community (Anderson *et al.*, 2001).

In general, children who sustain TBI may experience a complex array of physical, cognitive, psychosocial, behavioural and emotional problems (DeBoskey, 1996), with the course of recovery difficult to predict for any child.

While sequelae are well documented, outcome is highly variable even among children with more serious injuries (Fletcher *et al.*, 1995). Taylor (2004) note that heterogeneity of outcomes of TBI is unexplained, even after grouping children into traditional severity classifications. This is complicated by the interaction of a number of complex variables and may be compounded by a number of methodological problems inherent in the investigation of childhood TBI (Wade *et al.*, 1995).

The impact of childhood TBI on both the child and family is well established (Anderson *et al.*, 2001, 2006; Wade *et al.*, 1996; Ylvisaker *et al.*, 2003). However, it is only within the last few years that the reciprocal role of family/injured child has been demonstrated in the literature (Taylor *et al.*, 2001).

Because the onset of TBI is sudden and catastrophic, the principal morbidity and source of burden for parents often arises from long-term cognitive, behavioural, and academic deficits rather than from physical impairments (Taylor, 2004).

Quantitative methodologies such as those detailed above have contributed greatly to our knowledge and understanding of childhood TBI and its impact on the parents and the family. However, while standardised measures and generic instruments yield reliable and valid data they may conversely obscure the presence of and be insensitive to the stresses and changes in family experiences that are unique to TBI (Wade *et al.*, 1995). From the perspective of the current study, quantitative studies have two further limitations. First, various models of statistical analysis tell us nothing about 1)

individual differences and commonalities among parents, or 2) the nature of parental experience from a qualitative perspective.

Second, much childhood TBI research (and a common feature of TBI family research) is that the mother is usually the sole respondent. The omitting of fathers from childhood clinical research is recognised as a serious limitation to understanding parental responses and contributions to family adaptation in a range of child health conditions (Kazac *et al.*, 2003; Phares *et al.*, 2005), an observation that can be extended to childhood TBI research.

Kazac (2003) argues that there is much to be learned from the broader inclusion of families in our conceptualisation of children and health. In their recent review Phares *et al.*, (2005) found that fathers were clearly underrepresented in child and family research that focus on clinical issues. They argue that there is a clear need to increase the inclusion of fathers in research related to child well-being. In the context of TBI, this is all the more relevant given that the research of Wade *et al.*, (1995) suggests that fathers react differently to the injury than do mothers.

The goal of the present study was to put parents – mothers *and* fathers - at the centre of this study. In order to promote their voices, a narrative analysis was chosen to investigate the parental experience of their child sustaining TBI.

The current study aimed to investigate how parents experience the traumatic brain injury of their child, and what it means to them.

## **METHODOLOGY**

Qualitative researchers argue that positivist methods are but one way of telling stories about societies or social worlds (Denzin and Lincoln, 2005). In all research, validity or ‘truth’ of findings is paramount: but how to determine ‘truth’? Truth in the post modern world allows all viewpoints to be heard with no one view held as an absolute truth. As Cheek (2000 p20) points out ‘...*post-modern thought emphasizes that reality is plural and that there are multiple positions from which it is possible to view any aspect of reality*’. Thus Richardson (1994) cited by Lincoln and Guba (1994) argues delivery of the definitive truth to be an impossible task for one single research

method.

That human beings develop subjective meanings of their experiences – meanings directed towards certain objects or things - is at the heart of this study (Berger and Luckman, 1967). These meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrowing meanings into a few categories or ideas. Research from the perspective of social constructionism (and the assumptions it brings) relies as much as possible on the participants' views of the situation being studied.

In support of qualitative methods, postmodernists have contributed to the understanding that there is no clear window into the inner life of an individual. Any gaze is always filtered through the lenses of language, gender, social class, race and ethnicity. This implies that there are no objective observations, only observations socially situated in the worlds of – and between – the observed and the observer. Subjects, individuals, participants, are seldom able to give full explanations of their actions or intentions; all they can offer are accounts, or stories (Denzin and Lincoln, 2005).

### **Methodological rigour**

When undertaking qualitative research the issue of trustworthiness needs to be addressed. By definition, trustworthiness is the degree to which findings of a study can be viewed as worthy of confidence (Stiles, 1993). Guba and Lincoln (1985) identified the four aspects of trustworthiness as being credibility, dependability, transferability and confirmability. Through the use of an open-ended interview schedule in this study, the first aspect of credibility was addressed. By using open ended questions, the participants were encouraged to discuss their own experiences and perceptions, contributing to credibility. This study attempted to maximize dependability, confirmability and credibility through the use of member checking (Emden, 1998) where interview transcripts were returned to participants for their comments. With regard to plots and subplots, three researcher supervisors also examined the data which helped reduce the bias that comes from one individual doing all the analysis.

One aim of this study was to place parents at the centre of the investigation; to make them the experts of their own experience, to elicit their meanings and constructions, and to make as few assumptions about their experience as possible, and most importantly of all, to hear (and listen) to their voices. Such an approach, it could be argued, concurs with the philosophy of various Department of Health documents published in the last decade (e.g., DoH, 2005: 1999) which espouse ‘person centred care’, where the needs of service users are recognised, understood, and attempts made to address them in service delivery.

Given such aims it was decided that a narrative account from parents could provide a alternative but complimentary lens to existing literature through which to gain further understanding of their experience. That no narrative analysis could be found in this area of clinical research only strengthened the argument for narrative inquiry.

Reissman (1994) speaks of narratives as the means for us to create who we are and how we define situations in our daily lives. Narratives also allow us to order our worlds and make connections (meanings) between our past and present, and between ourselves and the worlds we live in.

## **DESIGN**

### **Sampling Strategy**

When using qualitative methods it is appropriate to use a small number of participants (Silverman, 1997) owing to the large quantity of verbal data requiring analysis (LoBiondo-Wood and Haber 2002). This enables the study of meanings, experiences, and to gain an “insiders” perspective by collecting a lot of individual data (Chamberlain et al., 1997). Given the specificity of the research question, purposive sampling was employed.

### ***Participant recruitment***

#### ***Participants***

The study was conducted in collaboration with a charity for children with multiple disabilities. Potential participants who met the inclusion criteria were identified by staff at the charity. A list of potential parents was then made. Invitation ‘packs’ to

participate were posted to selected parents. Each pack contained a 'flyer', an invitation letter, an information sheet about the research, and three consent forms.

### **Narrative Interview Schedule**

A lightly structured interview schedule was specifically designed for this study. It used generative questions in areas identified in the literature as important (such as child's functioning before the accident, the accident, hospitalization, and rehabilitation) to encourage parents to 'tell their story' around the child's injury and several types of prompts to invite parents to expand on responses.

### **Procedure**

Parents contacted the researcher to give their consent and interviews were arranged. On arrival at parents' homes, an introduction to the interview was given. This highlighted confidentiality (and its limits) and what parents could expect. Ongoing consent was a constant theme of the study. All interviews were tape recorded for accuracy of narratives. Notes were taken during the interview so that I could return to important points made by parents without interrupting their accounts.

After the interview, parents were given de-briefing information about why the study was being conducted. They were again reminded of confidentiality and assured of no personal identification.

### **Analysis**

The framework described by Emden (1998) was chosen as the method of narrative analysis most closely attuned to the parent-centred nature of the study as it allows for "member checking" (Emden, 1998 p. 35). Emden suggests that all the interviewer's words should then be removed from the text before deleting all words that detracted from the key idea of each sentence or group of sentences uttered by the participant. Fragments of "constituent themes" (Emden, 1998 p.35) or subplots were identified before moving fragments of the themes together to create one coherent 'core story'. Following distilling of interview transcripts, they were returned to participants for their comments and invited to comment on accuracy. This added to methodological rigour.

## RESULTS

Eight parent dyads participated in the study. Parents all lived in their own homes, and lived in geographically dispersed areas of England.

### **‘Selected’ families**

The parents selected were homogenous in the following way. Parents had a child (under the age of 16) that has sustained ‘severe’ TBI, as the literature indicates ‘severe’ TBI will make the greatest demands on the family in adjusting to the event. Perlesz *et al.*, (1999) note that the greatest functional recovery from TBI is within 6 months after trauma. Second, to obtain rich and deep experience from parents, the child needed to have been discharged from residential rehabilitation services and be living at home. This would have enabled parents to experience the range of situations and events which the research questions were designed to investigate.

Also important was that mothers and father were still living together. This was to address some of the weaknesses in previous studies by including fathers. That fathers were included here constitutes a methodological advance (Phares *et al.*, 2005).

Equally, parents of children who had certain pre-injury characteristics were excluded. These included non-accidental brain injury, history of previous closed head injury (disentangling one head injury from another would be methodologically difficult). Parents whose injured children include such characteristics were not invited to take part because another key focus of this study is that the injury was sudden and unexpected, in that parents had no time to prepare emotionally or psychologically for the event, as this was an important qualitative issue in this study.

The results are presented. Table 1 summarises family constellations and the nature and dates of injuries sustained by children. To preserve confidentiality, all names used are pseudonyms. Information identifying locations and professionals has been removed. Information is presented in the order that interviews took place.

Table 3 Family constellations

<b>Parents</b>	<b>Name of child &amp; age at injury</b>	<b>Nature of injury</b>	<b>Date injury sustained</b>	<b>Time since injury</b>	<b>No. of siblings</b>
Tony & Jacqui	Michael, 13	Infection: Encephalitis	November 2003	4 years	2
Neil & Jessica	Lucy, 15	Road Traffic Accident	December 31st, 2003	4 years	1
Jeff & Angela	Gary, 13	Road Traffic Accident	24th September, 2005	2 years	2
Paul & Judith	Steven, 13	Road Traffic Accident	December 2004	3 ½ years	1
Ian and Sally	Chloe, 15	Stroke	December, 2004	3 years	2
Ahbhass & Zulehka	Badaal, 6	Stroke	April 2006	2 years	2
Jonathon & Melanie	David, 13	Stroke	February 2005	2 years	3
Colin & Nicki	Sammy, 13	Road traffic accident	June 2006	2 years, 10 months	2

### *The Core Stories*

Following Emden (1998), the core story is an abridged amalgamation of parent's narratives, where speakers are not identified.

## **ANALYSIS**

In line with Emden's (1998) methodology, Table 2 summarises the plots and corresponding subplots derived from parents' narratives.

Table 4 Plots and Subplots

<b>Plots</b>	<b>Subplots</b>
1. The early stages: disbelief and disociation	i) Disbelief ii) Intensive Care Unit: Realisation and Dissociation
2. Fighting for Services	i) Continually fighting
3. The role of parents	i) Part of a team ii) Organisation Skills iii) Online learning
4. After-care and long-term impact	i) Shattered narratives ii) Lack of joined-up services

## Plots and subplots

The following plots from narratives were created.

### 1. The early stages: disbelief and dissociation.

*'I was devastated, knowing that we might not see him tomorrow, or we might not see him in an hour' (N1: 658-660).*

The first plot to emerge was parents' learning about the event. All parents gave varying descriptions of 'shock' to the event, and recalled in detail their reaction.

Jeff, who was at a football match when he had a phone call about his son had been involved in a road traffic accident, said,

*'I just think that you cannot believe...or you don't want it to happen... it's not happening.'* (N3:80).

### ii) Paediatric Intensive Care Unit (PICU): Realisation and Dissociation.

This may have been a highly significant time for parents because arguably, it was here that the realisation of the seriousness of the event began to take hold. Parents spoke at length and in considerable depth about their experience in the PICU.

Jacqui recalled, *'bearing in mind your mind's not there when your child's – you think your child's going to die'* (N1:835-836).

On arriving at hospital to be told of the seriousness of her daughter's accident, Jessica:

*'...before we saw her they took us into a little room and, you know, explained what had happened. But I felt like I was in a film. Well I just – it wasn't real, just didn't feel real at all, peculiar. It felt like I was watching the telly. It was odd, I didn't feel involved'* (N2: L87-91).

Paul recounted his reaction to his son not waking up, despite the administration of nine different drugs over three weeks in the paediatric intensive care unit:

*'Once they'd started to wean him off those, they said he could become conscious. That's when they had to take us to one side and tell us the seriousness of...Well that was when it was devastating to us.'* (N4: 165-169).

### 2. Fighting for Services.

*'It's worth fighting. Because we have got a reasonable level of support as a result.'* (N7:916-917).

#### i) Continually fighting.

Narratives suggest that for all but one pair of parents, fighting for services was among the challenges that parents faced in addition to the dramatic change in their

circumstances and lifestyle as a result of their child's injury. Most parents' spoke of 'fighting', 'battling', and that it was a 'constant struggle'.

In some cases, parents explained how they have been changed by this process:

Neil said:

*'It's turned us into people who, you know, push to the front of the queue, and that's not, that's not our natures.'* (N2: 409-411).

However, for Tony and Jacqui, their efforts at attempting to secure services for Michael came to nothing:

*'We've fought tooth and nail to get help for him, and nobody cares. They chucked him out of school basically.'* (N1: 64-65).

3. The Role of fathers. *'...with my skills I'll persevere and do anything.'* (N4: 1202)

Without exception, fathers played a reportedly consistent and positive role in the care of their injured children, and in some cases took long periods of time off work in order to care for their child. Fathers played a big role in organising their child's care and turned to the internet for information.

i) Organisation skills

Paul and Judith stayed with their son, Steven, in hospital for six months. Paul took a very proactive part in his son's care, learning some of the medical maintenance tasks:

*'I didn't leave Steven when he was at the Children's Hospital...I had to learn how to maintain his trachi, give his feed. Yeah I did all that from day one.'* (N4: 319-320).

ii) Online Learning

For fathers in particular, the internet emerged as a powerful resource. Most fathers used it to find out about their children's condition, prognosis and as a tool to educate themselves about their child's prognosis. Colin and Joanne give an example of this, and the reason they turned to the internet for information:

*'there were Internet access PCs on the wards. So 10 o'clock at night, you can't go to sleep...so you're on the Internet looking up. Every time they mentioned something, temple bone fracture, right where is the temple bone?' (N8: 619-622).*

4. After care and long term impact.

*'No one explained, we didn't know what we were going to face when we came home. Oh that was a nightmare.'* (N1:146-147).

The long term impact of children's injuries is without exception highly significant and includes many issues, one of which is the extent to which parents' lives have changed

as a result of their experiences since their child sustained injury.

i) Shattered Narratives.

Most parents commented on the extent to which their lives had changed since their children's accident:

*'it's like somebody's just hit you over the head with a mallet. Because your life – our life was so full then. we were planning things.'* (N3:630-632).

*'And it's terrible, it's awful, and this doesn't figure in anything you read, that people's lives are torn apart by this.'* (N5:605-606)

ii) Lack of joined-up services

Many parents spoke about a lack of 'joined-up services' where after their child had returned from rehabilitation when parents were forced to take on responsibility for organising and providing for their children's needs.

*'...some things are so difficult to I mean it's so hard finding the people who are there to help you, it's just not very joined up at all, the sort of – the care that's available after the event. You largely stumble across things by accident'* (N2: 816-820).

This inquiry was conducted through the lens of social construction. Having spoken at considerable length to all parents about their experiences since their child sustained traumatic brain injury, perhaps Melanie and Paul poignantly sum up the 'feeling' with different perspectives that has been lost in translation from full and often emotionally charged interviews with parents in their homes, to edited text:

*'...nobody knows what – what's going to be ahead for you so. ...so never give up hope, because things can change, and they do change. Because your experiences are, in reality, different.'* (N7:956-961).

*'There is no finite finish, it's continuous. And it will continue.'* (N4: 1344-1345).

## DISCUSSION

The purpose of this study was to put parents at the heart of this thesis by enabling them to tell their stories about their experiences since their child sustained traumatic brain injury. As the majority of research within this area has used quantitative methods which have tested specific research hypotheses, this study aimed instead to

use a qualitative approach in order to gain a contextual “insider’s perspective” (Chamberlain et al., 1997). The length of parent interviews suggests that parents – mothers *and* fathers - had much to say.

Several main plots emerged: that parents are themselves traumatised in the process; roles played by mothers *and* fathers, and the fight for services that parents were forced to engage in throughout the process.

### **Vicarious Trauma**

Many parents reported difficulty in processing many aspects of their experiences – and used powerful metaphors (‘ploughing through blancmange’: going ‘numb’) to describe their reactions. There is an emerging literature where some investigators likening the experience of having a child sustain TBI as traumatic, with symptomatology comparable to those of posttraumatic stress disorder (Taylor, 2001). Colville and Gracey (2006) note that there has been increasing recognition in the recent literature of the impact of trauma on witnesses, where the threat to life or integrity of a loved one is itself sufficient to qualify as a traumatic event. Thus, some parents experiencing this event may themselves undergo trauma as a second-order factor. Colville and Gracey (2006) found that 18% of mothers scored above threshold for diagnostic criteria for PTSD. However, conclusions from their study are difficult as the authors highlight two main limitations of the study; a small sample size which limited the statistical power of the study and a low response rate.

### **Role of parents**

The finding in this study that mothers *and* fathers reportedly contributed consistently and positively to the care of their child is novel and important. This may be due to several factors, not least for example that fathers are generally excluded from paediatric research in general (Phares *et al.*, 2005). Wade *et al.*, (1995) suggest from their focus group research that the emotional reaction of fathers is different to that of mothers. They found that fathers ‘shut down’ emotionally, and consequently the mother is left with the burden of looking after the injured child. This has not been the finding here.

In the current study, fathers appeared to occupy specific roles in the process, from literally nursing their children in the ICU to wrestling with bureaucratic processes when their child returns home. This may also represent a broader issue of communication between parents where they negotiated their different roles in the process, where individual parents are aware of their skills in certain areas and have utilized them accordingly – at times in the face of great uncertainty and resistance from service providers. Numerous example of this were provided in narratives. Rivara *et al.*, (1992) found that a high level of family cohesiveness and positive family relationships were predictive of good child adaptive functioning 1 year following TBI. Many of the families in the current study could be described as ‘cohesive’, where communication and mutual support within family systems and teamwork were important in facilitating a positive transition.

While fathers have experienced and expressed similarly disturbing reactions, fears and emotions to those of their wives (particularly in the early stages), narratives indicate that fathers have none the less been ‘part of the team’ with their wives in performing various tasks related to their child’s rehabilitation. These tasks have varied in nature at different points and places throughout the process – and continue to do so.

Kazec *et al.*, (2003) argue that there is much to be learned from the broader inclusion of families in our conceptualisation of children and health. They note that historically, families of ill children tend to be viewed as disrupted, complicated, or even pathological. Perhaps the paediatric TBI literature is ahead of the ‘standard’ paediatric literature in this respect, as it is well documented that the way parents – including fathers – respond to the event is a significant determinant in outcome (Taylor, Yeates). The findings obtained here support the argument of Kazac et al (2003).

### **Fighting for services**

Given that supporting parents’ mental health is one of the underpinning assumptions of this study, and the emphasis on patient centred care espoused in Department of Health documentation (e.g., DoH, 1999: 2005), the finding that so many parents are left to fend for themselves and have to fight for services when they return home after rehabilitation is a finding of great concern. The finding that support is not routinely

available over the long-term can only add to an extremely stressful event and its long-term consequences, and add to parents' perceptions of being 'alone'. It raises many questions as to the lack of – and a major gap in - provision of services. There are however, exceptions to this. Where a case manager becomes involved, the role of this person appears to be one of organisation and co-ordination of services, a role which for many parents appeared to be a great relief to relinquish – especially after the acute and early rehabilitation phases. This seems only to happen where insurance companies are involved (from road traffic accidents).

Interviews suggest that the long term impact of childhood TBI – particularly the return home - is poorly recognised by services and is an area of clinical importance and service provision that represents urgent need of development. The fact that head injury was described as the '...foremost cause of death and disability in young people...' by the Parliamentary Health Select Committee as early as 2001 makes this all the more alarming.

## **CONCLUSIONS**

Parents themselves appear to often undergo a significant degree of trauma as a result of their child sustaining severe TBI. Because of this, they may have difficulty processing the event on cognitive and emotional levels. The finding that parents themselves undergo trauma will contribute to the emerging literature. As Colville and Gracey (2006) note, this is not surprising as the event of their child sustaining TBI is a very real threat to the life and integrity of their child, as well as their ongoing survival as a family.

Parents are primary caretakers of their children and face significant change and vicarious trauma when confronted with their child's TBI. Yet the services to support them through this deeply emotional and uncertain transition appear at best disjointed, and at worse, non-existent. This is perhaps the most alarming finding of the study.

That fathers played (and continue to play) an important and influential role in their child's rehabilitation is a major finding, and should give impetus to future research about the roles fathers play in the rehabilitation of their children.

One of several key plots within this study that unifies parent narratives is that parents go through a series of transitions – where mothers *and* fathers play a pivotal role – which culminates in fighting for services. It seems that what is needed throughout these transitions is a person or network of people with a broad skills base, who with sensitivity, empathy and warmth can guide parents through the minefield of service provision, and logistics. This may help alleviate the shock and turmoil of an experience that so dramatically changed the lives of parents and their families.

### **Strengths and Limitations of this study**

#### *Strengths*

That this study included fathers *as well as* mothers constitutes a methodological advance (Phares, 2003: 1992: Kazac et al 2003).

A qualitative narrative methodology was used which should add to and compliment existing qualitative and quantitative studies. This methodology enabled processes to be explored through a chronological sequence of events since before the injury. The method of analysis (Emden, 1998) enabled the researcher to summarise the data in a structured and organised manner, and then expand on this analysis as necessary to accommodate the evolving findings. Transcripts were returned to participants for ‘member checking’, which added to the trust worthiness and rigour of the process.

#### *Limitations*

Retrospective interviews were chosen to collect the data for the study. One possible limitation is the problem of retrospective data collection, which implies that memory reconstructions can be unreliable. One area to be considered is the influence of the researcher on the narratives produced. As narratives are bound within a context, it was impossible to be present at the interviews and not have an influence on the narratives. Despite the researcher not suspecting that he occupied many alternative roles within the interviews, other than researcher, research indicates that “characteristics” (age, gender, etc.) of a researcher can influence the narratives produced (Kirsi et al., 2004). Therefore, it needs to be remembered that such aspects of the researcher may have influenced the narratives produced.

Finally, participants were interviewed only once. Narratives were thus obtained at a 'snapshot' point in time. Resources were too limited to look at the possible evolution of parental narratives over time.

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