Posttraumatic stress after childbirth:
A qualitative account of the impact on relationships

by

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Where to start?....

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Finally to Stephen, words aren’t really enough. I think you deserve this more than I do. You’ve been a complete star. Hopefully now you’ll have your wife back x
ACADEMIC
DOSSIER
Summary of the Academic Dossier

This section contains four essays, intended to represent the range and depth of work covered over the three years. They are presented in the order in which they were completed. This is intended to demonstrate how my academic skills have developed over training. The four essays are from core client groups – adult mental health, people with learning disabilities, child and family and older people. They were selected to demonstrate a broader understanding of psychological theories, in the context of cultural, ethical and social issues.
Would there ever be a scenario in which a psychodynamic rather than a cognitive behavioural approach might be more appropriate in the treatment of obsessive-compulsive disorder?
INTRODUCTION

There are a number of similarities between cognitive behavioural and psychodynamic approaches to the treatment of obsessive-compulsive disorder. Both approaches include the opportunity to express one's thoughts, the opportunity to gain better self-understanding and involve the support of the relationship with the therapist (Luborsky, Digeur, Luborsky, Singer, Dickter & Schmidt, 1993). However the theories upon which both treatments are based are very different. With such diverse theoretical backgrounds, measures of outcome and effectiveness are hard to compare, although attempts are still made (Elton Wilson & Barkham, 1994).

This essay will begin by defining the terms psychodynamic, cognitive behavioural and obsessive-compulsive disorder (OCD). Diagnostic criteria for OCD as outlined in DSM-IV will be described and information regarding prevalence presented. The psychodynamic approach to treatment of OCD will be described and outcome studies discussed. The cognitive behavioural approach to understanding and treating OCD will be presented. Information regarding outcome studies using cognitive behavioural therapy will be discussed. Overlaps between the two approaches will then be discussed. It will be concluded that outcome studies favour a cognitive behavioural approach to treatment. However, this approach is not suited to everyone and it will be suggested that there are circumstances when a psychodynamic approach may be more appropriate in the treatment of OCD.
DEFINING TERMS

Psychodynamic

For the purpose of this essay ‘psychodynamic’ is understood to mean psychodynamic psychotherapy and is considered to be similar in form to psychoanalysis (Miller, Luborsky, Barber & Docherty, 1993). Bateman, Brown & Pedder (2000) state that all forms of psychodynamic therapy can be traced back to the work of Freud and psychoanalysis.

Psychodynamic psychotherapies have a number of concepts in common. Concepts such as conflict, anxiety or psychic pain, defence mechanisms, motivational drives, phases of development, models of the mind and the importance of the therapeutic relationship (Bateman et al., 2000). Psychodynamic therapy aims to provide conditions to increase the patient’s self-understanding and ‘resolve the patient’s main conflicts by means of working on transference and resistance’ (Miller et al., 1993, p.xx).

Cognitive behavioural approach

In a broad sense the term cognitive or cognition refers to the processes and apparatus that support thinking and in thoughts themselves (Wells, 1997). The cognitive behavioural approach’s main premise is that emotional disorders are the result of an individual’s distorted interpretation of events. These misinterpretations lead to behavioural change, which in turn maintain the distortions (Wells, 1997). In treatment the individual is helped to identify dysfunctions in thoughts and behaviour. Through discussion and behavioural assignments patients are encouraged to evaluate and
change their distorted thoughts and behaviours (Hawton, Salkovskis, Kirk & Clark, 1989).

Characteristics of therapy include an emphasis on the here and now, with therapy aiming to facilitate desired changes in patients’ lives. Terms are expressed clearly and goals defined explicitly. There is openness to therapy and the relationship between therapist and patient is seen as a collaborative one. Both partners are involved in planning strategies and problem solving (Hawton et al., 1989).

**Obsessive-compulsive disorder (OCD)**

OCD is an anxiety disorder, alongside phobias and anxiety states (de Silva & Rachman, 1992). Other terms used to describe the disorder include: ‘obsessive-compulsive neurosis’; ‘obsessive-compulsive illness’; ‘compulsive disorder’ or ‘obsessive (or obsessional) disorder’ (de Silva & Rachman, 1992). Historically it has been termed a ‘neurotic’ disorder, and thus been classified with less disabling conditions. However, OCD is considered one of the most difficult problems to treat (Emmelkamp, 1986) and severe OCD can affect people’s lives dramatically causing major disruption (de Silva & Rachman, 1992).

**DIAGNOSTIC CRITERIA OF OCD**

The diagnostic and statistical manual four (DSM-IV) (APA, 1994) states that essential features of OCD are recurrent obsessions or compulsions. These are severe enough to cause significant impairment, marked distress, to be time consuming (take more than one hour a day) or significantly interfere with social or occupational functioning or relationships with others. The individual with OCD must recognise at some point
during the course of the disorder that the obsessions or compulsions are unreasonable or excessive. If they occur alongside another disorder then the obsessions and accompanying compulsions should not be restricted to that area (for example, hair pulling in the presence of Trichotillomania or preoccupation with food in the presence of an Eating Disorder). In order for a diagnosis of OCD to be made, the disturbance must not be able to be accounted for in terms of the physiological effects of a substance (e.g. medication, drug abuse) or a medical complaint.

**Obsessions**

DSM-IV states that obsessions are persistent thoughts, ideas, impulses or images that are experienced as inappropriate and intrusive and lead to distress or marked anxiety. The individual is able to tell that the obsession comes from within his or her own mind. However, the content of the obsession is often perceived as 'alien' and does not appear to be in the control of the individual, nor is it the kind of thought they would expect to have (APA, 1994).

Common obsessions include continual thoughts about contamination (for example, being contaminated by a hand shake), a need to have things in a particular order (for example, objects placed symmetrically or to some other specified system and distress when this is disordered), repeated doubts (for example concern about having performed or not performed an act, turning the gas off, running over a pedestrian), horrific or aggressive impulses (for example to hurt a loved one or to shout obscenities in a religious establishment) and sexual imagery (for example a recurrent sexually explicit picture in one’s mind) (APA, 1994). These thoughts, images and impulses are
not related to everyday concerns for example school, work or family problems, and are not likely to be associated with a ‘real-life problem’ (p. 418).

**Compulsions**

Compulsions take two forms, either that of repeated behaviours (for example, hand washing, checking or ordering) or mental acts (for example, praying, repeating words silently or counting). The goal of compulsions is to reduce levels of anxiety or prevent its occurrence, rather than a means of deriving pleasure in the acts themselves (DSM-IV, APA, 1994). In many cases individuals feel compelled to complete a task in order to alleviate the anxiety provoked by the obsessional thought. For example an individual who has continual thoughts that they have not turned off the gas may reduce the anxiety this produces by being compelled to check every few minutes. Compulsions are ‘clearly excessive’ or not linked in a realistic way with what they are aimed at preventing (p.418).

Common compulsions include cleaning, washing, checking, counting, requesting or demanding assurances, ordering and repeating actions (DSM-IV, APA, 1994). When an individual attempts to resist the temptation to perform a compulsion the ensuing rise in anxiety and tension is often so aversive that this is eventually relieved by performance of the compulsion. In a chronic example of OCD the compulsions may have been resisted, yielded to and then been absorbed into part of everyday activities and routines.
Prevalence

OCD was considered to be relatively uncommon until the late 1980s, following community epidemiological studies conducted in America (e.g. Kano, Golding, Sorenson & Burnam, 1988). These studies found the lifetime prevalence rates of OCD to be between 1.9% and 3.3%, across five communities in the United States. Across five sites they found the one-month prevalence for males to be 1.1% and 1.5% for females. Similar results have been found for the British population. Bebbington (1998) reports that The British National Survey of Psychiatric Morbidity found one-month prevalence rates were 1% in males and 1.5% in females.

Although the standardised instruments used in epidemiological studies do not provide ideal measures of identifying individuals with OCD, such studies have been useful in highlighting the fact that OCD is more common than was previously considered (Bebbington, 1998).

PSYCHODYNAMIC APPROACH TO OCD

Psychodynamic therapies share the assumption that obsessions and compulsions are “symptoms of underlying unconscious problems” de Silva & Rachman (1992, p.75).

The aim of therapy is to bring to light these “buried” factors and resolve them.

The psychodynamic approach to OCD is based upon Freud’s observations in the early 20th century and very little has been added to the literature since then (Esman, 2001). Briefly, Freud’s theory is based on the notion of conflict; different aspects of the self are in conflict. The basic structure of the self contains three elements, the Id, Ego and Super-ego. The Id contains basic instinctual drives, for example sexual and aggressive
drives and is largely unconscious. The Ego is the conscious rational aspect of the self and is involved in external perception and intentional movement. The Ego’s role is to “referee” the conflicting desires of the Id and the Super-ego. The Super-ego represents the conscience and is the internalisation of standards laid down by parents, teachers and other similar figures (Bateman et al., 2000).

Many theorists have proposed stages through which individuals progress in their development. Freud’s psychosexual development proposed that individuals pass through a number of stages until they reach adult maturity. Each stage’s various aspects need to be successfully negotiated in order for the individual to function as a healthy adult. Difficulties faced at different stages of development can lead to an individual regressing to a former level, especially if conflicts at particular stages have not been fully resolved. The stages in Freud’s theory begin with the oral phase (age one or below) when the individual derives pleasure from the mouth. The anal stage (ages 1-3) is where pleasure is gained from mastering control of elimination or withholding of faeces. The phallic-oedipal stage (age 3-5) is when the child is aware of his or her own sexual differences and may develop a passionate attachment to the opposite sex parent, and have negative feelings towards the rival that stands in the way. Latency ends with puberty and is associated with a time of prudishness, when attentions are turned away from sexual interest. At puberty the sexual impulse is re-ignited and the genital stage begins (Bateman et al. 2000).

Freud’s theory of obsessive-compulsive disorder (or obsessive-compulsive neurosis) states that problems faced during the Oedipal situation leads people to regress back to the anal stage of defences. The anal stage is associated with bladder and sphincter
control – toilet training. Individuals may have taken a long time to master control, or experienced failures later on and are therefore ‘fixated’ or stuck at this stage of development (Freud, 1908). Although no associations have been found between obsessive traits and difficulties in the ‘anal’ stage of development, many of the clinical descriptions Freud made are still accurate and useful (Storr, 1990).

A key feature of psychodynamic theory is that of defence, this is the process by which the Ego defends itself against prohibited impulses or wishes from the Id. In OCD the impulse is usually aggressive or hostile in nature. Defence mechanisms act to keep such impulses out of conscious awareness and so reduce the associated anxiety and guilt (and other painful emotions) that their occurrence may produce. One main defence mechanism is that of repression. When this fails, other processes are brought into play (Tallis, 1995). Other defences include reaction formation, when individuals go to opposite extremes to hide true, unacceptable, feelings. An example would be excessive tidiness to conceal a desire to be messy (Bateman et al., 2000). Other defence mechanisms are isolation of affect, doing and undoing (Gabbard, 2001).

**Psychodynamic approaches to treatment of OCD**

As with other disorders, when working with a patient with OCD the psychotherapist has two tasks (Storr, 1990). The first is to assist in bringing to the surface the underlying instinctual impulses that the person is defending himself or herself against. The second task is to develop a relationship with the patient that is based on more equal terms.
The relationship between therapist and patient is an essential part of the process of psychotherapy (Bateman et al., 2000). The therapeutic relationship is seen as a safe place where experiences can be explored and understood. The therapist often acts as a mirror through which the patient is able to see himself, or how he sees others. A key aspect to the relationship is the use of transference. Individuals do not approach others as though they are ‘blank sheets’. Instead, they project experiences of past relationships on to others; this is known as transference. Within psychodynamic therapy transference is used to explore and examine past relationships, which may otherwise have remained unconscious (Storr, 1990).

The use of communication is also an important part of the treatment process. The extent to which non-verbal communication supports verbal communication can be a measure of how genuine the communication is. Discrepancies can alert the therapist to areas not yet discussed or are being avoided (Bateman et al., 2000). Putting thoughts into words makes them explicit and this can be a powerful experience when individuals have not had the opportunity to do this before.

In psychodynamic therapy the patient is actively involved in understanding themselves and their problems. By exploring the origin and meaning of the problems, the patient gains greater insight. In order to be therapeutic this insight and discovery then has to be associated with a process of integration and change (Bateman et al., 2000).

Obsessinal patients are often reported as being difficult to work with in psychotherapy (Storr, 1990). This is largely due to a tendency to intellectualise the
process, using words to distance themselves from emotions. They may acknowledge an interpretation as reasonable, but find it hard to take it on board in such a way as to lead to change. Such patients are likely to persist with therapy, but a tendency to look forward to the effects of therapy in the future may lead to a failure to fully participate in the relationship with the therapist in the present (Storr, 1990).

**Outcome studies**

Broadly speaking, outcome studies have found no differences between dynamic psychotherapies and other forms of psychotherapy (Luborsky et al., 1993). Some specific forms of treatment have been matched with patients with particular disorders. Luborsky et al. (1993) did not find a specific treatment to match patients with OCD.

However, until the 1960s it was generally acknowledged that there were two options for patients with OCD – psychosurgery or long-term hospitalisation. Indicating that before the advent of behavioural therapies, success with psychodynamically based therapies was limited (Edelmann, 1992). Indeed, despite a long history of treating OCD with psychodynamic psychotherapy, reports of a symptomatic cure are scarce (Gabbard, 2001). There are few systematic outcome studies of psychodynamic psychotherapy as a treatment for OCD (van Balkom, van Oppen, Vermeulen, van Dyck, Nauta & Vorst, 1994). Even those championing the cause for psychodynamic psychotherapy have admitted that it has little to offer those with severe symptoms of OCD (e.g. Storr, 1990).

One reason that psychodynamic approaches have not fared well in outcome studies is a lack of agreed diagnostic criteria. Psychodynamic approaches are reliant on
assessing personality type or character, aspects of psychological integrity and transference issues. Jacobson & Cooper (1993) argue these areas are not included in current DSM criteria. A reliance on “analysability” (which types of patients do well in therapy), as opposed to diagnostic specificity has meant psychodynamic approaches have lagged behind other treatment approaches in outcome research. Studies of “analysability” have failed to produce well-defined diagnostic categories that could reliably predict outcome or clear descriptions of the types of patients who would do well in analysis (Jacobson & Cooper, 1993).

Another difficulty faced by researchers into psychodynamic therapy is an agreement about meaningful outcome measures. Much outcome research uses measures of symptoms of the illness, for example the BDI (Beck Depression Inventory) measures symptoms of depression. Bateman et al. (2000) argue that the illness constitutes more than the symptoms. Psychodynamic psychotherapy is involved in unravelling complex human problems, of insight and personality change, not simply symptom reduction (Corvin & Fitzgerald, 2000).

Relying on reductions in symptoms as an outcome measure also excludes small, but important improvements. For example, while symptoms may remain, the lack of a suicide attempt could be a critical outcome of therapy (Bateman et al., 2000). Many therapeutic elements are hard to quantify and therefore measure (Corvin & Fitzgerald, 2000).

Esman (2001) highlights the current state of the contribution psychodynamic therapy to understanding and treating OCD. While Freud had much to offer in understanding
and interpreting the content of obsessions and compulsions, there has been little in subsequent literature to explain why some individuals go on to develop OCD and others do not.

**COGNITIVE BEHAVIOURAL APPROACH TO OCD**

Wells (1997) has argued that limited research, diverse theoretical concepts and the need for an established framework have led cognitive models of OCD to be underdeveloped. The number of theories and research interests is as diverse as the number of researchers (Wells, 1997). A dominant cognitive behavioural model of OCD disorder has been put forward by Salkovskis (e.g. 1999).

The cognitive behavioural model of OCD is based upon Beck's (1976: cited in Salkovskis, 1999) theory of emotion. This model proposes that the way emotions are experienced is a result of how events are appraised or interpreted (Salkovskis, Forrester and Richards, 1998). This implies that the same event can lead to different emotions in the same individual depending on the mood and past experiences of the individual, as well as the context (Salkovskis et al., 1998). People are more likely to interpret events in certain ways depending on the assumptions and beliefs that they hold. These beliefs were learned during an earlier period of their life and may have been useful in the past, but may not be helpful when facing a different challenge. Examples of beliefs include 'If I don't worry about things then everything will go wrong for me' and 'It is important to be perfectly calm at all times' (Salkovskis et al., 1998).
Beliefs about different areas have been associated with different conditions, for example beliefs about loss are associated with depression. If beliefs are concerned with danger or harm, then this may lead to anxiety. Specific beliefs are associated with particular types of anxiety, for example hypochondriasis, social phobia and panic. Beliefs and assumptions can be aroused when faced with life events or ‘critical incidents’ and can lead to a range of situations being interpreted in an excessively threatening way (Beck, 1976: cited in Salkovskis et al., 1998).

Salkovskis et al. (1998) also highlight the contribution that the consequences of the appraisal may have. The below equation highlights this (Salkovskis et al., 1998, p.56):

\[
\frac{\text{perceived probability}}{\text{of threat}} \times \frac{\text{perceived cost/awfulness of danger}}{\text{perceived ability to cope}} + \text{perceived 'rescue' factors}
\]

The perceived probability of something occurring may be quite high, but unless the individual attaches some danger to that occurrence then it is unlikely to result in increased anxiety. For example, someone may be quite certain that they had left their shed door unlocked, but may not feel unduly anxious unless they believed that the consequences would be dreadful (e.g. being responsible for an expensive lawn mower being stolen).
For individuals with OCD, concerns or fears are often acknowledged as being unfounded, but the awfulness of the consequences of the event occurring is so dreadful that anxiety is increased. The effects of risk and cost are moderated by the extent to which the individual perceives theirs, and others, ability to cope if and when the situation arose. People with OCD (and other anxiety disorders) often have distorted perceptions of theirs and others ability to cope (Salkovskis et al. 1998).

If individuals’ beliefs are associated with a suggestion that they are in some way responsible for harm or its prevention, then it can lead to an obsessional pattern of behaviour (Salkovskis, 1999). Individuals often interpret the occurrence and content of the intrusive obsessional thoughts as meaning they are in some way responsible for any harm that may befall themselves or others. Such interpretations lead to unfavourable mood, such as anxiety or depression, which leads to an increase in motivation to participate in neutralising (compulsive) behaviours.

Increases in unfavourable mood and in neutralising behaviours increase the likelihood of occurrence of obsessional thoughts, the perceived threat and perception of responsibility – which leads to a cycle of neutralising behaviours and negative thoughts (Salkovskis, 1999).

**Cognitive behavioural approach to treatment of OCD**

A crucial element in the treatment of OCD using a cognitive behavioural approach is the development of a shared understanding of the psychological basis of the problem. If a shared understanding of the problem is not reached it is likely that therapy will not succeed (Salkovskis et al., 1998).
Therapy is a combination of discussions explaining the processes involved in establishing and maintaining the OCD and in behavioural experiments (e.g. exposure and response prevention). Exposure and response prevention techniques involve patients being exposed to situations that would normally provoke compulsive behaviours, but being prevented from performing them (Edelmann, 1992). These techniques are used to assist patients to understand that ways in which neutralising behaviours (compulsions) maintain beliefs (Salkovskis, 1999).

Outcome studies of OCD with cognitive behavioural therapy

If a therapy is shown to be effective it does not necessarily follow that the theory upon which it is based is supported. However, questions would have to be asked of the theory if outcome studies showed a therapy to be less than effective (Salkovskis, 1999).

Meta-analyses of the treatment of OCD using cognitive therapy, behaviour therapy (a combination of exposure and response prevention) and cognitive behaviour therapy have found these therapies to be superior to placebo therapy (e.g. van Balkom et al., 1994). Abramowitz (1997) suggests that van Bolkem et al.'s conclusions may be based on an overestimation of effect size, so must be viewed with caution.

Abramowitz (1997) reviewed eight psychological treatment studies with randomly assigned patients. The effect size was calculated as the difference between control groups and the treatment group, a technique that Abramowitz says previous studies have failed to do. Abramowitz's findings largely support previous studies. He found
behaviour therapy (in the form of exposure and response prevention) to be highly effective in the treatment of OCD, and cognitive therapy to be as least as effective as exposure and response prevention techniques (Abramowitz, 1997).

Studies examining the effects of combined cognitive and behavioural techniques have found cognitive behaviour therapy to be effective in the treatment of mental acts (e.g. praying, counting etc.) as well (e.g. Freeston, Ladouceur, Gagnon, Thibodeau, Rheaume, Letarte & Bujold, 1997: cited in Salkovskis, 1999).

**CAN A PSYCHODYNAMIC APPROACH BE MORE APPROPRIATE?**

There are a number of similarities between psychodynamic and cognitive behavioural approaches to treatment. These include the opportunity to express one’s feelings to a supportive, non-judgemental clinician in an attempt to gain a greater insight into one’s problems (Luborsky et al., 1993). However, as can be seen above, the ways in which the therapist and client then proceed to tackle the problem are quite different in the two approaches.

For many OCD patients, giving up their symptoms is a challenge, but for some the special meanings and interpersonal control the symptoms exert on others makes them especially reluctant to do so (Gabbard, 2001). Many controlled outcome studies exclude such patients, due to their poor motivation or refusal to comply, so they are often not researched. While van Balkom et al. (1994) report more favourable drop-out rates for a combination of cognitive and behaviour therapy (5%), than for behaviour therapy (8%) and cognitive therapy (25%), it is clear that not all patients with OCD continue with cognitive behaviour therapy. Outcome studies, especially randomised-
controlled trials (RCT), have been criticised for using unrepresentative patients (e.g. Chiesa & Fonagy, 1999). A reliance on strict inclusion criteria, with patients with multiple or co-morbid problems excluded, has meant many results from RCTs cannot be usefully translated into clinical practice. According to Chiesa & Fonagy this places psychodynamic approaches at a disadvantage, as the trials do not adequately reflect the complex cases that are routinely seen in clinics.

Despite the relative lack of support from outcome studies Gabbard (2001) suggests that psychodynamic approaches have a role to play in the treatment of OCD. Psychodynamic therapy can help patients address relationship issues resulting from the illness. Identifying stressors and maintaining factors which have particular meaning to individuals with OCD may help both the patient and their family to be aware of precipitating events and try to reduce their impact.

Gabbard (2001) also stresses the role psychodynamic therapy can play in improving compliance to medication or behaviour therapy regimes. He stresses that greater understanding of the meanings of obsessive thoughts and of transference issues can help address these issues. A cognitive behavioural approach may argue that this is not necessary. The use of an idiosyncratic formulation of individuals’ difficulties goes some way to understanding the meaning of obsessions to that individual. Indeed Salkovskis’ (1999) approach focuses on the meaning and responsibility individuals take on in response to obsessional thoughts.

Gabbard (2001) argues that a psychodynamic approach can assist where individuals have a characterological dimension that may make them resistant to treatment of their
OCD. As Storr (1990) highlighted, individuals with characteristics associated with OCD can be very difficult to treat.

Cognitive behavioural therapy is not suitable for all individuals. If the patient and therapist are not able to develop a shared understanding of the problem from a cognitive behavioural perspective, then cognitive behavioural therapy is unlikely to be effective or appropriate. There may be occasions when an individual seeks therapy to explore long-standing issues. Psychodynamic approaches seek an understanding of the person in a developmental way, through the integration of what they were with what they are going to be. Some patients hope to gain an insight into their problems that leads to a sense of continuity of identity (Bateman et al., 2000). Psychodynamic psychotherapy promotes a continuation of this process even after the end of therapy sessions, as the patient has identified and understood their own way of working out problems (Richardson & Hobson, 2000).

Attempting to link the choice of therapy to a diagnosis is problematic, as individuals are more complex than that choice suggests (Bateman et al., 2000). It is important that the emotional maturity of an individual is considered. If the problem has its origins in an earlier stage of development, then it may be that longer term psychodynamic work is implicated (Bateman et al., 2000). Unlike other areas of medicine choice of therapy is very reliant on the individual client. The understanding a patient has of how his broken leg is fixed is not an essential part of the healing process. In psychological approaches the patient is an active participant and "it is essential that the therapy makes sense both to the patient and to the doctor" Balint and Balint (1961: cited in Bateman et al., 2000, p. 200).
CONCLUSION

Obsessive-compulsive disorder is more common than was considered in the past. Although often associated with less severe 'neurotic' disorders it can be severely disabling. Obsessions are persistent thoughts, images or ideas that are considered to be inappropriate and intrusive. The individual experiencing them can tell that the obsession comes from within their own mind, but the content is experienced as 'alien' or unlike any thought they would expect to have. Compulsions take two forms, either repeated behaviours or mental acts. By definition, compulsions are excessive and not linked in a realistic way with the obsessions they aim to prevent.

There are similarities between the psychodynamic and cognitive behavioural approaches to treatment, in terms of opportunities to discuss issues, support from a non-judgemental therapist and opportunities to gain a greater insight into oneself. However, how OCD is understood is very different for both approaches. The psychodynamic approach to OCD has its roots in Freudian theory and there has been little development since that time. Although there is support for psychodynamic psychotherapy in general, there is little in the research literature that supports a psychodynamic approach to OCD.

By combining cognitive techniques with the behavioural aspects of exposure and response prevention a cognitive behavioural approach is able to offer individuals with OCD significant hope of successful resolution of their symptoms and distress. However, despite support from outcome studies, there may be instances when individuals with OCD do not engage in cognitive behavioural therapy. While the cognitive element of the approach may offer detailed understanding of the meaning of
obsessive thoughts as part of an idiosyncratic formulation, it may be that individuals are looking for more than this. A psychodynamic approach to treatment may be more appropriate in circumstances where an individual is looking to examine longer-term issues. It may be that techniques employed by a cognitive behaviour approach are not suited to a particular individual. In these instances, a psychodynamic approach to treatment of OCD may be more appropriate.

In conclusion there is overwhelming support for a cognitive behaviourial approach to the treatment of OCD. However, there may be instances where individuals do not engage in cognitive behaviour therapy. Psychodynamic psychotherapy can offer an alternative and possibly support individuals in working towards accepting a cognitive behavioural approach.
REFERENCES


Should people with autism and a learning disability go on holiday?

What role might a clinical psychologist have in the decision making process?

Discuss with reference to aspects such as consent, specific impairments of people with autism and equal opportunities.

People with Learning Disabilities Essay

July 2002

Year One
INTRODUCTION

Individuals with autism can benefit as much as any one else from going on holiday (e.g. Meldrum, 1990). However, there are a number of important issues that may influence the decision making process. Clinical psychologists can have an important role to play in assessing whether individuals are able to make the decision themselves and facilitating this process. They are also well placed to take into account the specific impairments that individuals with autism have and how this may affect not only how decisions are made, but also how going on holiday is supported.

Initially the terms autism, learning disability and holiday will be defined. Then issues relating to consent, specific impairments of people with autism and equal opportunities will be discussed. The role the clinical psychologist has to play in this process will be highlighted throughout. This essay will conclude that clinical psychologists can have an important role to play in the process, but that ultimately whether an individual with autism and a learning disability goes on holiday depends on that particular individual’s needs and desires.
DEFINING TERMS

Autism

'Autism is a pervasive developmental disorder that is usually apparent from early childhood' (Volkmar, Stier, and Cohen, 1985; cited in Howlin (1998b, page 307). Diagnostic Statistical Manuals – Four (DSM-IV, cited in Cooper, 1997) states that individuals should have a qualitative impairment in social interaction (e.g. marked impairment in the use of non-verbal behaviour, failure to develop peer relationships appropriate to developmental level), qualitative impairments in social communication (e.g. delay in development of or lack of spoken language) and restricted repetitive and stereotyped patterns of behaviour, activities and interests (e.g. apparently inflexible adherence to specific, non-functional routines or rituals). These impairments are found in individuals with all levels of cognitive functioning and to varying intensity.

Checklists and assessment schedules are available (for example the Childhood Autism Rating Scale, Schopler et al.,1986 cited in Cooper, 1997), but the absence of any clear psychological or biological marker can make diagnosing autism problematic (Wing, 1997).

Learning disability

Following a review of definitions of 'Learning Disability' Dodd & Webb (1998) suggest that many definitions include some of the following aspects. That an individual has a learning disability if 'they have both an impairment of cognitive functioning and an impairment of social functioning that has been present since childhood’ (page 13).
Cognitive functioning is usually measured using the Wechsler Adult Intelligence Scale – the most recent edition being the WAIS-III (Wechsler, 1997). Revisions made between the WAIS-R (Wechsler, 1981) and the WAIS-III (Wechsler, 1997) have improved the floor of the test and made it more appropriate for use with people with learning disabilities (Kaufman & Lichtenberger, 1999). If an individual’s Full Scale IQ is below 70, then they are classified as having a cognitive impairment (Dodd & Webb, 1998).

Dodd & Webb (1998) neither found an agreed definition of social functioning in the literature, nor a universally approved measure. However, social functioning is usually understood to include two aspects – personal independence and social responsibility (Dodd & Webb, 1998). There are numerous measures that can be used to assess this aspect of a learning disability, for example the Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984, cited in Dodd & Webb, 1998) or the Hampshire Assessment for Living with Others (HALO) (Shackleton-Bailey & Pidcock, 1983, cited in Dodd & Webb, 1998).

‘High’ and ‘low’ functioning autism

The majority of individuals with autism have some learning disability (75%), with as many as half having an IQ below 50 (Howlin, 1998b). ‘High functioning’ autism is the term often used to describe those individuals who have the same types of behavioural abnormalities present in autism, but who have an average or above IQ (e.g. Gillberg, 1998). There are numerous similarities between those individuals with high functioning autism and Asperger’s Syndrome. While there continues to be some
debate as to the exact difference and similarity between the two, it is generally accepted that the two lie on the same continuum or ‘autistic spectrum’ (Wing, 1992).

Individuals with high functioning autism or Asperger’s Syndrome can face very different problems from those individuals who have a learning disability as well as their autism (Howlin, 1998b). This essay will therefore focus on those individuals classed as having ‘low functioning’ autism.

**Holiday**

The Concise Oxford Dictionary’s (1990) definition of a holiday is ‘an extended period of recreation, esp. away from home or in travelling; a break from work’.

Participation in recreation and leisure activities is valued greatly within our society. Such activities can provide opportunities to develop social relationships, promote confidence and positive self-concepts, as well as promoting physical health (Meldrum, 1990).

**Role of clinical psychologist**

The specific role the clinical psychologist has to play in learning disability services is in terms of the application of scientific process to everyday working i.e. assessment, interpretation, intervention and evaluation (Cullen and Tennant, 1992). The role also involves multidisciplinary working, which may include working with psychiatrists, speech and language therapists, occupational therapists, physiotherapists, nurses, carers and parents.
Clinical psychologists can make a contribution to the decision making process of whether an individual with autism and a learning disability should go on holiday.

CONSENT

Assessing capacity

In law, the assumption is that adults can make their own decision to give consent, unless it is proved otherwise (Making Decisions, 1999). Even if an individual chooses a course of action that is advised against by interested parties, they are able to go ahead with their decision. The only time it is possible to intervene legally is under the Mental Health Act (1983) – but intervention under the Mental Health Act can only be in relation to a person’s mental health issues. For example, In re C (1994, cited in Holland, Crichton & Robinson, 1999) a man detained in a special hospital with a diagnosis of schizophrenia had delusions that he was a doctor. He developed gangrene in his foot and medical opinion stated he ought to have his leg amputated. He disagreed with this course of action, and under the Act could not be forced to have the operation.

It is important that individuals have the autonomy and freedom to make decisions for themselves, when they have the ability to do so (Arscott, 1997). However, it is also essential that individuals are protected from making harmful decisions where they are not able to make decisions. The difficulty for health professionals often lies in balancing protection with autonomy (Arscott, 1997).
There are three approaches to determining capacity to consent: outcome, status (or diagnosis) and functional (Wong, Clare, Gunn & Holland, 1999; Arscott, 1997). The outcome approach takes into account the consequences of the decision an individual makes. While erring on the side of protection, this approach has been rejected by case law as it simply implies individuals are only able to consent if they accept the opinion of health professionals and does little to promote autonomy (Wong et al., 1999). The status or diagnosis approach uses the individual’s membership of a particular group or population as means of determining their competence. Whether an individual has a learning disability, autism, psychiatric diagnosis or dementia is used as a measure of competency (Arscott, 1997). Though a simple measure, this method is rarely used as it implies that all individuals making up a particular group share similar characteristics. It also fails to take into account context and the fact that individuals are able to make some decisions, while not able to make others (Arscott, 1997).

The functional approach to assessing capacity is the most commonly used in English Law (Law Commission, 1991, cited in Arscott, 1997). It is also that suggested by ‘Making Decisions’ (1999) the Government’s proposals for making decisions on behalf of mentally incapacitated adults. It allows for situations where an individual is able to make some decisions, but not others, and promotes the idea that wherever possible the individual’s decision-making abilities should be maximised (Making Decisions, 1999).

Making Decisions (1999) outlines three definitions aimed as assisting whether a person lacks capacity to consent. The first is concerned with whether an individual is ‘unable by reason of mental disability to make a decision on the matter in question; or
unable to communicate a decision on that matter because he or she is unconscious or for any other reason’ (page 8). It defines ‘mental disability’ as ‘any disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance in mental functioning’ (page 8). An individual is deemed ‘unable’ to make a decision due to mental disability if at the time the decision needs to be made the disability is such that the person is ‘unable to understand or retain the information relevant to the decision, or unable to make a decision based on that information’ (page 8, Making Decisions, 1999).

It also states that unless ‘all practicable steps’ are made to enable the individual to communicate their decisions, and this has proved unsuccessful, then the individual cannot be regarded as incapable of communicating their decisions (Making Decisions, 1999).

While this approach allows for the fluctuating nature of capacity, the need for regular assessment and the possibility of improving an individual’s abilities, there are some criticisms (e.g. Arscott, 1997; Wong et al., 1999). It can be time-consuming, as in theory it must be applied to every decision an individual makes (Wong et al., 1999). It is still unclear as to how concepts such as ‘understanding’ and ‘retaining relevant information’ should be assessed (Arscott, 1997).

There are issues specifically relating to people with learning disabilities that are also important when considering ability to consent. Individual factors include people’s verbal expression and understanding, their general cognitive functioning, memory and speed with which they process information (Arscott, 1997). Acquiescence is also high
in this population (Sigelman, Schoenrock, Winer, Spanhel, Hromas, Martin, Budd and Bensberg (1981), cited in Felce and Perry, 1995). There is the issue of power differentials – people have limited experience of asserting their own wishes and may not want to refuse treatment from someone who has power over them (Arscott, 1997).

Arscott (1997) also outlines some environmental factors that may exacerbate an individual’s difficulties. These include the medical context in which information is presented, the nature of the doctor/patient relationship and the way in which information is presented to clients. Any unfamiliar situation in which an individual is expected to make a decision may induce stress and anxiety, which may make decision-making harder (Arscott, 1997).

The clinical psychologist may have a role in highlighting individual and environmental factors that may influence an individual’s capacity to consent, perhaps to other people involved in the individual’s care. Clinical psychologists may also be involved in assessing an individual’s capacity to consent to a certain event/procedure. The Ability to Consent Questionnaire (ACQ) has been proposed as one way to assess people with learning disabilities capacity to consent to treatment (Arscott, Dagnan & Stenfert Kroese, 1999). The ACQ is comprised of three vignettes relating to different treatments requiring informed consent and a series of questions relating to the nature of the problem, alternative interventions, proposed treatment/procedure, risks and benefits, rights and options and impact of choices. The ACQ can be adapted for assessing capacity to consent in a particular circumstance, for example going on holiday. Arscott et al. (1999) suggest other measures including IQ and memory and verbal ability may also contribute to the assessment of capacity.
One criticism of the ACQ is that it is not ‘real life’ and has not been compared with individuals’ ability to consent in situations that provoke fear and anxiety and where perhaps power imbalances are key (Arscott et al., 1999). It has not been validated for people with autism, so may be difficult to use with this population. However an understanding of individuals level of functioning on IQ and verbal and memory ability may help to ensure information is presented in a way which will best facilitate understanding (Arscott et al., 1999) – and hence take all ‘practicable steps’ to enable an individual to make their own decisions.

‘Best interests’

For those who are deemed unable to consent, it is not possible for consent to be given on their behalf (Holland, Crichton & Robinson, 1999). For people with cognitive impairments there are allowances in common law that enable professionals to act within an individual’s ‘best interests’ (Holland et al., 1999). While it is good practise to ensure interested others are informed and happy with decisions made about an individual – if they do not agree then they have little recourse within the law.

Making Decisions (1999) proposes that in the case of individuals who are unable to make day-to-day decisions for themselves that under the ‘general authority to act reasonably’ others can act on their behalf. Under general authority any decisions made ‘should be reasonably believed by the decision-maker to be in the person without capacity’s best interests’ (page 10). Decisions can include paying bills, providing help with dressing and feeding, giving medication (Making Decisions, 1999). Decisions that no one is able to take on behalf of another individual, even when acting under
general authority include consent to marriage, consent to divorce, consent to sexual relations, discharging of parental responsibilities, consent to adoption or voting at an election (Making Decisions, 1999).

A clinical psychologist may be involved in assessing whether an individual is able to consent to going on holiday, may be involved in preparing information in such a way that all ‘practicable steps’ are taken so that they are able to make that decision. It may also be that in the case where an individual does not possess capacity to consent, that they may be involved in the process of deciding whether, under general authority, it is in the person’s ‘best interests’ to go holiday.

SPECIFIC IMPAIRMENTS OF PEOPLE WITH AUTISM

There are specific impairments that people with autism have, which may affect both the assessment of capacity to consent to going on holiday and the decisions regarding ‘best interest’ for those unable to consent.

Capacity to consent to research is significantly related to receptive language ability (Arscott, Dagnan & Stenfert Kroese, 1998) and verbal and memory ability has been found to affect ability to consent to treatment (Arscott et al., 1999). This has implications for the specific impairments of people with autism.

Individuals with autism have been shown to exhibit particular patterns of cognitive impairments, despite the great variability in cognitive abilities within the autistic population (Green, Fein, Joy & Waterhouse, 1995). Impairments specific to people
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with autism are seen in the selectivity and shifting of attention, abstraction of
information and reasoning, language (particularly social aspects) and social cognition.
Areas of functioning that are relatively preserved are visuospatial and sensorimotor
abilities, as well as abilities to sustain attention. In the area of language, aspects such
as phonology and grammar are also relatively preserved, along with the acquisition of
written language (Green et al., 1995). This pattern of impairments indicates that
individuals with autism experience specific problems over and above those that could
be explained in terms of their learning disability (Green et al., 1995).

Such specific cognitive impairments have implications when assessing for capacity to
consent to going on holiday and in supporting individuals with autism to make that
decision. Selectivity of attention may lead to difficulty attending to information
presented. Problems with reasoning and abstracting information will make evaluating
alternative actions and their consequences difficult, again making decision-making
harder. Language difficulties are often the most distinctive cognitive impairment in
autism (Green et al., 1995). Comprehension is often more impaired than function, so
people's language skills are often overestimated. An example of the types of language
difficulties people experience can be seen in a situation described by Howlin (1998b).
A young girl became extremely distressed and anxious when told that on an upcoming
trip to France she would be “going to sleep on the train” This changed to pleasure and
relief when she was told she would be “going to bed in the train” (Howlin, 1998b).

Personal accounts by people with high functioning autism have also demonstrated that
even people who use language and speech regularly can find verbally presented
information difficult to understand. For example Jolliffe, Lansdown & Robinson
(1992) in a personal account of someone with autism: ‘when somebody talks to me I have to really try and listen carefully, if I am going to stand any chance of working out what the words are’ (page 14).

These cognitive impairments mean that people with autism as well as a learning disability may need specific support to be able to make choices and decisions (Caldwell & Hoghton, 2000). Practical steps can be taken, for example initially it is important to ensure that the individual’s attention is gained then choices must be presented in an understandable and non-threatening way. It may be that other modes of communication can assist people’s understanding, for example gestures or objects of reference (Caldwell & Hoghton, 2000). It may be the role of the clinical psychologist to liaise with speech and language therapist colleagues to ensure that communication is facilitated in the best way possible.

Where individuals are not able to make the choice or decision for themselves, it may be that it must be decided whether or not it is in an individual’s ‘best interest’ to go on holiday. The need for routine and a resistance to change can be very apparent in people with autism (Howlin, 1998a) and may need to be taken into account when considering ‘best interest’. Reliance on routine and resistance to change can be seen even in very young children, who become distressed if, while out in their buggy, their parent chooses to deviate from the normal route (Howlin, 1998a). Changes that are usually enjoyed by others can be particularly anxiety provoking for people with autism, for example, school holidays, parties, Christmas. (Howlin, 1998a).
Ritualistic and stereotyped behaviours are ways in which individuals with autism deal with stress and anxiety (Howlin, 1998a). Jolliffe et al. (1992) state that even people with high levels of intellectual functioning rely on routine and rituals to help order ‘an unbearably chaotic life’ (page 16). Routines and rituals are likely to increase when people are placed under too much pressure and have been shown to increase in unfamiliar situations and with unfamiliar people (Runco et al., 1986, cited in Howlin, 1998a). Therefore stability of the environment is an important aspect in reducing these behaviours (Howlin, 1998a).

However, this does not mean that individuals with autism should be prevented from experiencing changes such as holidays. For some individuals any kind of change can lead to grave distress and anxiety, however, other individuals with autism find it is the unpredictable nature of change that is hardest to deal with (Howlin, 1998a). The role of the clinical psychologist may be to assess how much change an individual is able to accept and intervene by tailoring any holiday to take this into account. Interviewing key people in the individual’s life about how past changes have been dealt with and planning holidays to take into account particular interests may help.

If left to their own devices individuals with autism are likely to become increasingly isolated and engage in stereotypic and obsessive behaviours (Cooper, 1997), which cannot be regarded as being in an individual’s ‘best interests’. An essential feature of any treatment, or intervention for someone with autism is to ensure that they receive social interaction and the opportunity to develop social relationships (Cooper, 1997), going on holiday and having new experiences may provide the opportunity for this.
The clinical psychologist’s role may include supporting staff and the client to cope with the upcoming changes of going on holiday. Ways of facilitating this include using visual representations (calendars, pictures or written lists) of forthcoming events or activities – or planned alterations of the expected routine. Increasing flexibility in this way and using other behavioural interventions can help individuals to successfully handle gradual change in routine or environment (Howlin, 1998a; Cooper, 1997).

EQUAL OPPORTUNITIES

For many people with learning disabilities leading a life with limited opportunities for pleasurable and meaningful activities can result in experiencing behavioural problems and poor self-image that are not a result of their cognitive impairment (Reynolds, 2002). In 2001 the Government began to acknowledge these issues and published a White Paper outlining its strategy to ensure a cross-departmental approach to learning disability (British Institute of Learning Disabilities (BILD), 2002). The White Paper ‘Valuing People’ stresses four key principles ‘rights, independence, choice and inclusion’ for people with learning disabilities (Mitchell, 2001). Funding and development initiatives have been set up try to put some of these principles into practice (BILD, 2002).

All four principles may have implications for the decision about whether an individual with autism and a learning disability should go on holiday. The first principle (‘rights’) includes an individual’s right to be treated with respect by public services, as services may be involved in the decision making process, it is important individuals decisions are treated with respect. The second principle highlights the aim the
Government has that public services will support independence, this may have implications for service providers conflicting role of protection and autonomy (e.g. Arscott, 1997). Individuals’ right to make choices and be facilitated to make choices - this is what we have been talking about with regard to making decisions. The fourth principle is inclusion and includes people being part of the ‘mainstream’ and being able to do ordinary things and be fully included in the community (BILD, 2002).

For workers in the field of learning disabilities many of these ideas are not new. Wolfensberger has been advocating similar approaches through his principles of ‘normalization’, and ‘Social Role Valorization’ (SRV) (e.g. Wolfensberger, 2000). A key assertion of SRV is that people’s welfare is dependant on the roles they occupy within society. If people fill roles that are positively valued by others, then they will generally be ‘afforded by the latter the good things in life’ (Wolfensberger, 2000, page 105). If people fill roles that are perceived in a negative way by others, then they will be treated badly by them. According to Wolfensberger (2000) by somehow upgrading the social roles occupied by those who are devalued by others, then it is possible to improve quality of life. Both principles of ‘normalization’ and Social Role Valorization have had a great impact on how people with learning disabilities live, for example in the types of activities people are encouraged to engage in (age-appropriate, culture appropriate), the language used to describe people with learning disabilities, and in supporting people to wear clothing that fits and is age appropriate (Wolfensberger, 2000).

Unfortunately the underlying ideas of normalization and SRV are often misrepresented and individuals with learning disabilities have been encouraged to
participate in leisure activities that are ‘statistically normative’, rather than having
been chosen by the individuals themselves (Beart, Hawkins, Stenfert Kroese,
Smithson and Tolosa, 2001). It is worth remembering “one man’s work is another’s
leisure”, for example, an individual may really enjoy sweeping the garden path, while
to others it may be seen as a boring ‘work-like’ task (Meldrum, 1990).

Meldrum (1990) highlights numerous difficulties in applying normalization and SRV
to services for people with autism. Generally there is a lack of understanding as to
what the concept means and is often taken as meaning to make people ‘normal’.
While being compounded by attitudes generally to disability, this is further
confounded by the specific problems that people with autism have around
socialisation. There are also difficulties with lack of resources, supporting individuals
in the development of these principles requires a lot of one-to-one support, which is
costly. This has been supported by research into accessing leisure for people with
barriers to experiencing and participating in leisure activities for people with learning
disabilities tend to include lack of availability of staff, poor staff morale and difficulty
identifying types of activities individuals would like to engage in.

Organisational difficulties such as poor staff morale, which may impact on difficulties
identifying activities, are issues that Meldrum (1990) also highlights. While managers
may show a commitment to normalisation, inclusion and access, staff who are already
dealing with challenges of working with people with autism, may see this as one
hurdle too many (Meldrum, 1990). Lack of training and relative isolation may
compound these problems. Such difficulties are mirrored in family settings too, with
parents of adult autistic children settling for an ice cream in the park as being like ‘holiday time... as there is no point in going anywhere’ (Gray, 2001, page 1252).

There are also client-centred difficulties. Trying to reduce the ‘differentness’ of the person with autism (while simultaneously increasing the public’s degree of acceptance of differentness) is an uphill struggle. Some people with autism have already been placed into specialist services that set them apart from other people, which may compound the problem of social integration. Additionally, there are the factors influencing the capacity of people who are autistic to adapt to society. This ability depends on three main skills: being able to think and to use language; being able to handle interpersonal relationships effectively; being able to live independently in terms of self-care and vocational activities. All of which are particularly difficult for people with autism and a learning disability (Meldrum, 1990).

Although these hurdles seem high, it is such issues that services need to be aware of and try to overcome in order for individuals with autism and a learning disability to access ‘ordinary’ living. Clinical psychologists may have a role to play in working with staff teams around the best ways to facilitate this, in light of the challenges they already face. They may also be involved in advocating on an individual’s behalf for access to increased resources.

However, it may equally be the role of the clinical psychologist to assert the rights of individuals to make their own choices about going on holiday. Although in keeping with public and ‘normal’ conventions, it is as equally important that individuals are treated as such, and if going on holiday induces increased anxiety and distress, then
surely it is within the rights of the individual to not go through that and to stay at home. There is a difficult balancing act between social inclusion and equal access to opportunities, and individual needs, wishes and choices.

Howlin (1998a) suggests that thinking creatively about how individuals with autism are supported may be the answer. She asks why put people through unnecessary distress? It may be that having a ‘break from work’ or ‘time away from home’ is feasible, as long as individual needs are taken into account. Being flexible as to what a holiday consists of, starting with day trips and increasing these as they become more acceptable, and ensuring people have access to things they are particularly interested in may all help the process run smoothly.

CONCLUSION

Should people with autism and a learning disability go on holiday? What is the role of the clinical psychologist in the decision making process? Individuals with autism and a learning disability are entitled to the same rights and opportunities as any other member of society. Society values the opportunity to spend time away from mundane tasks and to go on holiday. Where possible individuals with autism and a learning disability need support to make choices about whether or not they would like to go on holiday. Clinical psychologists have a valuable role to play in assessing whether an individual is able to make that decision and in supporting them to do so. While the specific difficulties that people with autism have may make understanding and making these decisions difficult and the change itself difficult to cope with, it is not impossible. For many people with autism and a learning disability support and
awareness of that change will be sufficient to enable them to go on holiday. For others, a change as large as a holiday could prove too stressful and anxiety provoking. So for those individuals it may be necessary to think about changing the concept of a holiday to meet their needs – either by reducing the length of time away, ensuring important objects are taken with the person or arranging for the holiday to involve something the person is really interested in. To conclude, the clinical psychologist has an important role to play in ensuring individuals are supported to make their own decisions about whether or not they go on holiday, where possible and in facilitating this. They also have a valuable contribution to the question of whether it is in an individual’s ‘best interests’.
REFERENCES


Critically discuss any two psychoanalytic concepts that a Clinical Psychologist might use to enhance their understanding and practice in work with children.
INTRODUCTION

Two psychoanalytic concepts that a Clinical Psychologist might use to enhance their understanding and practice in work with children are attachment and containment. Initially the term psychoanalysis will be defined; there will then be a brief discussion of psychoanalysis' relationship with children. The concept of attachment will be discussed; it will be presented as a psychoanalytic concept, distinct from Bowlby's Attachment Theory. There will be some discussion of the relationship between Attachment Theory and attachment as a psychoanalytic concept. There will be a discussion of the necessity of the two areas to work together. Examples of the importance of attachment will be presented and how a Clinical Psychologist might use attachment when working with and understanding work with children.

The second psychoanalytic concept that will be discussed is containment. Initially this will be defined and discussed. Examples of the misuse of the term will be discussed. Criticisms of the concept will be presented. An example of its use in clinical practice will be given, both as a process where the developing child's anxieties have failed to be contained by its mother and also as a therapeutic process.

There will be some discussion of psychodynamic work with children and young people in general with reference to evidence-based practice. It will be concluded that there is little evidence to support psychodynamic approaches generally and even less for specific concepts such as attachment and containment. However an important distinction to be made when looking at outcome studies is the difference between effectiveness and efficacy and this will be briefly discussed. There is support for
aspects of attachment from within developmental research and despite limited evidence to support the effectiveness of the process of containment both concepts continue to be used when working with children.

The terms psychodynamic and psychoanalytic will be used interchangeably.

**Psychoanalysis**

The root of all psychoanalytic thought lies with Sigmund Freud, who not only developed a particular psychotherapeutic technique, but also proposed a set of theories of, amongst other things, development and psychopathology (Lemma-Wright, 1995). Central to psychoanalysis is Freud’s idea that beneath our consciousness there are processes at play that influence our behaviour over which we have no control, or knowledge of. The idea that such unconscious processes existed and that they were largely sexual in nature was rather abhorrent to much of society in the early twentieth century when Freud was developing his theories. It is not surprising, therefore that his theories were greeted with controversy (Lemma-Wright, 1995).

Despite the controversy, Freud’s influence on psychoanalysis continues and aspects of his ideas underpin every school of psychoanalytic thinking. However most schools have developed and evolved his original theories into new theories of development and personality (Lemma-Wright, 1995).
Freud and children

Despite his theories of psychosexual development and personality development being based on childhood experiences, Freud had little direct clinical experience of children. He drew on his own experiences of childhood and those of his children, but his theories of child development were based largely on the recollection of adult patients (Hinshelwood, 1991). When he decided to put his ideas to the test on real children he asked colleagues to note observations of their own children. One of his most famous child cases, of Little Hans, was actually based on the short hand notes of observations of Little Hans by his father (Hinshelwood, 1991).

Freud’s reluctance to work directly with children, either therapeutically or for research purposes was emulated by his followers at the time. It was not until people like Melanie Klein and Freud’s daughter Anna that psychoanalysts began to work more directly with children (Hinshelwood, 1991).

ATTACHMENT

Attachment as a psychoanalytic concept

A key aspect of psychoanalytic theory is the importance given to relationships, particularly to the first relationship. In our society this first relationship is invariably with the mother (Lemma-Wright, 1995). Freud (1938) described the relationship the child has with his mother as ‘unique, without parallel, laid down unalterably for a whole lifetime, as the first and strongest love-object as the prototype of all later love relationships, for both sexes’ (cited in Hopkins, 1990, p 465). Freud saw attachment as a secondary drive, derived from the mother’s gratification or frustration of instinctual needs (Carlson & Sroufe, 1995).
It was a new school of psychoanalysis, the object-relations theorists (e.g. Fairburn, 1952, Guntrip, 1961, Winnicott, 1965, cited in Bateman, Brown & Pedder, 2000) who began to identify the importance of the motivational drive to seek relationships with others (Bateman et al., 2000). Contrary to previous understanding about the nature of motivational drives, object-relations theorists suggested that the drive for relationships with others is present throughout life, but that it is the developmental stage that the person is at, that determines how this is shown (Bateman et al., 2000).

Holmes (1993) suggests the term 'attachment', as a psychodynamic concept, has both experiential and theoretical overtones. He defines it as a term that refers to the quality and condition of an individual’s attachments. Holmes states that these can be divided into secure and insecure attachment. The experience of feeling attached is to feel secure and safe. In contrast, the feelings of an insecurely attached person are likely to include a mixture of intense love and dependency, irritability, vigilance and fear of rejection, in relation to their attachment figure (Holmes, 1993).

From a theoretical perspective, Holmes suggests that their lack of security has ‘aroused a simultaneous wish to be close and the angry determination to punish their attachment figure for the minutest sign of abandonment’ (Holmes, 1993, page 67-68). This type of insecure attachment is known as ‘ambivalent insecurity’ (Holmes, 1993).

Support for different styles of attachment can be found in research. Ainsworth, Blehar, Waters & Wall (1978, cited in Carlson & Sroufe, 1995) developed a procedure for assessing individual differences in the quality of attachment relationships. The
procedure, known as the ‘Strange Situation’ (Ainsworth et al., 1978, cited in Carlson & Sroufe, 1995) is laboratory based and consists of eight elements. 1- the caregiver and infant enter a sparsely decorated room, that contains age-appropriate toys; 2- the infant explores the room, with the caregiver present, sitting in a chair; 3- a stranger enters the room, sits quietly, then begins making conversation with the caregiver, then interacts with the infant, taking cues from its reactions; 4- the caregiver leaves; 5- the caregiver returns, then the stranger leaves quietly; 6 - the caregiver leaves the infant alone; 7- the stranger returns and tries to comfort the infant if needed; 8- the caregiver returns (Carlson & Sroufe, 1995).

The procedure is intended to simulate every day situations that 12-18 month old infants in Western societies encounter on a daily basis. Differences in the quality of relationship with the caregiver are coded with respect to the extent to which the infant gains comfort from the caregiver’s presence and uses the caregiver as a secure base from which to explore. An effective attachment relationship is demonstrated by the infant readily leaving the caregiver to go and explore and by being comforted by the caregiver when distressed. An ineffective relationship is described as being when the infant cannot separate to go and explore and does not seek or gain comfort from the relationship when distressed (Ainsworth et al., 1978, cited in Carlson & Sroufe, 1995).

Bowlby’s Attachment Theory
Holmes (1993) has found it useful to distinguish between the interrelated aspects of attachment, attachment behaviour and attachment behavioural system. He suggests that these broadly divide into the psychodynamic, behavioural and cognitive aspects

Attachment Theory has its roots in psychoanalytic theory (Cassidy, 1998), though at various times, neither Bowlby nor the psychoanalytic establishment have acknowledged this. Bowlby was a trained psychotherapist and continued practising as such (Steele & Steele, 1998), one of his supervisors was Melanie Klein (Holmes, 1993). Bowlby developed psychoanalytic ideas, drawing on other disciplines, such as evolutionary theory, ethology and biology to develop Attachment Theory (Steele & Steele, 1998). Attachment Theory caused a major stir among psychoanalysts at the time it was developed. When Bowlby presented it to the British Psychoanalytic Society in the 1950s he faced rejection and hostility (Holmes, 1993).

A major and irreconcilable split occurred with Melanie Klein over the weight Klein gave to unconscious processes. Bowlby argued that environmental factors had a significant role to play in causing a child’s disturbance. Klein continued to attribute such disturbance to unconscious processes stemming from the child’s appreciation of the object of the mother. Bowlby was criticised by his psychoanalytic colleagues for paying little attention to such unconscious processes, in effect rejecting the very essence of psychoanalysis. He continued to argue for the importance of actual experiences. He suggested that the infant is psychologically and biologically determined to seek out attachment figures and will not respond with fear or hate unless actually mistreated by the caregiver. This is in sharp contrast with Klein’s view that the infant’s relationship with its mother is heavily tinged by anger, frustration and
suspicion following inevitable moments when the mother does not respond to its needs immediately or satisfactorily (Steele & Steele, 1998).

**Attachment – a foot in two camps?**

Despite such fierce animosity between psychoanalysts and attachment theorists much has been written about the similarities between the two and how they both may contribute to increasing our understanding of that first relationship and its importance on subsequent development (e.g. Steele & Steele, 1998; Fonagy, 2001).

Bowlby drew extensively on Freud’s work, particularly the importance of early experience and early relationships (Carlson & Sroufe, 1995). Contrary to Bowlby’s criticism, modern psychoanalysis shares the key assumption with Attachment Theory that the relationship between the infant and caregiver is not founded solely on physical needs, but on the need for a relationship (Fonagy, 2001). In many ways psychoanalysis has caught up with Bowlby in this respect (Steele & Steele, 1998).

There are numerous instances in psychoanalytic writing where the concept of attachment has been described using different language (Fonagy, 2001). Erikson’s concept of ‘basic trust’ (Erikson, 1959, cited in Fonagy, 2001) describes attachment processes. For example in how it is derived from early infant experiences and is mediated by the quality of maternal relationships, rather than by oral gratification or demonstrations of love. He also describes how failure of basic trust can lead to the development of the converse of the ‘healthy personality’ (Erikson, 1964, cited in Fonagy, 2001). Even Anna Freud, who was completely opposed to the theory,
describes attachment behaviours in her accounts of the impact of separation of children in wartime (Fonagy, 2001).

Klein also identifies the anxiety that small children feel when separated from their mothers as she observed in 1932 – 'I have over and over again found that in older children the absence of their mother reactivated the earliest anxiety-situations under whose pressure they had, as small children, felt her temporary absence a permanent one' (p.179, cited in Steele & Steele, 1998, p. 101).

Although there are agreements regarding the nature of attachment relationships and the importance such relationships to later mental health, the underlying reasons for this differ considerably for psychoanalysis and Attachment Theory (Fonagy, 2001).

**Criticisms of psychoanalytic attachment**

A key psychoanalytic expectation is that the infant's relationship with its mother will predict subsequent relationships, specifically, that of the father-infant relationship (Hopkins, 1990). The importance of the mother-infant relationship has been supported by Main, Kaplan & Cassidy (1986, cited in Hopkins, 1990). They found that six-year olds' representations of attachment (as demonstrated using projective tests) were based upon their relationships with their mothers, not with their fathers.

However it has been shown that the child's relationship with its mother is not the prototype for attachment to the father (Hopkins, 1990). For example Steele, Steele & Fonagy (1996) (cited in Steele, 2002) observed 96 infants in the 'Strange Situation' with mother at 12 months and father at 18 months. Both parents had completed the...
AAI (Adult Attachment Interview) prior to the birth of their child. The AAI (George, Kaplan & Main, 1985) examines adults’ thoughts and feelings about their attachment to their own caregivers (Steele, 2002). Steele et al (1996, cited in Steele, 2002) found that mother-infant interaction was predicted by the mother’s attachment interview. They also found that the father’s interview predicted father-infant interaction, but interestingly this was independent of the infant’s attachment relationship with mother. Clearly this does not support Freud’s premise that the mother-infant relationship is the model for all further relationships (Steele, 2002).

Although this does not support the psychoanalytic proposition that all relationships stem from the one with the mother, Steele (2002) states that follow-up studies have demonstrated that it is the infant’s relationship with the mother that has unique long-term influences on the emotional inner-world. For example it is in the mother-infant relationship where the child gains an understanding of complicated feelings. As opposed to the father-infant relationship, where the child learns outer-world social lessons, such as functioning in peer relationships (Steele, 2002).

Hopkins (1990) identified three key reasons why psychoanalysis should take more note of Attachment Theory. The first is a wish not to be left behind - Attachment Theory has stimulated a significant move forward in ideas of developmental psychology. The second is research - there has been a wealth of research into child development that has been stimulated largely by Attachment Theory. The third is prevention of mental health problems – research into attachment has increasing relevance for prevention. Hopkins (1990) also adds that more can be learned about the developmental psychopathology by combining psychoanalytic ideas and insight with
observations from Attachment Theory. There is evidence that psychoanalysts have
taken this advice on board, as articles and books such as Fonagy’s (2001) *Attachment
Theory and Psychoanalysis* suggest.

In turn, there is much that psychoanalysis can offer Attachment Theory. Steele &
Steele (1998) suggest that psychoanalysis has much to offer in terms of theory, to the
field of Attachment Theory and by combining the two it may be possible to acquire
fresh insights into developmental research (Steele & Steele, 1998).

**Why is attachment important? Examples of use**

Effects of early attachment can be seen in later childhood, studies have shown that
insecurely attached one year old children showed more behavioural and social

Many links have been made between early attachment relationships and subsequent
mental health problems (Carlson & Sroufe, 1995). Individuals who are insecurely
attached may be at greater risk of developing psychopathology, in the complex
interplay between environmental and biological factors. These factors may make them
more likely to respond to stress in an adverse way, increasing the vulnerability to
mental health problems (Carlson & Sroufe, 1995).

So assessing the quality of children’s relationships with caregivers, attachment, is an
important aspect of a clinical psychologists work with children.
CONTAINMENT

A definition

The concept of ‘containment’ is based on the Kleinian notions of projective identification and introjective identification (Hinshelwood, 1991). Projective identification is the largely unconscious process by which a person tries to rid themselves of difficult or unwanted parts of themselves, by projecting it into another (Miller-Pietroni, 1999). The process of containing another’s unwanted material is called introjective identification. This is not necessarily recognised at a conscious level and is often felt somatically before it is psychically recognised, if it is dealt with at a conscious level at all (Miller-Pietroni, 1999).

Bion’s (1962 cited in Fonagy, Target, Steele & Gerber, 1995) work distinguished between two forms of projective identification. The first is the violent expulsive form, where the meaningless, useless part of the mind is simply expelled, with the state of the object (in this case the mother or therapist) not considered. The second, and less pathological, is the communicative form. This involves the expectation and ability to allow the object to perform certain functions (Hinshelwood, 1994) and may underpin the normal processes of understanding and empathy (Fonagy et al., 1995).

Bion (1959) was aware of the communicative aspect of projective identification through times when it did not succeed (Hinshelwood, 1994). He proposed what Hinshelwood (1991) describes as a ‘mature’ description of containing, the process of containment. Bion (1959) describes a patient who uses the process within therapy: ‘When the patient strove to rid himself of fears of death which were felt to be too powerful for his personality to contain he split off his fears and put them into me, the
idea apparently being that if they were allowed to repose there long enough they would undergo modification by my psyche and could then be safely reintrojected’. (Bion, 1959, pp.103-104, cited in Hinshelwood, 1991).

Containment is therefore, according to Bion, a process by which the container (be that therapist or mother) transforms difficult communications (confused, violent, painful, inarticulate) by taking them in, mulling them over and detoxifying them and handing them back in a form that the individual is able to bear (Miller-Pietroni, 1999).

The term ‘reverie’ was used by Bion (1962, cited in Hinshelwood, 1991) to describe the state of mind the container had to be in, in order to adequately accept the infant’s projective identification. The mind of the container must be in a state of reflective calm, but reverie describes the process of the container making some sense of infant’s terror and anxiety that it has projected into her (Hinshelwood, 1991).

Winnicott (1960, cited in Hinshelwood, 1991) describes a state of readiness of the mother’s mind to accept the infant’s anxiety that resembles in part Bion’s description of reverie. Hinshelwood (1991) suggests that the concepts are clearly different as they come from different theoretical backgrounds. He suggests that Winnicott’s holding is ‘to support the infant’s unwavering belief in his own omnipotence’ (Hinshelwood, 1991, p420). He argues that Bion’s reverie is the attempt by the mother to ‘provide a containing function of understanding the infant’s reality in order to support his loss of omnipotence’ (Hinshelwood, 1991, p421).
In contrast Lanman (1998) suggests that containing and holding are on the same continuum, but have a slightly different emphasis. She argues that Bion's containment is by far a more active process, with the container transforming and processing the infant's projected state of mind. Holding, on the other hand, though far from passive is described as more of an acknowledgement of knowing and understanding the infant’s anxiety by the mother or therapist (Lanman, 1998).

The process of projective identification seems to be a vital element in developing emotional contact with others who also have an intrapsychic world (Hinshelwood, 1994). If a projective identification is rejected, containment is not successful, it can result in a serious disturbance in someone who was already highly anxious or distressed (Hinshelwood, 1994). In the case of the infant: 'If the projection is not accepted by the mother the infant feels that its feeling that it is dying is stripped of such meaning as it has. It therefore reintrojects, not a fear of dying made tolerable, but a nameless dread.' (Bion, 1962a, p.116, cited in Hinshelwood, 1994).

It is important to understand the processes involved when the container fails to contain. This failure can lead to difficulties in the development of the mind and it may also be a source of aggression (Hinshelwood, 1994). The caregiver's capacity to contain and deal with, not to be overwhelmed by the distress is central to the notion of containment (Fonagy et al., 1995).

**Misrepresentations and misuse of the concept of containment**

The concept of containment is often misrepresented and has been used commonly and inappropriately by those in the 'helping professions' (e.g. Lanman, 1998, Miller-
Pietroni, 1999). According to Lanman (1998) its use often implies a theoretical underpinning, perhaps to explain why a piece of work has been successful. However, it is often used colloquially and as such has become misunderstood and seriously weakened as a result (Lanman, 1998).

One consequence of this is that it is often used without proper reference to the unconscious processes at play. It is often used to describe the process by which the counsellor or therapist receives and responds to the client’s description of the problem. Responding to the presenting problem is, according to Lanman (1998), like one who is ‘behaving in a similar way to the mother who expects the baby to know what is the matter’ (p. 467). Lanman (1998) argues that the other, be it therapist or mother, is necessary to help process what is largely unconscious.

**Criticisms of containment**

Containment’s occurrence in early infant-hood makes a number of assumptions about the abilities of such young children. One assumption of containment, as a communication, is that infants are able to understand that the object (into which they are depositing their ‘difficult emotions’ through the process of projective identification) has a mind too. Admittedly this is not a conscious process. However, this is not in keeping with what we understand of the development of the mind, which is usually considered to move from an early stage of physical perceptions towards a more mature sensitivity of other’s minds at a later, more mature stage (Hinshelwood, 1994).
Meissner (1980, cited in Hinshelwood, 1991) argues that the use of the term projective identification outside the arena of a description of psychotic patients has lead to the term becoming meaningless. He argues that its use in relation to containing and containment is an extremely loose use of the term. In this context projective identification is used to describe any relational or cognitional phenomenon where there are common themes of 'relation, containment or implication' (Meissner, 1980, p.59, cited in Hinshelwood, 1991, p.201). Meissner argued that unless the term is confined to its use in relation to psychotic experience, then it relapses into 'projection' and leads to confusion (Hinshelwood, 1991).

However, despite Meissner's (1980, cited in Fonagy et al., 1995) criticisms of the use of the term projective identification it continues to be used as it is valued clinically (Fonagy et al. 1995).

**Containment in practice**

The use of the concept of containment as a way of evaluating parent-child relationships is an example of how containment can be used by clinical psychologists working with children and families. Clinical psychologists may use the term containment to describe the ability of the primary caregiver to contain the child's anxieties. Another way in which a clinical psychologist may use containment is as part of the therapeutic process, in that the therapist demonstrates an ability to contain the anxieties of a child, family or other system (e.g. Sprince, 2002).

An example of the use of containment as part of the therapeutic process can be seen in Sprince (2002). She used the concept of containment at an organisational level with
work with ‘uncontained’ adolescents. She worked in various residential schools for children with emotional and behavioural difficulties.

Her initial work with individual children, she saw as some kind of trial by terror, with teachers referring some of the most frightening and disturbed children to ‘test’ her out. Her observations of the systems within the school in general highlighted the fact that the adults were experiencing similar levels of terror. The adults were unable to engage with the children on an emotional level largely, she hypothesised, through fear of the feelings invoked in them. Sprince (2002) describes work she undertook developing groups for staff which looked at supporting them to contain the feelings projected into them by the children in their care. By acknowledging and discussing such feelings, these staff members were themselves ‘contained’ and could therefore go on to work with the children in an emotionally sensitive way.

Sprince’s (2002) article describes the work undertaken in a school that is a conglomeration of many schools she has worked in, to preserve confidentiality. Although she has not used standardised measures of evaluation, there are objective measures of the benefit of such intervention. The support and maintenance staff began by keeping a record of the cost of repairing damage to the buildings – replacing curtains, fixing stuffing falling out of chairs etc. There were also records kept of the disturbances reported from the nearby village, which initially had borne the brunt of the school’s inability to recognise and deal with its children’s indiscretions. Both repair bills and complaints from the village reduced dramatically following the intervention. There were also more qualitative changes, with staff and pupils feeling safe to discuss and address their feelings and an openness that allowed this process to
occur. This is a useful example of how containment can be used therapeutically in working with children and how it can inform formulation and understanding of processes.

Containment continues to be seen as useful clinical concept and has strengthened the links between cognitive development and emotional disorder. This process, according to Fonagy et al. (1995) can only continue to enhance advances in the field of developmental psychopathology.

EVIDENCE FOR USE OF PSYCHOANALYSIS WITH THIS POPULATION

Although there is evidence to support the types of attachment relationships (e.g. Ainsworth et al., 1978, cited in Carlson & Sroufe, 1995) and as discussed some evidence for the use of containment (e.g. Sprince, 2002), there are few studies that have looked at the efficacy of specific psychoanalytic concepts (Kazdin (1993). In fact there has been limited investigation of psychodynamic psychotherapy for children in general, least of all specific concepts (Kazdin, 1993). A summary of a recent review of all outcome treatments of psychiatric disorders in childhood (Wolpert, Fuggle, Cottrell, Fonagy, Phillips, Pilling, Stein & Target, 2002) found insufficient evidence to draw conclusions about the effectiveness of psychodynamic psychotherapy for children for many psychiatric disorders in childhood. However, evidence was found to support the use of psychoanalytic psychotherapy to improve diabetic control in children with hard to control diabetes (Wolpert et al., 2002).
Baruch & Fearon (2002) reported the outcome of a 12-month follow-up study of young people attending for community based psychodynamic psychotherapy. Using self-report data taken at 3 months, 6 months and a year they found improvement in three areas. Firstly, in the change in mean scores. Secondly, in the change in numbers from clinical to non-clinical range. Thirdly in statistically reliable change in the level of adaptation. They concluded that there were high rates of general improvement for the 12-18 year olds attending for psychodynamic psychotherapy. However, they also concluded that rates of improvement dropped significantly over time (Baruch & Fearon, 2002).

Studies such as Baruch & Fearon’s (2002) are relatively unique in the psychodynamic literature, as it is not common for psychodynamic clinician’s to systematically monitor outcome using objective measures (Baruch & Fearon, 2002). The reliability of such studies could further be improved by using methods other than self-report to collect information regarding outcome. Baruch & Fearon (2002) suggest the use of reports from significant others to improve this.

Studies like Baruch and Fearon’s (2002) are important as they bridge the link between research studies and clinical practice. Guthrie (2000) stresses the difference between the efficacy of therapy (as demonstrated by findings from a research trial) and clinical effectiveness (as shown by outcome in routine clinical practice). She argues that as research into efficacy has become increasingly internally valid, its relevance to clinical work is becoming less clear (Guthrie, 2000). Although it is important for any research into outcome to be internally valid, it is also important for the studies to use clinically relevant methods. For example for clinicians delivering therapy to be more
representative of clinicians in the NHS, for research to focus on more clinically relevant and representative patient groups and for therapy itself to be more responsive to individuals (Guthrie, 2000).

CONCLUSION

Two psychoanalytic concepts, attachment and containment, have been introduced and discussed in relation to how they may be used by a clinical psychologist working with children. While attachment as a psychoanalytic concept has close links with Bowlby’s Attachment Theory, the similarities and differences between the two have been discussed. It has been concluded that the two areas have much to learn from each other and that closer work could lead to interesting developments in the study of developmental psychopathology.

Containment is a useful concept for use in studying relationships both between caregiver and child, but also between therapist and client. An example of its use within organisations has demonstrated how it can be used in a variety of ways for the benefit of the child.

There is insufficient evidence available to be able to draw conclusions about the use of psychoanalysis with children generally. There is even less evidence regarding specific concepts within psychoanalysis. However, studies from child development literature have supported the importance of early relationships in development. There has been some discussion of the importance of making outcome research relevant clinically and an example of how routine monitoring can demonstrate effectiveness was discussed.
Finally, containment and attachment issues are used regularly in clinical practice and continue to help inform understanding when working with children.
REFERENCES


"Race and ethnicity are relatively unimportant variables in both the incidence and treatment of mental health difficulties in older people".

Critically discuss this statement.
INTRODUCTION

According to the National Service Framework for Older People (NSF-OP, Department of Health, 2001) older people from ethnic minorities make up a small but increasing proportion of the population in the United Kingdom. There is increasing concern about the lack of use of formal services by older people of racial and ethnic minority groups (Bowes & Dar, 2000).

This essay will begin by defining the terms ‘race’, ‘ethnicity’ and ‘incidence’. Next, what the essay will cover in terms of treatment will be outlined. The essay will concentrate on two main mental health difficulties for older people, dementia and depression, as national initiatives for older people (e.g. the NSF-OP, DoH, 2001) have tended to focus on these two areas. Following this there will be a brief discussion as to what is meant by ‘older people’.

This will be followed by a discussion of the methodological difficulties in measuring incidence and treatment and how these are influenced by race and ethnicity. Incidence can be measured by looking at service use or through population surveys. Access to services is influenced by factors such as health beliefs, stigma, education, transport and availability and communication, how these are influenced by race and ethnicity issues will be discussed. Population surveys and research are also influenced by race and ethnicity and this will be outlined. Specific measurement issues will also be discussed.
Although many of the issues concerning incidence also relate to treatment, there are issues specific to treatment. These will be discussed in relation to medication and psychological therapies. Social care can also play an important role in both physical and mental health difficulties of older people; this will be discussed briefly.

Race and ethnicity are relatively unimportant variables when seen in context of other variables such as age, disability, social economic status and gender. The importance of considering all aspects of an individual will be discussed. Although race and ethnicity per se are relatively unimportant, racism and oppression may influence other areas of individuals’ lives, so therefore race and ethnicity cannot be ignored.

**DEFINITIONS**

**Race and ethnicity**

The terms race and ethnicity are often used interchangeably; distinctions between the two can be ambiguous and definitions varied (Cardemil & Battle, 2003). The term ‘race’ has generally focussed on biological or physical characteristics, whereas ‘ethnicity’, while emphasising physical characteristics, tends to refer to cultural patterns and shared identities of groups from specific parts of the world (Cardemil & Battle, 2003).

The term ‘ethnic minority’ will be used throughout this essay. Although this means minority in the United Kingdom, this is not the case worldwide (Cardemil & Battle, 2003).
Incidence

The term 'incidence' is a measure of disease occurrence and is used to describe the number of new cases of a disease, or the number of disease onsets (Silman, 1995). In terms of mental health difficulties, for example, first-ever incidence would mean all those who present with depression for the first time during a particular period. The episode incidence considers whether the disease has occurred within a particular time period, regardless of whether or not it was the first occurrence. For mental health services this would include those reporting to the GP with symptoms of depression within a particular time period, regardless of whether they had presented with a previous episode twenty years earlier. Prevalence, another measure of disease occurrence, measures the number of cases in the population, usually at a specific point in time (Silman, 1995).

Treatment

Ideally interventions for older people with mental health difficulties are tailored to individual need, as with other populations. However, treatment options may include medication, psychological intervention and social care packages. Due to limited space and the fact that much social care is concerned with supporting older people’s physical health, the focus will be on medication and psychological intervention.

Mental health difficulties

This essay will focus on depression and dementia as they can be considered the ‘two most important illnesses of later life’ (p. 322, Copeland, Beekman, Dewey, Jordan, Lawlor, Linden, Lobo, Magnusson, Mann, Fichter, Prince, Turrina & Wilson (1999).
The National Service Framework for Older People (NSF-OP, DoH, 2001) Standard Seven aims to treat and support older people with dementia and depression, as well as promoting good mental health in older people. It states that depression and dementia are particularly common in older people and focuses on these two areas. The NSF-OP states that older people with a severe mental illness due to a psychotic illness, such as schizophrenia, will require a package similar to that set out in the National Service Framework for Mental Health and that older people should receive the same standard of care as working age people (DoH, 2001).

Depression is a mood disorder and may be characterised by: low mood and feelings of sadness, loss of enjoyment, poor memory and concentration, tiredness and fatigue, unexplained pain, feelings of guilt, suicidal thoughts or impulses and delusions (NSF-OP, DoH, 2001). Dementia is a syndrome characterised by the loss of mental function, including: memory loss, language impairment, disorientation, changes in personality, self-neglect, and behaving out of character (NSF-OP, DoH, 2001).

**Older people**

The concept of ‘older people’ is culturally bound and may be based upon work capacity, chronological age or social performance (Dein and Huline-Dickens, 1997). In many non-Western societies people are considered young if they are still able to carry out their responsibilities, so ‘old age’ is considered in terms of functional ability, rather than chronological age. According to the NSF-OP (DoH, 2001) older people are not to be seen as a homogenous group, but have varying and differing needs. In the UK mental health services are generally split so that ‘older people’ have a separate service. This is usually defined by age, rather than by function. Some services see
people over the age of 65, others over 75. This is variable even within certain areas (for instance Greater London). For the purposes of this essay 'older people' will be taken to mean those over the age of 65 unless otherwise specified.

DIFFICULTIES MEASURING INCIDENCE AND TREATMENT OUTCOME

Measures of incidence rely on an individual receiving a diagnosis. This may be within the context of presenting to health services for treatment (either historically in retrospective reviews or prospectively), or in large epidemiological surveys where diseases are screened within a particular population (Silman, 1995). If measures of disease rates relied solely on data based on service use, this would have huge implications for the accuracy of incidence figures for older people from ethnic minority groups. There are many reasons why people may not come into contact with services and hence do not receive a diagnosis.

Access to services
There are a number of barriers to people accessing services, and hence treatment – these can be related to race and ethnicity.

Health Beliefs
Dein & Huline-Dickens (1997) state that levels of consultation with health professionals are influenced by patients’ belief systems. Leventhal and colleagues (e.g. Leventhal, Meyer & Nerenz, 1980; Leventhal & Nerenz, 1985, cited in Ogden, 1996) proposed five dimensions related to illness beliefs. These were: identity, perceived cause, time line, consequences and curability/controllability. Identity relates
to the diagnostic label an individual may give an illness. The perceived cause may be biological (an infection) or psychosocial (stress-related). The time line refers to the length of time the person believes the illness will last for, that is to say short term or chronic. Consequences are the individual’s perception of the effects of the illness, for example these may be emotional (loss of social contact) or physical (lack of mobility). Curability/controllability refers to the extent to which patients believe that the illness is possible to cure, either by themselves or by others (Ogden, 1996).

Experimental studies have supported the five dimensions of illness beliefs (e.g. Lau, Bernard & Hartman, 1989). There is some evidence to support the cross-cultural nature of the model too (e.g. Weller, 1984, cited in Ogden, 1996). Leventhal’s model is useful when considering how individuals decide whether or not a set of symptoms needs a particular intervention. In order for action to be taken symptoms need to be identified as an ‘illness’. For action to be taken the model states that there must be evidence of curability/controllability.

Cultural influences, including race and ethnicity, play a role in all five of Leventhal’s dimensions of illness beliefs (e.g. Evans & Cunningham, 1996). It is important to elicit individuals’ beliefs and models of their illnesses, and try to explain any treatment or understanding of the illness in these terms. This will improve the clinician-patient relationship and increase the chances that the individual will follow any medical advice given (Dein, 1997).

Marwaha & Livingston (2002) demonstrated how beliefs about the cause of an illness influence the type of support sought. They conducted a qualitative analysis of semi-
structured interviews. 40 older people were presented with two vignettes. One described an older man with symptoms of depression, the other, a woman with psychosis. Half the participants had been depressed, 21 were White British and 19 were Black Caribbean.

They found that, regardless of ethnicity, participants identified that there was something wrong with the older man in the first vignette. There were differences between White British and Black Caribbean participants in terms of identifying causes. White British participants tended to say that his condition was due to the death of his wife, loneliness or part of normal ageing. Black Caribbean participants also highlighted these as possible causes, but they tended to attribute his difficulties to a lack of contact with his community or having a spiritual problem. Few of the participants identified him as being ill. Interestingly all Black Caribbean participants who had not been depressed highlighted the church as a source of support, while no Black Caribbean participants who had been depressed did. More White British participants suggested a luncheon or social club may be a source of support than Black Caribbean. Members of both ethnic groups suggested a trip to the GP might be worthwhile.

This is in stark contrast to the other vignette. Nearly all the participants, regardless of experience of depression or ethnicity, believed that the woman in the vignette was seriously psychologically ill. The most common source of support suggested was a psychiatrist.
Older people may not seek medical help for depression because they do not identify depressive symptoms as being a medical illness. In this study, many older Black Caribbean participants who had not experienced depression identified a spiritual cause and hence suggested support be sought from the church (Marwaha & Livingston, 2002). This could influence incidence rates and treatment data where such data is gained from levels of service use.

Stigma

Mental health services continue to be associated with a degree of stigma. Stigma could be compounded by experiences of racism and discrimination and hence reduce access to services by particular sections of the community (Abramson, Trejo & Lai, 2002). Where services rely on inappropriate ways of disseminating service information (such as through translated leaflets and posters) this can lead to distrust of services by some black and ethnic minority communities (NSF-OP, DoH, 2001) and to reduced service use.

Education

Some older people and their families see mental health problems as an inevitable consequence of aging, which may exacerbate the problem of under-diagnosis and use of services (NSF-OP, DoH, 2001). The perception that older people are miserable, depressed and tired of life pervades the general public and health and social service providers in Europe (Copeland et al., 1999). Such views may impede recognition of a problem and hence service use.
Limited education and knowledge of caregivers has been associated with a failure to recognize signs and symptoms of mental health problems such as dementia (Espino & Lewis, 1998). Public education policies specifically designed to increase awareness of the early signs of problems, like dementia, are needed if people are to be diagnosed early (Ross, Abbott, Petrovitch, Masaki, Murdaugh, Trockman, Curb & White, 1997).

Transport and availability

Negotiating access to mental health services is difficult for many older people, but the problem is exacerbated if an individual is not from the mainstream of society (Abramson, Trejo & Lai, 2002). If services are not located in minority communities then this can reduce access and lead to under-utilization of services, this is compounded by inadequate transport (Espino & Lewis, 1998).

Communication issues

Communication issues can influence diagnostic interviews and hence incidence rates and treatment. This does not simply refer to the difficulties of not having a shared language, although clearly language difficulties can impede communication. Access to interpreters is essential when assessing and working with older people from diverse ethnic backgrounds (Hassett & George, 2002). Working with an interpreter can be complex and few health professionals are trained in their use, this can lead to limitations being placed on the clinician-patient relationship (Hassett & George, 2002). There may be concerns about the confidentiality and appropriateness of interpreters, especially if the community is small (Hays, 1996).
There can be difficulties accessing appropriate interpreting services and inevitably family members are used. Using family members can cause problems of translator bias, inaccurate paraphrasing and poor understanding of terminology (Espino & Lewis, 1998). This may also be compounded by breaking taboos regarding family hierarchy (especially if younger family members are used) and may impede the development of a therapeutic relationship (Hays, 1996).

Even if language is not usually an obstacle, emotional distress can lead to reduced fluency in a second language (Bradford and Munoz, 1993, cited in Hays, 1995), so additional care may need to be taken. Sensory impairment can also impede communication in older people (NSF-OP, DoH, 2001), this may compound the problem of not having a shared language.

Non-verbal communication can be equally important to consider. Differences in the use of personal space, eye contact and tone of voice can impede an interaction and lead to miscommunication (Cardemil & Battle, 2003).

**Accessing individuals for epidemiological and other research studies**

If measures of incidence were to rely on service use alone, then studies looking at incidence in minority racial and ethnic minority groups are likely to underestimate incidence for the reasons outlined above. Other methods, such as population surveys can have similar difficulties accessing individuals from minority groups.

Mills & Edwards (2002) highlight the general lack of research into depression, anxiety and psychological well being in African-Americans. They suggest this lack of
research may be attributable to a negative view of research among African-Americans, the small numbers of African-American researchers and clinicians and perhaps a reluctance to be treated as a 'guinea pig' (Mills & Edwards, 2002). Bowes & Dar (2000) note that similar issues are apparent in the UK, where many research organisations are predominantly white dominated, so issues of power, control, exclusion and marginalization must be taken into consideration.

Some studies have found that accessing older people from ethnic minority communities is best achieved using a variety of approaches, such as accessing GP lists, liaison with community and religious leaders and through the use of snowballing (e.g. McCracken, Boneham, Copeland, Williams, Wilson, Scott, McKibbin & Cleave, 1997).

There are some practical issues that may need to be overcome when researching people from older ethnic minority communities, while it is important to acknowledge the heterogeneity of members of any ethnic minority group and be aware that this is not the case for everyone (Bowes & Dar, 2000). One issue relating to researching ageing and ethnicity can be the ability of the researchers to overcome an apparent lack of trust among participants (Silveira & Allebeck, 2001). A reticence to put across personal views is not uncommon in older participants, but discussions can be eased once participants feel that they can trust researchers (Bowes & Dar, 2001). This can be achieved by ensuring researchers are from a similar background to participants and that they show an understanding of and respect for participants' views (Bowes & Dar, 2001).
Measurement

How depression and dementia are measured is important because accurate measurement can influence levels of diagnosis in services, epidemiological studies and treatment. Service level policy decisions are influenced by service use, incidence rates and research, so accurate measurement tools are important. Effective intervention also depends on accurate assessment (Hays, 1996). If tools are not reliable or valid for use with people from different racial and ethnic groups then this has implications for treatment, for example access to anti-dementia medication. According to NICE (National Institute of Clinical Excellence) recommendations, access to anti-dementia drugs is reliant on a Mini-Mental State Examination score of over 12 points (NSF-OP, DoH, 2001). As will be discussed later the MMSE contains culturally biased items.

Screening instruments for depression and dementia were developed in the white indigenous population and ‘Western’ ideas of distress are often difficult to translate, even with the use of interpreters (Rait, Burns & Chew, 1996; Hassett & George, 2002). As many tests have been developed from Euro-American perspectives this can increase the chances of people from ethnic minority communities being misunderstood or misdiagnosed (Hays, 1996).

Formal screening tests are less valid for people from different cultural background due to reduced levels of education and literacy (Rait et al., 1996). Hays (1996) gives the example of an older Khumer (Cambodian) woman, who could become distressed when asked to copy letters or designs if she had never learned to read or write.
Tools that rely on measures of somatic symptoms, such as sleep disturbance, energy loss and feeling exhausted should be avoided when assessing depression in older age, as physical symptoms and illness are confounding factors (Copeland et al. 1999). Some older people may become tired easily or have difficulties concentrating in the test situation and this may increase anxiety in an already anxious client, hence confounding the results (Hays, 1996). Depression is often measured using tools that are highly correlated with somatic complaints. For example the CES-D Scale (Centre for Epidemiological Studies-Depression Scale) is highly correlated with somatic complaints (Mills & Edwards, 2002). Physical health problems are often higher in certain populations, so measures that rely on somatic symptoms can give inaccurate results. The CES-D has been found to be less effective at detecting depression in African-Americans than White Americans, due to higher levels of somatic symptoms in African-Americans (Mills & Edward, 2002).

There is an educational bias in many dementia-screening assessments that may have implications for people from minority racial and ethnic groups (Espino & Lewis, 1998). McCracken et al. (1997) found a language bias in the Geriatric Mental State Examination (GMS). They interviewed 418 people using the GMS. The GMS yields eight syndrome clusters, including organic disorder (i.e. dementia) and depression. It has been used extensively in Asia, North and South America and Europe. McCracken et al. (1997) found that the numbers of people with dementia were similar among all English-speaking ethnic groups and the prevalence was similar to that found in previous studies (e.g. MRC Alpha Study). However, they found a higher prevalence of dementia among non-English speaking members of any ethnic group than the English-speaking members of that same group. They concluded that levels of depression and
dementia are similar among older people from ethnic minority groups to levels in the general population. However, they suggest that there are issues of diagnosis of dementia for people who do not speak the dominant language.

Stewart, Johnson, Richards, Brayne, Mann & MRC CFAS (2002) found similar biases in the Mini-Mental State Examination (MMSE). They found that the differences in scores of UK African-Caribbean participants and UK Caucasian participants could be accounted for principally by cultural bias in certain items. These items included naming the season. African-Caribbean participants were more likely to divide the year into winter/summer, so gave a technically incorrect response in spring or autumn (Stewart et al., 2002).

In areas where there are large numbers of older people from a specific ethnic group, it may be appropriate to have specifically modified assessment tools. For example a modified culture-specific version of the MMSE was devised for Jamaican-born community residents in Manchester (Stewart et al., 2002). However, where there are more mixed populations, or where there are fewer numbers of individuals from particular communities, this may not be feasible. In these situations it may be more appropriate to have a general tool, but with normative scores for particular groups (Stewart et al., 2002).
TREATMENT ISSUES

Issues of race and ethnicity may present similar barriers to accessing treatment as they do to accessing services. However, there are some issues relating specifically to treatment and these are discussed below.

Medication use

Issues besides culturally biased measurement tools also influence medication use. As part of the Duke Established Populations for Epidemiologic Studies of the Elderly participants were interviewed in 1986-1987 and then followed up on three subsequent occasions over a ten-year period. Participants were community residents aged 65 years and over. Blazer et al. (2000) used data from this large prospective study and found a marked difference in anti-depressant use between white American and African Americans, with white Americans being almost three times as likely to be taking anti-depressant medication than African Americans. Health insurance and use of outpatient medical services were controlled for in this study, so the results are even more striking. Blazer et al. (2000) conclude that the findings probably reflect a combination of relative under-diagnosis of treatable conditions in older African Americans and prescribing practices that are partially determined by the race of the patient.

While prescribing practices may influence medication use, there may be issues relating to family caregivers administering medication. This is not specific to older people from ethnic minorities, but could compound difficulties understanding instructions and possibly lead to misadministration of medication (Espino & Lewis, 1998). There may also be issues of conflicting remedies, where culturally specific
alternative therapies interact with ‘Western’ medication. For example, some compounds found in certain herb teas can exacerbate memory and behavioural problems (Espino & Lewis, 1998).

**Psychological intervention**

The race of the clinician can impact on the treatment of mental health difficulties in older people (Abramson, Trejo & Lai, 2002). A fundamental part of any therapeutic situation is the building of rapport. Where the therapist and older person are from different cultural groups this may impede the development of a successful relationship. It is especially important to develop a good therapeutic relationship as this reduces the risk of premature termination of therapy (an increased risk with clients from minority groups (Cardemil & Battle, 2003)). In order to ease development of a good relationship, therapists and clients must be able to communicate expectations, values and beliefs to each other, as this can impact on how thoughts, moods and behaviours are expressed and interpreted (Abramson et al., 2002).

Cardemil and Battle (2003) suggest a number of practical ways in which therapists can have open discussions with clients about issues of race and ethnicity. While lengthy discussions may not be appropriate for all clients, it may be that by raising the subject of race and ethnicity the therapist can demonstrate an openness to discuss these issues. Generally psychotherapy training teaches therapists to avoid making assumptions but it is especially important not to assume a client’s racial and ethnic background simply from appearances (Cardemil & Battle, 2003).
It is important to keep in mind that cultural issues (including race and ethnicity) are not something that can be split off and ‘done’ to an individual. Or more specifically to an individual who seems obviously ‘different’ from the therapist. Self-awareness and continually challenging assumptions and prejudices is an essential element of both professional and personal development (Cardemil & Battle, 2003).

Most psychotherapies (e.g. behavioural, psychodynamic, cognitive-behavioural, humanistic) were developed with little consideration of ‘difference’, in terms of gender, age, race, and sexual orientation (Hays, 1995). However, Hays (1995) suggests that cognitive behaviour therapy in particular is very flexible and lends itself to working with people from diverse racial and ethnic groups.

Social care

Social care services are those provided by social work departments and might include day-care services, access to ‘home-help’ services and meals on wheels etc. (e.g. Bowes & Dar, 2000). Although services may not be specifically for older people with dementia and depression, social care can have an important role in their treatment.

Research commissioned by the Royal Commission on Long Term Care (1999) showed that older people from black and ethnic minority communities did not want separate or special services, but mainstream services that were culturally sensitive and more responsive. This is reflected in the findings of Bowes and Dar (2000) who found that while service users were generally more satisfied with community-based voluntary sector services, it was incorrect to assume that they would prefer specialist services over accessible generic services, open to all. There is a danger that
developing specialist services increases marginalization of ethnic minority communities and leads to a failure to reform generic services (Bowes & Dar, 2000).

**IMPORTANCE OF CONSIDERING OTHER ASPECTS OF THE INDIVIDUAL**

Generalisations based on racial or ethnic group should be used cautiously as they can easily lead to stereotyping (Evans & Cunningham, 1996). There are many negative stereotypes based on an individual's ethnic background that can impede access to services. For instance the stereotype that many Asian families provide close support to their elderly relatives (e.g. 'They look after their own – don’t they?' Social Service Inspectorate Report, 1998).

Ethnic minority groups are heterogeneous and when considering variables influencing incidence and treatment of mental health difficulties in older people it is necessary to consider a range of issues. For example Hays (1996) cites the American Psychological Association's (1993) guidelines for psychological services that highlight a number of cultural influences that psychologists must take into account in their work. The cultural influences form the acronym – ADRESSING. The letters stand for Age and generational factors, Disability, Religion, Ethnicity, Social Status (occupation, education, income, rural or urban origin), Sexual orientation, Indigenous heritage, National origin and Gender (Hays, 1996). The acronym serves to highlight the diverse nature and individual experiences of every client and that assumptions based on one aspect of an individual are not helpful. It helps to highlight within-group differences
and discourages inaccurate generalizations about the client’s culture based on appearances (Hays, 1996).

When taking into account factors besides race and ethnicity it could be argued that they seem relatively unimportant. For instance health status, economic status and gender may have greater influences on incidence and treatment of older people with mental health difficulties. For example Stoppe, Sandholzer, Huppertz, Duwe & Staedt (1999) found that family doctors were significantly more likely to diagnose a female older patient with depression, than a male older patient, presenting with the same symptoms. This suggests that gender stereotyping may play an important role in the recognition of depression in older people (Stoppe et al., 1999).

Years of oppression and discrimination have meant that large sections of the community that can be defined in terms of race and ethnicity have low social economic status. Social economic status impacts on predisposition to disease, recovery rate and management of chronic illness (McKenna, 1989, cited in Evans & Cunningham, 1996). Many older people from ethnic minority groups face the ‘triple jeopardy’ of ageism, racism and low social economic status (Norman, 1985).

Depression is associated with chronic physical conditions; African Americans are at increased risk of developing chronic medical problems (Mills & Edward, 2002). Other factors associated with aging, such as health declines, loss of social role and economic status may place increased stress upon individuals who have already had to cope with racism or traumatic immigration experiences (Silveira & Allebeck, 2001).
Risk factors for older migrants may be the same daily stressors as the majority of older people of a similar age. However, minority status and past experiences of immigration may lead to increased likelihood that they have experienced unique life events (Silveira & Allebeck, 2001). Different experiences and levels of support from family may buffer this, so it cannot be assumed that those from minority groups will automatically have increased risk of depression or dementia. Equally assumptions cannot be made about the level of family support open to particular individuals either (Harris, 1998). Such assumptions can be seen as both false and racist (Rait, Burns & Chew, 1996).

**CONCLUSION**

There are many ways in which race and ethnicity may influence the incidence and treatment of older people with mental health difficulties. However, rather than defining actual differences between racial and ethnic groups, the influences are largely in how measures of disease and treatment are influenced by access to services, exclusion and marginalization.

Race and ethnicity are important variables. However, it is vital to consider other aspects that may be just as, if not more, relevant to the development of mental health difficulties in the individual and therefore their treatment. By considering broader cultural influences when working with individuals we can begin to work towards developing a way of working that is effective when working with individuals who are a different age, have a different experience of disability or who are from a different
racial group to our own. It is important to acknowledge all possible influences and not to make assumptions based on stereotypes of ethnic groups.
REFERENCES


Evans, C. & Cunningham, B. (1996). Caring for the ethnic elder: even when language is not a barrier, patients may be reluctant to discuss their beliefs and practices for fear of criticism or ridicule. *Geriatric Nursing*, 17 (3), 105-110.


CLINICAL DOSSIER
Summary of the Clinical Dossier

This section contains an overview of the placements undertaken over the three years. There are also summaries of case reports for four core placements and my first specialist placement. Case report summaries are for the core placements of adult mental health, people with learning disabilities, children, adolescents and families, and older people. The specialist placement case report summary is for the pain management service. Case reports are chosen to demonstrate a range of diversity within ages, gender, presenting problem, ethnicity and model. They are presented in the order in which they were completed. This is intended to demonstrate how my clinical skills have developed over training.
Core Adult Mental Health Placement

Placement Details

Dates: September 2001 to March 2002

Supervisors: Dr David Brock (Consultant Clinical Psychologist) and Dr Alison Conning (Consultant Clinical Psychologist).

NHS Trust: Surrey Oaklands NHS Trust

Base: Wingfield, Redhill.

Summary of experience

Worked individually with nine people (five women) ages ranged from 23 to 54 years. Referrals were mainly from the GP. Presenting problems included: chronic fatigue syndrome, obsessive compulsive disorder, depression, anxiety and panic disorder. Based in service for people with longer term mental health problems I also worked with two individuals with longer-term mental health needs.

Observed and conducted cognitive assessment using the WAIS-III.

Mostly work involved CBT intervention or behavioural interventions. Attended monthly CBT supervision group and presented case.

Experience gained on placement included visiting in-patient units and residential homes. Also visited community based workshops.
Core People with Learning Disabilities Placement

Placement Details

Dates: April 2002 to September 2002

Supervisor: Simon Powell (Consultant Clinical Psychologist).

NHS Trust: Oxleas NHS Trust


Summary of experience

Conducted joint assessments with my supervisor and other members of the psychology team. I worked with people with a range of disabilities, from mild to severe learning disabilities. Saw 15 clients (6 men), ages ranged from 18 to 76 years. Examples of individual work included anger management, bereavement work and depression. Work also included working with staff teams around issues such as absconding behaviour and other ‘challenging behaviour’.

Assessment opportunities included conducting cognitive assessments to see if individuals were eligible for the learning disability service. Assessments included: Quick Test, WASI, WAIS-III, BPVS, ABS.

There was the opportunity to conduct staff training (in autism) and to be part of a group home ‘away day’. Also fed-back results of the service related research, of observations of client activity levels.
Core Children, Adolescents and Families Placement

Placement Details

Dates: September 2002 to March 2003

Supervisors: Dr Jacqueline Hammond-Wyatt (Clinical Psychologist) and Dr Claire Tyler (Clinical Psychologist)

NHS Trust: South West London and St. George’s Mental Health NHS Trust.

Base: Kingston Child and Adolescent Mental Health Service.

Summary of experience

Based in the CAMHS service there was plenty of opportunity for multidisciplinary assessment and discussion in assessment clinics. Saw 18 clients (either jointly, individually or observing others). Saw six female clients, ages ranged from 2 to 17 years. Presenting problems included: sleep problems, behavioural problems, depression and queries about a social communication disorder. Models used included behavioural, cognitive behavioural and systemic.

Spent time observing the social communication disorder clinic, also conducted assessments for clinic. Assessments undertaken included: WISC-III, TOAD, Birleson Depression Scale, WORD and WAIS-III. Worked part time in the service for children with disabilities, observed specialist feeding clinic. Other visits included nursery and primary school visits, play specialists at Kingston Hospital, Portage, health visitors and inpatient unit for children with disabilities.

I conducted a training morning for staff working in a respite unit for children with disabilities. Training was an ‘introduction to behavioural work’.
Pain Management Specialist Placement

Placement Details

Dates: March 2003 to September 2003

Supervisor: Dr Hilary Rankin (Consultant Clinical Psychologist).

NHS Trust: Epsom and St. Helier University NHS Trust

Base: Centre of Pain Education (COPE), Sutton Hospital.

Summary of experience

Worked as part of a multidisciplinary team on a pain management programme for people with long term, chronic pain. Observed and participated in the group programme.

Worked individually or jointly with 15 clients (five men), ages ranged from 24 to 81 years. Presenting problems included: facial pain, pain associated with ileostomy site, endometriosis and sickle cell pain.

Used a cognitive behavioural model to inform understanding of chronic pain and to aid interventions. Set up a group for people with sickle cell disease, based on CBT model of management of chronic problems. The group did not run, due to low response rate (as over the summer) but good links were made with haematology team.

Attended the Pain Management Programme Conference, this was a good opportunity to see how clinical psychologists maintain their role within a multidisciplinary setting.
Core Older People Placement

Placement Details

Dates: September 2003 to March 2004

Supervisor: Clare Crellin (Consultant Clinical and Counselling Psychologist)

NHS Trust: West Sussex Social Care and Health NHS Trust

Base: Linwood Community Mental Health Centre, Haywards Heath.

Summary of experience

Worked with 16 clients (either directly or indirectly), 13 were women. Ages ranged from 64 to 83 years. Presenting problems included: depression, attempted suicide, anxiety, alcohol problems and communication problems associated with stroke. I conducted in-depth standardised assessment, other assessments included: NART-II, WMS-III, WAIS-III, HADS, BDI, BAI and Millon Personality.

Used a model of joint supervision which was a useful learning experience. Used mainly psychoanalytic models to inform formulation and intervention.

Set up a psychology group for patients on an acute inpatient ward. As an open group, it became difficult to maintain continuity due to the level of change of personnel on the ward.

Visited residential home, day centre and in-patient stroke unit. Also participated in psychoanalytic observation of people in nursing home.
Primary Care Specialist Placement

Placement Details

Dates: March 2004 to September 2004
Supervisor: Dr John Church (Chartered Clinical Psychologist)
NHS Trust: South West London and St George’s NHS Trust
Base: Balham Health Centre, Balham

Summary of experience

Experience has included assessing a number of clients with presenting problems including: depression, anxiety, bereavement, relationship difficulties, health anxiety and chronic pain. Intervention largely based on CBT, but some supportive counselling.
Cognitive behavioural assessment and therapy of a 34-year-old woman presenting with anxiety

Presenting Problem

Sharon was referred by her GP for assessment of her panic attacks. They had been occurring for the last few years, but had increased in frequency over the preceding few months. There was also mention of the series of losses that Sharon had experienced. Sharon’s first language was English and she was White British. She experienced physical symptoms; including a dry mouth, shaking, heart pounding, feeling sick and light headed. Such symptoms tended to occur in large social situations and were accompanied with thoughts such as ‘what if I have a panic attack’, ‘people will think I am not coping’, ‘what is going to happen, am I going to be ill?’

Assessment

The majority of information used was obtained via cognitive-behavioural interview and the completion of psychometric assessments. These included: Agoraphobic Cognitions Questionnaire (ACQ; Chambless, Caputo, Bright and Gallagher, 1984); the Beck Anxiety Inventory (BAI; Beck, Epstein, Brown and Steer, 1988) and the Beck Depression Inventory –II (BDI-II; Beck, Steer and Brown, 1996). This information was supplemented by self-monitoring data in the form of diary sheets. Assessment showed that Sharon had ‘severe’ levels of anxiety and depression. Despite her high score depression scores she did not exhibit any suicidal ideation. She had no previous history of self-harm.
Formulation

Sharon’s difficulties were conceptualised in terms of panic disorder with agoraphobia, as her symptoms were consistent with the DSM-IV (APA, 1994) criteria. The case was formulated using a panic cycle (after Clark, 1986).

**Figure 1: Panic cycle for Sharon, after Clark (1986).**

- **Trigger/physical symptoms**
  - feel peculiar, dry mouth, shaky, heart pounding.

- **Thoughts**
  - “What if I have a panic attack?”

- **Anxiety**
  - “What is going to happen?”
  - “Am I going to be ill?”
  - “People will notice and think I am not coping”

- **Increase in physical symptoms**
  - dry mouth, shaky, feeling sick, heart pounding, light headed

- **Maintaining/safety behaviour**
  - Avoid situation, put cool water on wrists
  - escape to toilet, keep eye on exit routes and sit near exit

Intervention

The intervention was based on a cognitive behavioural model of anxiety proposed by Wells (1997). There were nine sessions following the initial assessment sessions. A large part of the sessions included psycho-education about the nature of panic and anxiety and the contribution thoughts made to its development. Sharon learnt to identify her thoughts well and was encouraged to record her thoughts and feelings on a thought record form. Verbal reattribution techniques such as questioning the
evidence and examining counter-evidence (Wells, 1997) were used. Thoughts such as “what will other people think?” were challenged with “How would I react if someone else looked ill or upset?” Sharon began to record these challenges as part of her thought records, so she was encouraged to use the extended dysfunctional thought record form to illustrate the effect alternative thoughts had on the rating of emotion. Behavioural experiments were also used to counteract some of the avoidance behaviours Sharon was exhibiting. She no longer reported any panic attacks, but was continuing to avoid a number of situations. A hierarchy was devised through which Sharon could work slowly, it proved a useful way of breaking the tasks down into more manageable chunks and hence increased compliance.

**Outcome**

There were changes over time in the number of panic attacks and panic situations recorded. Initially Sharon reported six in the first week, this reduced to two over Christmas period and finally she did not record or report any attacks. However, further investigation of this in sessions revealed that she was avoiding a number of situations. This was addressed using the hierarchy.
References


An extended assessment of a 35-year old woman with learning disabilities.

Referral

Genye was referred for a cognitive assessment. There was doubt about the nature of her difficulties and a more detailed assessment of her needs was required. Genye’s first language was English and she was Black African.

Assessment

Assessment was carried out over three sessions. Information was obtained via interview with Genye and her husband and through completion of psychometric assessments. These included: Wechsler Adult Intelligence Scale – Third Edition (WAIS-III, Wechsler, 1995). Genye performed in the Extremely Low Range of Intelligence - her Full Scale IQ was 46 (43 – 51 with 95% confidence). Her Verbal IQ was 51 (48-57 with 95% confidence) and her Performance IQ was 50 (46-60 with 95% confidence). Both of these are also in the Extremely Low Range of Intelligence this would place her as having moderate learning disability according to ICD-10 (WHO, 1994).

Formulation

Genye’s schooling, other aspects of her history and her verbal abilities suggested that she was functioning at the mild end of the learning disability range, a different picture from that suggested by her performance on the WAIS-III. Genye did not present as someone functioning in the moderate learning disability range (ICD-10).
A possible formulation was that there might be an underlying genetic disorder, for example her webbed fingers, joint difficulties and balance problems. Some rare disorder may have led to such a large discrepancy. Cultural influences may have affected Genye's performance. Although she was brought up in England, recent experiences in Nigeria may have influenced her performance. Anxiety may have affected Genye's performance. She did not appear anxious, but was quiet and clearly found some instructions difficult to understand, this may have been due to anxiety. Genye did not perform poorly on subtests vulnerable to anxiety, for example Arithmetic or Digit Span, although anxiety may have influenced her overall performance. Genye may have overemphasised her difficulties to qualify for higher level of benefits. This may have been due to pressure from her husband or concern that she would not receive the support she needs. The WAIS-III might not be a valid measure of her abilities so further assessment was indicated.

**Intervention**

In light of the above formulation an extended assessment was conducted. Giving people the opportunity to agree that their first performance on a test was not optimal because of some plausible explanation can provide a face saving way of performing to the best of their ability on a subsequent administration (Lezak, 1995). Genye was given this opportunity, it was suggested that she may have been anxious at our first meeting, however, she denied this. The results of the second tests and rationale for their use are below.

did not seem appropriate to ask her husband with Genye present. It was difficult to rephrase questions, especially as Genye had difficulty understanding them so testing was abandoned.

*BPVS (British Picture Vocabulary Scale) – Short Form* (Dunn, Dunn, Whetton & Pintillie, 1982). Genye struggled to complete the training pictures. Ideally they should be repeated until examinees are able to complete four correctly. Genye was not able to do this, but the testing commenced after three correct pictures. Her raw score was 3 (scaled scores do not go that low for someone of her age) indicating she was functioning in the severely learning disabled range (ICD-10), significantly below her WAIS-III score.

*WAIS-III subtests* (Wechsler, 1995). The Wechsler Abbreviated Scale of Intelligence (WASI) consists of four subtests, similar to those from the WAIS-III. It is possible to complete two subtests and produce an estimated Full Scale IQ Score. It was not possible to access the WASI, but Matrix Reasoning and Vocabulary Subtest of the WAIS-III were repeated giving Genye the opportunity to perform more optimally (as outlined above). Genye’s raw score for Matrix Reasoning was one and her raw score for Vocabulary was two. Previously her Raw Score on Matrix Reasoning was two, while it was two on Vocabulary, although she got different words correct.

*Rey 15-item Memory Test* (e.g. Lezak, 1995) is used to assess ‘malingering’ in people with memory complaints. Examinees read 15 items and have ten seconds in which to remember as many as possible. The number of items and shortness of time is emphasised to make the task sound more difficult. Anyone who has not experienced
significant damage should be able to recall three of the five sets, i.e. nine individual items (Lezak, 1995). Goldberg and Miller (1986) suggest it can be used with people with learning disabilities. Common errors among people with learning disabilities are perseverative errors, while malingering errors are more likely to be numerous ‘I don’t know’ omissions. Genye was unable to recall any test items, but suggested that the number ‘six’ was present.

**Outcome**

Genye was not confronted with the suggestion that she was over-emphasising her difficulties, but was told she would be expected to score higher than she did, given her use of language. David and Genye were informed that it would not be possible state that she had a particular level of learning disability due to the mixed presentation.

A referral to speech and language therapy was made and it was recommended that a multidisciplinary meeting might find a legitimate explanation for the discrepancies found. As general cognitive testing could not identify a specific problem a referral was made for an in depth neuropsychological assessment.

Finally, in light of the amount of assessment Genye had undergone, the impact of further assessment should be taken into account. It was suggested that Genye be supported by Learning Disability Services to find more appropriate day activities and for support with household tasks.
References


Behavoural assessment and management of a four-year old boy

presenting with sleep problems and aggressive behaviour

Presenting problem

Reza’s parents identified three areas of concern with his behaviour: Sleep problems, trouble being left alone and aggressive behaviour. They reported that the sleep difficulties were the most difficult to manage. Reza and his family had recently moved to England from Iran. The family’s first language was Farsi, they were all proficient English speakers.

Assessment

Reza and his parents attended two one-hour assessment sessions, which took place in the family assessment room. Reza did not come to the third hour-long session. Information about bedtime routines, night-waking routines and daytime sleeping routines were supplemented with the use of a sleep diary.

Formulation

It was useful to understand Reza’s sleep problems in terms of difficulties settling and night waking. These fall under the DSM IV and ICD-10 diagnosis of insomnia (Carr, 1999). There are some limitations in using these criteria in pre-school children, as the disorder does not usually lead to clinically significant distress in the children (Carr, 1999). However, parents often experience great levels of distress associated with their child’s difficulties settling and waking through the night (Glaze, Rosen & Owens, 2002).
A behavioural model was useful in understanding the development of Reza’s sleeping difficulty. According to the model “operant conditioning” describes the process by which spontaneously occurring behaviours are controlled by their consequences, e.g. smiling and talking. The likelihood of the behaviour reoccurring, its intensity, speed and frequency are all influenced by the consequences (Fonagy & Higgitt, 1984). In this model a ‘reinforcer’ is the term used to describe the event that follows the behaviour and increases the chances of it reoccurring.

Reza had not developed self-soothing skills. Vulnerability factors included being a lively child, not needing a lot of sleep and a history of waking at night since he was a baby. His parents’ new environment, struggling with the demands of a new culture and life and having few friends with children influenced their response to the problem. They reinforced Reza’s difficulties by giving him cuddles and developing a bedtime routine that involved their presence. Reza learnt that crying led to parental attention.

By continuing with this pattern of behaviour Reza’s parents reinforced his difficulties falling asleep alone. He had not developed self-soothing skills, so woke his parents when he awoke during the night.

**Intervention**

Although well-established and supported empirically, extinction was not considered appropriate for Reza. Extinction with parental presence involves the parent ignoring the child, but allows the parent to stay in the room (Owens et al., 2002). This approach was used as it was unlikely that Reza’s parents would be able to comply with more drastic forms of extinction.
Positive reinforcement of desired sleep behaviour can also be used with children with sleep-onset association disorder. Rewards in the form of social praise or stickers can be effective in reinforcing desired sleep behaviour.

A two-pronged behavioural programme was proposed for Reza and his family. The first prong consisted of extinction with parental presence and the gradual increase in distance from Reza and decrease in interaction. The second prong involved positive reinforcement of desired behaviour. This took the form of a sticker chart. Reza was involved in choosing stickers to use on his chart and the family were encouraged to make a chart together.

Reza’s parents were offered sessions to support them in the intervention and to provide the opportunity to discuss parenting styles, consistency and to reinforce ideas of good sleep hygiene.

Reza’s parents were seen for a further nine sessions. Initial sessions involved socialising his parents to the behavioural model and formulation. A goal was set to reduce Reza’s waking to once per night.

Step-by step programme: The programme started with establishing a bedtime routine. Reza’s routine involved him choosing a song to listen to at bedtime. Up until that point his parents had sung him to sleep. Reza was restricted to two bedtime stories.

The initial step of the extinction programme involved one of his parents sitting next to Reza’s bed, but removing physical contact and keeping interaction to a minimum.
This acted as a gradual reduction in parental attention, which the formulation suggested was acting to maintain Reza’s behaviour.

Sticker chart (reinforcement of positive behaviour): Reza’s parents reported that he responded very well to the reward programme. The rules were changed so that Reza received two stickers on nights when he did not wake up at all and one when he woke once. The stickers were also associated with Reza’s weekly trip to the toyshop.

Problem-solving: It became apparent fairly early into the process that Reza’s parents wanted more from the sessions. Although they had agreed to tackle the sleep problems first it became clear that they also needed to spend time discussing the difficulties they were having managing Reza’s aggressive behaviour. Time was spent examining their current techniques and strategies.

Relapse prevention: Sessions ended before the programme had been completed so final sessions were spent discussing management of future setbacks.

**Outcome**

A behavioural model was used to develop a formulation and intervention plan for Reza’s sleep difficulties. The goal of reducing Reza’s night waking to once a night was achieved, he often slept through the night and he learnt to fall asleep alone.

There were a number of elements of the work that could have been improved upon and these were discussed. The formulation was behavioural and drove a behavioural intervention. However it was important that systemic elements were included in the
sessions, especially when considering aggressive behaviour. Therefore it was important to combine behavioural techniques with a systemic view.

References


Cognitive behavioural assessment and therapy with an 81-year-old woman presenting with chronic pain

Referral

Elizabeth was referred to the Clinical Health Psychology service by the Consultant Anaesthetist in relation to ongoing pain associated with the site of her ileostomy. Elizabeth's first language was English; she was White British.

Assessment

The majority of information used was obtained via interview in the outpatient clinic and from past notes.

Elizabeth reported that she had experienced pain for four years on the site of an ileostomy. An ileostomy is an operation performed on the lower part of the small intestine. The intestine is cut and brought through the wall of the abdomen, forming an opening called a stoma. Waste is emptied into a small disposable bag, or a pouch situated under the skin. A hernia operation on the site four years ago led to an increase in pain, this coincided with the death of her husband and sister. Since that time she found it difficult to cope with the pain, she received little relief from painkillers and her daily activities were severely restricted due to the pain.

Elizabeth completed a pain diary and thought record forms. She also completed a psychometric questionnaire – the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983). Her scores at assessment suggested she was a "doubtful" case for depression but were consistent with the presence of high levels of anxiety.
Formulation

Elizabeth's difficulties were understood in terms of a cognitive behavioural model of chronic pain. Her pain led to restrictions in her social activities which influenced thoughts such as “I can’t go out on my own”, “what will happen if I am overwhelmed with pain when I am out?” This led to her further restricting her social activities and gave her more time to ruminate over the loss of her sister and husband, which lowered her mood and led to a perceived increase in the pain. This led to greater restrictions being placed on her activities and so the cycle continued. This formulation can be seen in the table below.

Table 1: An initial formulation of Elizabeth’s pain cycle

<table>
<thead>
<tr>
<th>Pain</th>
<th>“I can’t go out because of my pain”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lowered pain threshold</td>
<td>Reduction in activities, reduced opportunities for socialization</td>
</tr>
<tr>
<td>Low mood</td>
<td>No opportunities to test fears</td>
</tr>
</tbody>
</table>

There is good evidence to support the use of cognitive behaviour therapy for people with chronic pain. The aim of intervention is not to reduce pain, but to reduce the associated distress and limited function. Components of therapy include: education/promoting reconceptualisation, promoting pain-coping strategies, reducing catastrophising and pacing. An action plan was devised concentrating on these components.
Intervention

Elizabeth was seen for twelve sessions. Sessions involved education about the nature of chronic pain, the pain gate theory and the cognitive behavioural model of chronic pain. By discussing situations in which Elizabeth had similar pain experiences but behaved differently, perhaps due to the presence of others, or where an emotion influenced her experience of pain, Elizabeth was able to move away from a biological model of her pain, towards a biopsychosocial model.

Elizabeth was using a number of pain-coping strategies. Sessions were used to explore these and help her to develop them.

Elizabeth was tense and anxious and so it was suggested that she try relaxation exercises. Initially, diaphragmatic breathing was practised within sessions and this also served to help Elizabeth identify how she tended to breathe fast and shallowly when she was anxious or uptight. Elizabeth practised relaxation as a homework task.

Typical thoughts that Elizabeth had included: “This is awful, I can’t go on”, “the pain is too bad”. Initially, intervention involved helping Elizabeth to develop a set of distraction techniques to help her reduce the impact of such thoughts.

Elizabeth kept thought records to help her learn to “catch” and identify unhelpful thoughts. She developed challenges to some unhelpful thoughts and reported that she found it useful to put the thoughts down on paper.
Elizabeth had developed a cycle of overdoing activities when she felt better and then 'paying the price' afterwards by being unable to do anything the following day. She reported this made her frustrated and increased the pain. After trying to pace activities as homework she reported that she could spend more time in the garden if she took regular, planned breaks, rather than continuing until the pain overwhelmed her.

Elizabeth set the goal of visiting a friend near the bowling area of the park. She was reluctant to go out alone, so a hierarchy of steps was developed to reach the goal of seeing her friend playing bowls in the park.

It became clear that Elizabeth valued the opportunity to talk about how the pain made her feel and she expressed gratitude at being listened to and taken seriously. With this in mind, care was taken to plan for the ending of sessions and to put in place opportunities to discuss difficulties with someone after the sessions had ceased. The frequency of sessions was gradually reduced, to allow Elizabeth time to practice some of the coping and self-management techniques independently.

**Outcome**

Elizabeth appeared to understand the psychological concepts introduced, but found it difficult to engage in some of the homework tasks. Although she was able to utilise some concepts, such as relaxation and pacing, she did not achieve her goal of going to the park.

Elizabeth's HADS scores reduced, showing a reduction in anxiety and depressive symptoms over the course of the sessions. Although Elizabeth seemed to make
substantial cognitive changes within sessions, she found it difficult to translate these into behavioural changes outside of sessions.

Difficulties with working with people undergoing continued medical intervention are discussed. Differences working as a clinical psychologist in a health setting and in a mental health setting are also discussed.

References

Assessment and therapy of an 81 year-old man presenting following a suicide attempt

Referral

Mr Salter was referred to the psychology service for older people by staff on the acute inpatient ward following an overdose.

Assessment

Mr Salter took an overdose after his wife was taken seriously ill. He felt guilty when he made the decision not to allow an operation to remove her leg to go ahead. Doctors had suggested this might save her life, but were unsure. Mr Salter told them she would be devastated to wake up without it. The operation did not proceed and his wife became worse. Following his suicide attempt Mr Salter explained he wanted ‘to get there before she [his wife] did’. She died while he was an inpatient.

During the initial interview Mr Salter reported that he was unable to remember anything good about his life and could only focus on negative aspects. He said he enjoyed the psychologist ‘drawing out the good’, during the assessment.

Mr Salter completed a Mini-Mental State Examination (MMSE, Folstein, Folstein & McHugh, 1975). He scored 27 out of 30. A score of 23 or below on the MMSE indicates significant impairment (Zarit & Zarit, 1998); although any score less than 30 may indicate some difficulties.
Mr Salter was considered to be at risk of further suicide attempts if he was to return home as he had difficulty recalling his thoughts and feelings leading up to his suicide attempt. It was agreed that he should stay on the ward until a place became available at a residential home.

**Formulation**

Jungian analytical concepts were used in supervision and to guide formulation. The formulation draws specifically on Jung’s notion of individuation. Individuation is the gradual realisation of the self over a life time (Samuels, 1985). The notion of individuation is not without its critics not least because Jung’s writings on the subject are obscure (Storr, 1973)

There were a number of factors in Mr Salter’s life that may have left him vulnerable to a suicide attempt. Risk factors for suicide in older people include physical illness, depression and previous suicide attempts (Zarit & Zarit, 1998), all of which were pertinent to Mr Salter. Other predisposing factors may be Mr Salter’s previous experiences of death. His father did ‘not cope’ with the death of his mother and Mr Salter demonstrated difficulty coping with his son’s death.

It may be that Mr Salter’s feelings of guilt regarding his wife’s illness led him to think that his life had no meaning. According to Samuels (1985) Jung asserted that ‘life without meaning is not worth living’ (page 89). Mr Salter’s memory difficulties may also have impeded his ability to make meaning out of his life and perhaps precipitated the suicide attempt.
Mr Salter was not expressing any suicidal ideation, had no problems with his appetite and his sleeping pattern had not changed, suggesting that he was not experiencing ongoing depression. However, he did have difficulty accessing some memories and as demonstrated by his scores on the MMSE was exhibiting some cognitive difficulties.

**Intervention**

Samuels (1985) suggests that Jung thought that ‘consciousness is the factor that gives the world a meaning’ (page 90). Therefore one goal of therapy was to rediscover meaning, to bring it into consciousness and to support Mr Salter to reflect on his past.

Mr Salter found the opportunity to reflect in the assessment helpful and it seemed that further opportunities to do this in therapy might prove beneficial (after Lemma, 2003). Mr Salter was seen on a weekly basis, spending time reflecting on aspects of his life that his memory difficulties meant he had difficulty accessing and developing a sense of meaning. It was hoped that regular meetings might ease his transition into residential services and monitor suicide risk.

**Further assessment**

Throughout sessions Mr Salter complained of problems with his memory. His anxieties were discussed in supervision and it was felt that he might benefit from objective confirmation or negation of his concerns. It may also help to shed light on the formulation that Mr Salter was experiencing difficulties processing his life, in individuation, due to memory difficulties. It was also thought that extra information about his memory might help him to make his decision about whether to return home.

Mr Salter’s error score on the NART-R was nine, this equates with a predicted Full Scale IQ Score of 114, placing him in the ‘high average’ range of intellectual functioning. In practice, Mr Salter’s scores of the WMS-III demonstrate a possible reduction in functioning in some areas, specifically in processing verbally presented information and in retrieval of information. This would suggest that although Mr Salter was still functioning in the ‘low average’ to ‘average’ range, his functioning relative to his overall intellectual functioning in some areas had reduced. This was reported to Mr Salter and it was explained that due to his previously high levels of functioning, that he was still broadly within the ‘normal’ range.

**Outcome**

By the end of sessions Mr Salter was still considering spending time at home. Despite feedback that he would probably find it hard to live independently he remained keen to try living alone. It was unlikely that his family or the professionals involved would support this, as he still lacked insight into the emotions that precipitated the suicide attempt.

Shortly before discharge further information arose from his residential home this is discussed in the reformulation.
References


RESEARCH DOSSIER
Summary of the Research Dossier

This section contains the service related research project, qualitative research project, major research project and research log book. It is intended to represent the range and depth of work covered over the three years. The reports are presented in the order in which they were completed. This is intended to demonstrate how my research skills have developed over training.
An audit of a group home for people with learning disabilities and challenging behaviour using momentary time sampling techniques.
Abstract

Title: An audit of a group home for people with learning disabilities and challenging behaviour using momentary time sampling techniques.

Objective: To assess the levels of activity, social acts, contact and problem behaviour in a service for people with moderate to severe learning disabilities and challenging behaviour.

Design: An observational study using momentary time sampling techniques.

Setting: A seven bedded residential home for people with moderate to severe learning disabilities and challenging behaviour.

Participants: Seven residents, age range 41 to 49 years (mean age=43). Residents have moderate to severe learning disabilities, six were men. Residents presented with several challenging behaviours including: throwing objects at others, hitting, pushing, kicking and self-injurious behaviour.

Main outcome measures: Momentary time sampling techniques were used. Observations were coded according to codes devised by Beasley et al. (1993). The Health of the Nation Outcome Scales – for People with Learning Disabilities was also used. The measure has been specifically adapted for people with learning disabilities and mental health needs.
**Results:** Residents were not participating in activities for almost three-quarters of observations. They initiated little interaction themselves and received little contact from others. The levels of problem behaviour are low. Inter-rater reliability for these higher frequency occurrences, was acceptable, but was not so for less frequent occurrences, therefore types of activity, interaction, contact and problems should be interpreted with caution.

**Conclusions:** Recommendations were made for staff training to include increasing activities residents participate in and initiating more interaction including both conversation and assistance.
Introduction

Theoretical rationale

The move from institutional hospital based care to community care is well established within the learning disability community. Initially people with mild learning disabilities moved (Felce, Lowe and Blackman, 1995), but the closure of many long-stay beds saw increasing numbers of people with more severe learning disabilities and challenging behaviours resident in community housing. The move from hospital to the community has not led to an automatic transformation of quality of life (Felce et al., 1995).

For many researchers quality of life encompasses two aspects, objective conditions of a person's life and their subjective satisfaction (e.g. Emerson, 1985; Cummins 1992, both cited in Felce and Perry, 1995a). Much research has looked at service quality and evaluation, to assess objective conditions (e.g. Raynes, 1988, cited in Perry and Felce, 1995).

Studying subjective experiences of quality of life for people with severe learning disabilities is a methodological challenge (Taylor and Bogden, 1996). Even when questions are presented in a range of ways, some people with severe learning disabilities and the majority of those with profound learning disabilities are not able to respond (Sigelman, Schoenrock, Winer, Spanhel, Hromas, Martin, Budd and Bensberg (1981), cited in Felce and Perry, 1995a). Acquiescence has also been identified as a problem with this group of clients (Sigelman et al (1981), cited in Felce and Perry, 1995a). Asking a 'significant' other has been one way to avoid the
problems associated with asking individuals themselves, but how valid a method of measuring 'subjective' elements of quality of life this is, is debatable (Felce and Perry, 1995a). For many individuals with severe to profound learning disabilities objective measures are the only sound, though limited method of assessing quality of life (Felce and Perry, 1995a).

Measures of levels of engagement and activity have been taken to be important aspects of quality of life (Felce, 1997, cited in Jones, Felce, Lowe, Bowley, Pagler, Strong, Gallagher, Roper, and Kurowska (2001). Examples of engagement in activity include the extent to which individuals are involved in personal, leisure, household, social or other pursuits. The opposite includes being passive, having nothing to do or participating in purposeless or challenging behaviour (Felce and Emerson, 2000, cited in Jones et al, 2001).

Studies looking at levels of engagement in activity in community homes have found these to be superior to those in institutional care and larger community units. For example Thomas, Felce, de Kock, Saxby and Repp (1986) cited in Holland and Meddis, 1993) found client engagement in appropriate activities was low in institutional settings (3% non-social, 1% social), it was higher in 25-place community units (11% non-social, 1% social) and higher still in smaller homes (40% non-social, 7% social).

Positive findings have not been replicated for all people with learning disabilities. Studies have shown people with more severe learning disabilities are less engaged in community settings, than more able clients (Felce and Perry, 1995b). Felce and Perry
(1995b) found that despite expectations to the contrary, clients with greater disabilities did not receive as much input from staff as their more able counterparts. In their study of 15 community residences for people with learning disabilities they found that staff in houses for more able residents interacted more with residents, on average (32% of the time) than those in houses for less able residents (20% of the time). They found staff: resident interaction to be significantly positively correlated with resident ability, and negatively correlated with the presence of challenging behaviour.

While studies have shown that levels of attention from staff are higher in community residences, than that typical of institutions, much interaction is in the form of conversation (e.g. Felce and Perry, 1995b; Hewson and Walker, 1992 cited in Felce, Lowe and Blackman, 1995). Conversational forms of interaction do little to enable residents to participate in activities (Jones et al, 2001).

Jones et al (2001) report ways of increasing levels of engagement in activity, these include:

1 - increasing assistance residents receive from staff.
2 - increasing positive staff contact.
3 - having a specialised service orientation.
4 - ensuring procedures are in place for planning and organising activities.
5 - staff working separately with individuals or in small residential groups.

Reduction in levels of challenging behaviour can lead to improvements in quality of life, through increased opportunities. Although challenging behaviour as a single term provides little understanding of the motivation and maintaining factors for the
particular individual (Felce et al, 1995), it seems common sense that if an individual is actively engaged then the opportunities for challenging behaviour will be reduced.

Although not all challenging behaviour is associated with mental health problems, people with learning disabilities are at increased risk of having mental health problems (Bernal and Hollins, 1995). Under stimulation and lack of employment may lead to impairment of both physical and mental health (Mental Health National Service Framework, 1999). Therefore, it is especially important to ensure people with learning disabilities are engaged in meaningful activity.

**Purpose of this study**

Staff in a residential home identified that residents were not engaged fully and the clinical psychology department were involved in supporting staff around many residents' challenging behaviour. Time and money had been set aside for staff training and the team wanted to know where this needed to be targeted. The purpose of the study was to assess residents' current quality of life through measuring levels of engagement in activities, social behaviour by the resident, contact by staff and problem behaviour, and mental health problems. The information from the study would be used to make recommendations about the content of staff training and to act as a baseline measure to evaluate its effectiveness.

This was an exploratory study therefore there was no formal hypothesis.
Method

Design

This was an observational study using momentary time sampling of activity, social behaviour, staff contact and problem behaviour.

Setting

The residential unit is a purpose built, single storey home for seven people with moderate to severe learning disabilities and challenging behaviour. The home is situated on a housing estate in South East London. The unit is staffed and managed by a voluntary organisation. There are three members of unqualified staff and one member of qualified staff on duty during the day.

Participants

All seven residents were included in the study. Their ages range from 41 to 49 years (mean age = 43). Six residents were men. One resident was black, while the others were white. Residents had moderate to severe learning disabilities. Two residents had a diagnosis of autism. Residents presented with a range of challenging behaviours (although not all present currently), these included: throwing objects at others, agitation, hitting, pushing, kicking, ripping clothes and self-injurious behaviours including biting arms, head banging, hitting self and scratching arms and legs.
Measures

Momentary time sampling

Momentary time sampling techniques of direct observation allow several behaviours to be observed and recorded at the same time. At twenty-second intervals a note was made of the resident’s behaviour on four categories: activity, social behaviour, staff contact and problem behaviour. Pocket Personal Computers were used to record the data and information was coded according to codes devised by Beasley, Hewson, Mansell, Hughes and Stein (1993) (see appendix for list of codes and explanations).

Health of the Nation Outcome Scales – Learning Disabilities (HoNOS-LD)

The HoNOS-LD is an outcome measure specifically adapted for people with learning disabilities. It was designed for use with people with learning disabilities and mental health needs as a measure of outcome for therapeutic intervention. In this study it was used as a baseline measure. The HoNOS-LD contains 18 questions including ‘behavioural problems directed towards others’ and ‘occupation and activities’. Informants are asked to rate residents behaviour over the past four weeks, on a five point scale with 0 = no problem and 4= very severe. Scores are summed to produce an overall score.

The HoNOS-LD has been shown to have good levels of inter-rater and test-retest reliability (e.g. Avilia, 1999). It has been used for people living in staffed groups homes (Avilia, 1999).
Procedure

Observations took place over a two and a half week period. Two members of staff from the home and three psychologists conducted observations. All observers had been trained in the use of momentary time sampling techniques. Inter-rater reliability was checked.

Each resident was observed at some point during the day they usually stayed at home (their training day) and during late afternoon/evening, after they had returned from the day centre. These times were chosen as they provided residents with the opportunity to participate in leisure and domestic activities. The majority of observations were carried out in public places. Where residents entered private areas, this was considered to be a missed observation. Observations were conducted in 10-minute slots. Observers watched residents for three seconds before and after the interval, in order to ascertain the purpose of particular behaviours.

Staff who knew the residents well completed the HoNOS-LD.
Results

Observational Data

Observational data was downloaded onto the MTS Win programme and data was analysed.

The number of minutes each resident was observed can be seen in table 1 below. The total number of minutes of observations was 660 minutes and the mean minutes of observation per resident was 94.

Table 1: Number of minutes of observations for each resident.

<table>
<thead>
<tr>
<th>Resident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minutes</td>
<td>120</td>
<td>120</td>
<td>90</td>
<td>70</td>
<td>40</td>
<td>100</td>
<td>120</td>
</tr>
<tr>
<td>observed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Inter-rater reliability of observations

Dividing the total number of agreements of occurrence by the total agreements plus disagreements for codes and multiplying it by 100 calculated the percentage occurrence agreement on each code. A similar technique was used to calculate percentage non-occurrence agreement for each code (Felce and Perry, 1995b). The reliability data for activity, social interaction, contact and problem behaviour are given in table 2.
Table 2. Inter-rater reliability for observational codes

<table>
<thead>
<tr>
<th>Category</th>
<th>Occurrence reliability (%)</th>
<th>Non-occurrence reliability (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No activity</td>
<td>83.3</td>
<td>42.5</td>
</tr>
<tr>
<td>Other activities</td>
<td>42.5</td>
<td>83.3</td>
</tr>
<tr>
<td>(average of all categories)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No social behaviour</td>
<td>91.2</td>
<td>35</td>
</tr>
<tr>
<td>Social behaviour</td>
<td>5</td>
<td>91.2</td>
</tr>
<tr>
<td>(average of all categories)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No contact from others</td>
<td>95.9</td>
<td>38.5</td>
</tr>
<tr>
<td>Contact from others</td>
<td>6.3</td>
<td>95.9</td>
</tr>
<tr>
<td>(average of all categories)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problem behaviour</td>
<td>73.7</td>
<td>7</td>
</tr>
<tr>
<td>Problem behaviour</td>
<td>7</td>
<td>73.7</td>
</tr>
<tr>
<td>(average of all categories)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Percentage agreement for occurrence of no activity is high (70% or above, Murphy 1987) as is no social act by the resident, no contact from others and no problem behaviour. The percentage agreement between observers for type of activity, type of social act by the resident, type of contact and type of problem behaviour is lower than desirable and therefore should be interpreted with caution.

Results from observations

The graphs below show the levels of activity, social behaviour, contact from others and problem behaviours. The percentages do not necessarily add up to 100, as more than one behaviour in each category can be recorded at one time. For some observations no recording was made, this will also affect the percentage.

Graph 1 below shows the percentage occurrence of type of activity for all residents, across all observations. For 75.3% of observations residents were not engaged in any activity. 14.5% of observations residents were engaged in leisure/ recreational
activities and for 6.5% of observations residents were engaged in personal/self care activities. For 0.3% of observations residents were engaged in other tasks.

![Graph 1: Activities for all residents](image)

The table below shows the range of activity levels across residents, percentage time spent not engaged in activities ranged from 41% of observations (for resident 6) to 95% of observations for resident 2.

### Table 3: Activity data for individual residents.

<table>
<thead>
<tr>
<th>Resident</th>
<th>No activity (%)</th>
<th>Leisure/recreation (%)</th>
<th>Personal/self care (%)</th>
<th>Other practical tasks (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>87</td>
<td>0</td>
<td>9.8</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>95.2</td>
<td>0.8</td>
<td>1.3</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>89.2</td>
<td>0.4</td>
<td>9.7</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>66.8</td>
<td>13.9</td>
<td>10.6</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>79.8</td>
<td>16.5</td>
<td>3.8</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>41.4</td>
<td>55.9</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>7</td>
<td>63</td>
<td>21.3</td>
<td>7.6</td>
<td>1.5</td>
</tr>
</tbody>
</table>
Graph 2, below, shows the percentage occurrence of social behaviour by all residents over all observations. As the graph indicates there were limited occurrences of social behaviour by the residents. For 89% of observations residents initiated no social act. For 3.1% of observations there were clear social acts, 2.5% of observations they were unclear and for 1.4% of observations the social act was directed towards the observer.

The graph below shows the contact residents had from staff, visitors and other residents. For 89.7% of observations residents received no contact from others. Of the contact they did receive they received mainly neutral or indeterminate contact from staff (5.7%), with limited contacts being positive (0.9%). There were instances of negative contact (0.2% of observations) and some contact from other residents (0.1%). Assistance occurred in 0.6% of observations.
Graph 3: Contact from others for all residents

Graph 4, below, shows the percentage of occurrence of problem behaviour. The majority of observations recorded no problem behaviour (72.3%). 19.9% of observations recorded some form of self-stimulatory behaviour. No aggression towards others was recorded and only minimal amounts of self-injury and damage to property. 3.7% of observational periods saw inappropriate vocalisation.
The HoNOS-LD scores for each resident can be seen in the table below. The scores range from 6 to 30 with high scores indicating more severe levels of difficulty.

<table>
<thead>
<tr>
<th>Resident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>HoNOS-LD Score</td>
<td>21</td>
<td>30</td>
<td>26</td>
<td>25</td>
<td>6</td>
<td>11</td>
<td>27</td>
</tr>
</tbody>
</table>
Discussion

Aim of study
The aim of the study was to examine activity levels, social behaviour, contact from others, problem behaviour and mental health issues among residents in a group home for people with moderate to severe learning disabilities and challenging behaviour, with a view to making recommendations about staff training.

Main findings
Residents spent less than twenty percent of observations engaged in any meaningful activity. This is less than would have been expected for a relatively small group residence. Thomas et al., 1986 found the number to be 40% in a small group residence. They engaged in limited social contact and received limited contact from others. Overall there were few instances of problem behaviour.

Activities
Activities participated in included leisure/recreation activities (14.5% of observations), personal/self care (6.5%) and other practical tasks (0.3%). It would have been expected that residents would be engaged in recreation, personal activities and other practical tasks at the times of day when observations generally took place.

Recommendation: Staff training to include ways to increase resident involvement in leisure activities and household tasks. For residents to be supported to participate in appropriate activities.
Social behaviour by resident

Residents demonstrated very little social behaviour, for most of the observations they demonstrated no social behaviour at all. These results are consistent with the fact that residents have moderate to severe learning disabilities and limited communication skills. The low level of social behaviour directed towards the observers suggests that the observations had limited impact on residents’ behaviour.

Recommendation: Staff training to include ways for staff to initiate interaction as residents are unlikely to do this.

Contact from others

For 88.7% of observations residents received no contact from others. Of the contact they did receive the majority was neutral or indeterminate. There were instances when residents received positive contact, assistance and some negative contact from staff. There was extremely limited occurrence of contact from other residents.

The lack of assistance is of concern, especially regarding the levels of learning disabilities of the resident group – but is not inconsistent with findings from other studies e.g. Felce and Perry, 1995b.

Recommendation: Training to emphasise the importance of staff interacting more frequently with residents – ideally interaction to include assistance, as well as positive conversation.
Problem behaviour

Levels of problem behaviour were relatively low, for 72.3% of observations no problem behaviour was observed. Problem behaviours that did occur included self-stimulatory behaviour, there were few instances of self-injury, damage to property and inappropriate vocalisations. These are fairly low levels of problem behaviour.

HoNOS-LD scores

The range HoNOS-LD scores underline individual differences between the residents. Although not all residents scored high levels, some individuals did.

Recommendation: Staff team to be aware that some individuals also have underlying mental health issues, training to include increasing understanding of this.

Problems with design and study

Limited observations

For some individuals in the study the number of minutes of observations was limited. This highlights the difficulties of conducting studies within service settings, as observers were ill and unable to complete the requested number of observations within the time frame.

Skewed to more activities

Despite the low levels of activity, observations took place at times thought likely to be the most busiest so data is likely to be skewed towards more positive findings and may mask less active times. However, some activities may be underreported, for
example residents were not followed out of the building on trips out, so this was not recorded.

**Inter-rater reliability**

Overall levels of inter-rater reliability were within acceptable limits for behaviours that occurred most frequently—no activity, no social behaviour, no contact from others and no problem behaviour. Observers did not reliably identify what types of social act residents initiated, what type of contact staff initiated and some types of problem behaviour. Therefore some of these findings may not be reliable. Reliability could be improved by more training, more frequent reliability checks and longer observation periods.

**Observer presence effecting resident and staff behaviour**

There were limited contacts from residents to the observers. Observers were ‘trained’ in making as little impact on residents as possible, for example being quiet and trying to blend in with surroundings. Resident/staff interaction and resident activity levels suggest that the observations did not unduly affect staff behaviour.

**Difficulties recording infrequent behaviours**

Some behaviour in the home occurred relatively infrequently. Momentary time sampling techniques are not the most effective method of recording this (Murphy, 1987). Other observational techniques may have been more appropriate for this, for example continuous monitoring, perhaps using video technology (Murphy, 1987).
Links with previous findings

Despite all of the above considerations, these findings are similar to those in other small group homes for people with moderate to severe learning disability. For example Jones, Perry, Lowe, Felce, Toogood, Dunstan, Allen and Pagler (1999) found mean levels of engagement in activities to be 33.1%, in houses for between three and four residents. The group home studied here is larger than those reported by Jones et al (1999), which may explain the lower levels of resident engagement.
References


### Appendix I

#### Codes and Definitions:

Summary of codes (from Beasley et al., 1993)

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>A No activity</td>
<td></td>
</tr>
<tr>
<td>B Leisure/Recreational/Unstructured educational</td>
<td></td>
</tr>
<tr>
<td>C Personal/self-care</td>
<td></td>
</tr>
<tr>
<td>D Practical tasks/chores using electrical/gas equipment</td>
<td></td>
</tr>
<tr>
<td>E Other practical tasks/chores</td>
<td></td>
</tr>
<tr>
<td>F Work/‘formal’ education</td>
<td></td>
</tr>
<tr>
<td>L Out walking</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SOCIAL BEHAVIOUR BY CLIENT</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>G No social act by client</td>
<td></td>
</tr>
<tr>
<td>H Clear social act by client</td>
<td></td>
</tr>
<tr>
<td>I Unclear social act by client</td>
<td></td>
</tr>
<tr>
<td>J To observer</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CONTACT BY STAFF/ VISITORS</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>M None</td>
<td></td>
</tr>
<tr>
<td>N Positive</td>
<td></td>
</tr>
<tr>
<td>O Negative</td>
<td></td>
</tr>
<tr>
<td>P Neutral/indeterminate</td>
<td></td>
</tr>
<tr>
<td>Q Assistance</td>
<td></td>
</tr>
<tr>
<td>R Contact from other client</td>
<td>(in addition to one of the above)</td>
</tr>
</tbody>
</table>

#### Problem behaviours

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>S None</td>
<td></td>
</tr>
<tr>
<td>T Self-stimulation/stereotypies</td>
<td></td>
</tr>
<tr>
<td>U Self-injury</td>
<td></td>
</tr>
<tr>
<td>V Aggression to others</td>
<td></td>
</tr>
<tr>
<td>W Damage to property</td>
<td></td>
</tr>
<tr>
<td>X Inappropriate vocalisation</td>
<td></td>
</tr>
<tr>
<td>K In seclusion</td>
<td></td>
</tr>
<tr>
<td>Y Missed observation</td>
<td></td>
</tr>
<tr>
<td>Z Reminder</td>
<td></td>
</tr>
</tbody>
</table>
Definitions of behavioural categories

The codes for 'Activity'

NO ACTIVITY:
- This is non-purposeful activity.
- Walking, sleeping, holding materials, sitting, standing, lying, or the transition from lying to standing (but if the person moves furniture out of the way then this is PERSONAL/SELF-CARE).
- Non-purposeful activities such as fiddling with buttons, smoking, tapping a pencil, wiping nose on hand or sleeve, making minor adjustments to clothing once dressed (unless this has been established as a stereotypy).
- Holding hands (unless in the act of reaching out), thumb sucking, nail-biting, nose-picking, talking to oneself quietly etc., are also coded as no activity.

LEISURE / RECREATIONAL / UNSTRUCTURED EDUCATIONAL:
- Using recreational or leisure materials purposefully or participating in an activity which does not involve materials (e.g. a football game).
- Getting out or putting away leisure materials, switching the television, radio or record player on or off, actively watching or listening to the TV or radio.
- Walking carrying leisure materials between the place of storage and place of use.
- Participating in a formal teaching session is WORK / FORMAL EDUCATION.

PERSONAL / SELF-CARE:
- Getting ready for a self-help activity.
- E.g. feeding self (not from the floor or other person’s plate).
- Also includes movements to furniture in the act of sitting down or standing up.
- If in doubt about whether materials handled are personal, code as practical task or chores (i.e. PRACTICAL TASKS or OTHER PRACTICAL).
- Also include serving oneself at mealtime (but carrying a plate, laying table, clearing away or serving other people is all coded as OTHER PRACTICAL).

PRACTICAL TASKS / CHORES USING ELECTRICAL OR GAS EQUIPMENT:
- Getting ready for or doing housework or out-door work which involves using electrical or gas equipment.
- E.g. power tools, cooker, kettle, washing machine, tumble dryer, microwave, blender, electric can opener, vacuum cleaner.
- Includes switching on and off, manipulating the equipment, setting it up or packing it away, loading or unloading it.
- Includes stirring or attending to food whilst cooking it.
- Excludes using the refrigerator (OTHER PRACTICAL as it is a special kind of cupboard).

OTHER PRACTICAL TASKS / CHORES:
- Simple domestic or outdoor chores.
- E.g. Sweeping, laying or clearing the table, picking flowers, serving for others, washing up, opening and closing doors or windows, operating light switches,
moving furniture (other than minor movements in the course of sitting down or standing up).
• Carrying these materials from place of storage to place of use.
• Also includes use of refrigerator.

WORK / 'FORMAL' EDUCATION:
• A formal teaching session (group or individual) in which a defined skill is being taught.
• Should not include practise of skills without teacher interaction, or doing a work-task.

OUT WALKING:
• Code when the client is out of the living unit, walking, running or roaming with or without a member of staff.
• Include standing, loitering or sitting down when out-of-doors or under covered walkways.
• If the client undertakes a new activity such as entering a shop, operating equipment, interacting with people, feeding animals and so on, code the relevant activity instead (e.g. OTHER PRACTICAL as the client opens the door to the shop, PRACTICAL EQUIPMENT for using a hedge trimmer).
• If the client is absconding and this has previously been recorded as a problem behaviour then do not code it as WALKING but as NO ACTIVITY and the key allocated for absconding.

Notes for activity codes:
• Activities can be coded together (e.g. watching television and drinking tea simultaneously) therefore enter both codes.
• If carrying materials from one place to another, code as engaged (e.g. walking carrying a teapot = OTHER PRACTICAL). The exception however is carrying a handbag, wallet, coat, mascot (e.g. doll) or other object which the client is reported to always carry.
• If just walking at the moment of observation, wait for three seconds to see whether the behaviour is fetching. If the client picks up an object within 3 seconds, code this as an activity, e.g. walking (at the moment of observation) and turns on radio two seconds later (LEISURE).
• If the member of staff does the task for the client then code the client behaviour as NO ACTIVITY. E.g. if staff tie up the shoe laces for the client, code it as NO ACTIVITY and NEUTRAL.
• If the assistance is actually enabling the client to do the task, code PERSONAL and ASSIST. If the client is fumbling with materials in a way that is unclear whether they are engaged in an activity (e.g. repeatedly taking their socks off and putting them on) code as NO ACTIVITY. If this is coded for the first few times as an activity (in this case PERSONAL) it does not matter.

The codes for 'Social behaviour by client'
NO SOCIAL ACT BY CLIENT:
• The client should not be engaged in any form of communication or interaction.
CLEAR SOCIAL ACT BY CLIENT:
- A recognisable attempt by the client to engage in a form of communication with someone else (e.g. a member of staff or another client).
- This includes recognisable attempts to speak, vocalise, sign or attend to (if the interaction had already commenced at the start of the observation).
- Include also gestures that appear intended to gain or maintain the attention of another person (as distinct from arm waving).

UNCLEAR SOCIAL ACT BY CLIENT:
- The client may be trying to interact but this is unclear.
- Include the act of receiving something handed to them (reaching and grasping).

TO THE OBSERVER (REACTIVITY):
- The client is reacting to the presence of the observer.
- E.g. by pointing, attempting to engage in conversation, or to gain attention.
- This code provides some assessment of subject reactivity.

Notes for ‘Social behaviour by Client’ codes:
- If the client merely mutters or talks to nobody in particular then this is not coded.
- There must be a definite focus of attention. It is not necessary for the other person to respond to the client’s attempts to communicate in order for it to be coded.
- If the client’s attempts to get the attention of a person are through problem behaviour (e.g. screaming) then this is coded using the problem behaviour codes.

The codes for ‘Contact by Staff / Visitors’

NONE:
- There is no interaction from the staff member to the client.

POSITIVE:
- The staff praises or encourages the client, or visibly demonstrates affection.

NEGATIVE:
- The staff contact with the client is negative, including shouting, expressing disapproval, restraining, forcibly moving the client, or denying them something.

NEUTRAL:
- All contact from staff which is neither positive or negative,
- E.g. conversation or chat, simply presenting materials (e.g. handing over a book).
- ‘Processing’ the client (e.g. doing their coat up, rather than helping them do it).

ASSIST:
- Help in the form of verbal instructions, demonstration, or any level of physical help or guidance that appears intended to result in a positive activity.
- E.g. pointing; positioning materials (e.g. bowl or coat ready); modelling a task.
- Verbal prompts could include: ‘put it on the top’, ‘do it like this’, (while demonstrating). Don’t include: ‘sit down’, ‘go away’, ‘stop it’, ‘come here’, etc.
- Restraint that stops someone doing a positive activity is NEGATIVE CONTACT.
If there is no specific client activity (e.g. pushing someone to walk or pushing their wheelchair) – then both of these are NEUTRAL CONTACT.

OTHER CLIENT TO OBSERVED CLIENT:
• Use this code if the other person in contact with the client is another client.
• This should always be coded with one of the other codes to indicate the nature of the other client’s contact.

Notes on ‘Contact by Staff / Visitors’:
• Do not code POSITIVE, NEGATIVE OR NEUTRAL interaction on the basis of what is already coded as ASSIST.
• Only code additional contact (e.g. chatting whilst guiding is NEUTRAL CONTACT plus ASSIST).

The codes for ‘Problem Behaviour’

Individualised definitions of problem behaviours can be provided for each client. If a problem behaviour occurs which has not been previously identified, either use one of the first five ‘problem’ keys, if the new behaviour fits into the category, or allocate another key and make a note of what the new key represents (number keys may have to added to the variable list in order to do this).

NONE:
• This code should be used when there are no behaviours present which present a problem or challenge.

SELF-STIMULATION / STEREOTYPIES:
• Repetitive or ritualistic movements.
• The movement must be repeated in the 6 second period (3 seconds before or after observation point) or, if a complex ritual, must continue throughout the period.
• Partial or single movements which are within the range of normal body movements (e.g. stretching neck, tapping fingers on face) are not coded.

SELF-INJURY:
• Any activity which directly harms the person doing it.
• E.g. head banging, eye poking (verbal threats to do it are INAPPROPRIATE VOCALISATION).

AGGRESSION TO OTHERS:
• Any activity which directly harms another person.
• E.g. hitting, kicking, pinching, pushing, spitting on, etc., to someone.
• Or physical threats such as fist-waving (verbal threats to do it are INAPPROPRIATE VOCALISATION).

DAMAGE TO PROPERTY:
• Any activity which directly damages, overturns or disarranges property.
• E.g. throwing crockery; cutlery; smashes window; tips over chair, table or vase; pours liquid on to carpet; chewing or picking at clothing or furniture; dropping food or other materials on to the floor.

INAPPROPRIATE VOCALISATION:
• Includes swearing; verbal threats; shouting; growling; roaring; screaming; belching; burbling; crying; talking loudly to self; laughing hysterically; verbal interruption.
• Talking quietly to oneself is not coded as a problem.
• Neither is disagreeing, (e.g. just saying 'no'), nor is conversing where the conversation doesn't make much sense to you (unless it includes pestering/interrupting).

OTHERS (e.g. Number keys 0 to 9):
• Any other inappropriate behaviours.
• Examples might include the act of incontinence, public masturbation or intercourse (but not minor kissing or petting), stripping, spitting, pica, touching faeces, pestering, interrupting by touch.

SECLUSION:
• When client has been placed in seclusion and is not available for observation.

Notes for Problem behaviour codes:
• For SELF-INJURY, AGGRESSION or DAMAGE code the behaviour if the person does it in the 6 second period (e.g. person bangs table in three seconds before observation point and has arm raised at moment of observation, shaking with rage, code DAMAGE).
• More than one problem behaviour can be coded at a time.

Reminder and missed observation keys

REMINDER:
• To be used when the observer needs to be reminded of an event that requires further interpretation.
• A note should be jotted down at the time and written up after the observation and presented at the same time as the data.

MISSED OBSERVATION:
• To be used when the observer is unable to see the client clearly enough to enter a code or something else prevents an observation being made.
• This excludes when a client has been placed in seclusion.
Appendix II

Copy of letter sent confirming feedback to staff team.
Dear Anna

RE: Your Small Scale Research Project

Thank you for your work in during your core placement with Adults with Learning Disabilities. I can confirm that you worked with the staff team at in assessing engagement levels for the service users living there, analysing the findings and presenting the results back to the staff team. During that time, the manager of the service was , and you and I discussed this work with him in the context of implementing the Active Support approach in the service.

Yours sincerely
Appendix III

Copy of ethical scrutiny form, confirming study did not need ethical scrutiny.
The nature of the proposed project is such that I am satisfied that it will not require scrutiny by the trust’s ethical committee.

Name of Supervisor: 

Signature of Supervisor: ..............................................................

Name of Trainee

Title of SRRP: An audit of a group home for people with learning difficulties and challenging behaviour

Sampling technique:

Date: 14/6/2022

.........................................................
‘I’m not a woman, I’m a glamour puss’.

Male transvestites’ perceptions of gender
Introduction

Transvestism, or cross-dressing behaviour, has been labelled an ‘illness’ by Western cultures and can be found in the Diagnostic and Statistical Manuals – Fourth Edition (American Psychiatric Association, 1994) under ‘transvestic fetishism’ (Dzelme & Jones, 2001). However, in order for a diagnosis of a mental disorder to be made, the behaviours need to have occurred in a male heterosexual for a period of at least six months and importantly the fantasies, sexual urges or cross-dressing behaviours must cause ‘clinically significant distress or impairment in social, occupational or other important areas of functioning’ (APA, 1994). For many cross dressers, levels of distress are not sufficiently significant to warrant a diagnosis. For those who do not suffer a significant degree of guilt or shame or whose relationships do not suffer as a result, it is not appropriate to consider it a ‘problem’ at all (Bordan & De Ricco, 1997).

Transvestism must not be confused with transsexualism, where individuals wish to live as a member of the opposite sex full time. It is uncommon for transvestites to live as women full time or to wish to. Docter (1988, cited in Bordan & De Ricco, 1997) found that fewer than 5% of those who fulfilled the criteria for transvestism ever lived in their transgender mode.

For the purpose of this study a working definition of transvestism was taken to be men who dress up in women’s clothing, who described themselves as transvestites (or a variation, such as ‘t-girl’ or ‘tranny’) and who had not undergone gender reassignment surgery.
While it is generally taken that whether a child is male or female is determined biologically at birth, gender can be seen as a distinct entity from biological sex: masculine and feminine gender roles are determined by society (Dzelme & Jones, 2001).

Wetherell (1996) argues that the use of quantitative measures of gender (such as the Bem Sex Role Inventory, Bem (1974, cited in Wetherell, 1996), supports the assumption that masculinity and femininity are traits, that these traits remain constant over time and that qualities within each trait are distinct. Wetherell (1996) suggests that these assumptions underlie the use of an inventory and that the use of more qualitative methods can demonstrate how characteristics can be fluid and change between contexts.

Men that dress in women's clothes are often criticised as presenting themselves as caricatures of women, as 'pantomime dames' (Greer, 1999). A few quantitative studies have succeeded in dispelling some myths about why this might be. For example, Bullough, Bullough & Smith (1983) looked at transvestites' childhood experiences and found that neither having an absent father nor a lack or interest in sport were present in the childhood experiences of transvestites. Perhaps as would be expected, cross-dressing was present (Bullough et al. 1983). However, there does not seem to be much research looking at dispelling other myths. This research was interested in hearing male transvestites' views of gender, in hearing more about what may have influenced these views and what has influenced how they present themselves when cross-dressing. Answers to such questions could have been sought
using a questionnaire design, but it was felt that a qualitative approach would allow a more in-depth, detailed investigation.

Method

Participants
The participants were recruited using ‘snowball’ techniques (Fife-Schaw, 2000) using a contact known to one of the researchers. Participants all knew the contact socially, through transvestite clubs. This is important to bear in mind when considering some of the comments and thoughts, as by implication participants were part of the same network. Using this technique it was not possible to sample individuals who dress up in women’s clothing privately.

Participants were eligible to take part in the study if they were over 18 years old, were fluent in English, were biologically male, would describe themselves as being a transvestite (rather than transsexual) and were not currently being treated for a psychiatric problem.

Would-be participants were sent a copy of the ‘information for participants’ sheet electronically, via e-mail. They were asked if they would be interested in participating and given the e-mail address and mobile phone number of one of the researchers. Participants contacted the researcher and arrangements were made about when and where to meet.
Four participants took part in the study. Ages ranged from 34-54 years, with a mean age of 43, all were white British. One was educated to degree level, two to diploma and one to O-level. Two were divorced/ separated, one was married and one was single. Three described their current relationship status as being single and one was living with a partner. Three stated their sexual orientation was bisexual and one heterosexual. Two had children.

**Interview procedure**

The interview schedule was created through a process of brainstorming – this enabled the researchers to discuss ideas and identify topics that warranted further exploration. The schedule initially centred on transvestites' views of womanliness and perceptions of women. However, following discussions with our (male) supervisor, it was decided to also include transvestites' views of men.

Due to time restrictions it was not possible to pilot the schedule. However, as the first interview elicited such rich verbal data the researchers decided not to change it. A copy of the introduction to participants and interview schedule can be found in appendix 1.

Interviews took place over a three-week period. One interview took place in a participant’s home, two in a researcher’s home and one in a neutral setting (a café). For all interviews two researchers were present. One interviewed, while the other researcher ensured recording equipment was working and took process notes, but also acted as safety measure.
At the time of the interview participants were given the information sheet to read again and asked to sign a consent form (copies in appendix 2). Each participant also completed a demographic information form (appendix 2). Interviews lasted between one and two-and-a-half hours; informal discussions continued after the formal questions had ceased. Each interview was audiotaped (with participants' consent) and later transcribed verbatim.

All four researchers were heterosexual women in their late twenties. Three were white and one was of mixed race (white and Asian). They were all in their second year of a doctoral level training in clinical psychology. All four had considerable experience of interviewing and working clinically. One researcher was familiar with transvestism through her social network. The researchers approached the topic with curiosity, but had no fixed beliefs regarding transvestites' views of gender (please see appendix 3 for a more detailed account of the researchers' standpoints).

**Analytic approach**

Data were analysed using the procedure IPA (interpretative phenomenological analysis) (Smith, Jarman & Osbourn, 1999; Macran, Stiles & Smith, 1999). IPA was chosen over other qualitative methods because it is concerned with subjective realities and because it assumes that a person's thoughts, emotions and experiences can be inferred through interpretation of texts and transcripts (Holt & Slade, 2003).

The transcripts were read and re-read by each researcher (a copy of one transcript can be found in appendix 4). Notes were made of any interesting statements or comments regarding the participants' views of women, gender and transvestism. The notes took a
number of forms, some summarised what had been said, some made associations and some were preliminary interpretations. One transcript was identified as containing the richest information. Each researcher reviewed the notes from this transcript, looking for titles of themes, topics or patterns. These titles were discussed among the researchers until a number of agreed titles emerged.

Using these agreed titles, each researcher reviewed their original transcripts and notes, again noting where titles were similar and where new titles emerged. Once this process was completed the titles were discussed again and a set of new titles agreed. In some cases the titles and themes appeared to cluster together and so a new title or theme was agreed upon. At each point, the transcripts were reviewed to ensure the title fitted with what the participants had actually said. As the process continued, new themes and understandings emerged.

The lists of titles were discussed amongst the researchers and an agreement was reached on how these could be grouped into broader domains. The researchers attempted to present transvestites’ views of women and gender in a coherent manner, as represented by their personal accounts (as suggested by Elliott, Fischer & Rennie, 1999).

As well as providing a coherent account, the researchers tried to maintain a sense of credibility with the data by grounding themes in examples, by clearly stating their perspective and by situating the sample (Elliott et al., 1999).
Analysis

A number of themes emerged from the text and these were clustered into three broad domains. Figure 1 outlines the domains and themes found. The three broad domains were *Perceptions of gender, biology and views in society*, *The story of becoming a transvestite* and *Interpersonal and interactional factors*.

<table>
<thead>
<tr>
<th>Perceptions of gender, biology and views in society</th>
<th>Interpersonal and interactional factors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender within society</strong></td>
<td><strong>Learning</strong></td>
</tr>
<tr>
<td>1. equality and inequality (a) intellectual/logical (b) enjoyment/ behaviour (c) fear( d) roles (e) physical (f) sexual (g) sexual power</td>
<td>13 – learning from/ influence of others (a) family (b) media (c) friends</td>
</tr>
<tr>
<td>2. awareness of society</td>
<td>14 – curiosity</td>
</tr>
<tr>
<td><em>Biology, gender and sexuality</em></td>
<td>15 – discovery/ evolving/ experimenting</td>
</tr>
<tr>
<td>3 – biology vs gender</td>
<td><strong>Purpose</strong></td>
</tr>
<tr>
<td>4 – sexuality</td>
<td>16 – confidence/ self-belief</td>
</tr>
<tr>
<td>5 – spectrum (a) gender (b) sexuality</td>
<td>17 – opportunities as a transvestite</td>
</tr>
<tr>
<td><strong>Physical appearance</strong></td>
<td>18 – identity of self/ continuity vs compartmentalise</td>
</tr>
<tr>
<td>6 – physical appearance (a) pride (b) creativity (c) attractiveness (d) preparation</td>
<td>19 – object of own desire</td>
</tr>
<tr>
<td><strong>Attributes</strong></td>
<td><strong>Consequences</strong></td>
</tr>
<tr>
<td>7 - feminine attributes/ personality</td>
<td>20- struggle vs coping</td>
</tr>
<tr>
<td>8 – masculine attributes (a) physical appearance (b) behaviour (c) roles (d) personality (e) emotions</td>
<td>21- vulnerability and mental preparation</td>
</tr>
<tr>
<td><strong>The story of becoming a transvestite</strong></td>
<td>22- ‘coming out’ vs secrecy</td>
</tr>
<tr>
<td><strong>Learning</strong></td>
<td></td>
</tr>
<tr>
<td>13 – learning from/ influence of others (a) family (b) media (c) friends</td>
<td></td>
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<tr>
<td>14 – curiosity</td>
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<tr>
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<td></td>
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<tr>
<td><strong>Purpose</strong></td>
<td></td>
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<tr>
<td>16 – confidence/ self-belief</td>
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Within the domain of *Perceptions of gender, biology and views in society* were four sub-domains – 'gender within society', 'biology, gender and sexuality', 'physical appearance' and 'attributes'. Within the domain of *The story of becoming a transvestite* were three sub-domains – 'learning', 'purpose of transvestism' and 'consequences'. Within the domain of *Interpersonal and interactional factors* were the themes – emotions (expression and understanding), wanting to belong/fitting in/acceptance, friendships (difference and quality) and being noticed/complimented.

Due to limitations of space the researchers have chosen to discuss separate domains. The domains were divided and distributed randomly. This paper will concentrate on the sub-domains of *Gender within society* and *Biology, gender and sexuality*. Participants' names have been altered to protect their identities and both male and female names are used, to avoid confusion. The female name is presented first, as the majority of participants were dressed in their female attire.

**Gender within society**

This sub-domain contains two themes and deals with the participants' perceptions of how gender is seen within society.

**Theme 1: Equality and inequality.**

Participants viewed the differences and similarities between men and women as being in terms of equalities and inequalities. These were seen to operate on a number of levels. For instance some participants identified that there were equalities in terms of intellect or logic (Diane/ David; Carol/Carl) whereas others felt that this was an area
of inequality - Helen/Howard thought that ‘men seem to have a limited concentration, women seem to be able to concentrate a little bit more’. Jenny/Jim thought that there were differences in terms of ‘slight mental deviations’ and that a woman may be more intuitive and a man ‘would step back and think and perhaps be more logical’.

It was felt that men and women could equally enjoy life and perhaps would have similar fears.

It was highlighted that there is a certain amount of equality between men and women as far as roles are concerned. Jenny/Jim stated that ‘I think the stereotyped divide between the two is a lot less now that it used to be’. She/he said ‘women are doing a lot more of men’s jobs and vice versa these days’. However, inequalities in roles were also highlighted: it was acknowledged that ‘[equality] doesn’t seem to be necessarily to be borne out by the evidence if you read these publications about salaries and positions’ (Diane/David). However, there was hope that ‘society has changed sufficiently now that there are no differences when it comes to employment’ (Diane/David). On a more interpersonal level, Carol/Carl stated how she/he hoped that any relationship they had would be one where each partner had an equal share of the roles: ‘I’ll iron the shirt today, I’ll iron your blouse tomorrow, sort of thing’.

Inequalities were identified in terms of physical differences - ‘I guess most females tend not to be quite as strong as males’ - but then this was qualified with ‘but that is not necessarily strictly true either’ (Diane/David). Differences in terms of reproduction were stressed. This biological difference was also stressed as a particular
difficulty that women might face. Carol/Carl highlighted how women might have difficulties menstruating and that a biological clock might motivate women.

There were equalities noted in terms of sexual desire: ‘I don’t think men and women have a different appetite for sex, just think women are more choosy’ (Diane/David). Differences were noted too, that women were less able to express their sexuality in terms of what they could wear: ‘if you start wearing a lot of cleavage and stockings and show the stocking tops and high heels you’re going to get called, a, a few things’ (Carol/Carl).

There was an inequality highlighted between men and women in terms of sexual power. Diane/David suggests that women have a power when it comes to who and whether they chose to sleep with someone: ‘if a woman wants a man she will pretty much get him’. Carol/Carl also suggested that women hold power: when talking about getting her/his bottom pinched at a party ‘I don’t slap them round the face you see. You would have slapped them’.

Theme 2: Awareness of society.

Participants were aware of the influence of society on gender. For instance Jenny/Jim stated ‘the way that society sort of guides us. It guides us down two set channels’. Society was seen as ‘pigeon holing’ the sexes (Carol/Carl). Some acknowledgement was made that ‘obviously we live in a very male dominated world’ (Carol/Carl), and that society treats men, women and ‘the third gender’ differently. There was a sense of the role society plays in discrimination, this was highlighted as being a challenge that women might face (Helen/Howard).
There was an awareness of how society might view their dressing up. Jenny/Jim said ‘obviously, mainstream society ...would see my behaviour as being Jenny for short periods of time perhaps not normal, or with suspicion.’ Some places are more friendly and used to seeing transvestites, but others may be less so (Jenny/Jim). These difficulties were not necessarily seen as the fault of the individual: ‘It’s not their fault they don’t understand because there’s not enough knowledge on the subject’ (Helen/Howard). There was a sense that society could be changed through increased contact with transvestites. When talking about a club - ‘People do walk past and the local people do know it exists. They don’t have a problem with it and they don’t interfere. ...hopefully we’ve erm given them a little bit of education now’ (Helen/Howard).

**Biology, gender and sexuality**

This sub-domain contains three themes and deals with the issue of biology, sexuality and gender.

**Theme 3: Biology vs. gender**

This theme dealt with the complex issue of being born a particular sex (male) but expressing both feminine and masculine traits. Diane/David states ‘Somebody once asked me the question if I thought I was male or female, I don’t think, well I think I am male but have some femininity and masculinity... Diane is an outlet for my femininity’.

Carol/Carl agreed that while born male, he seemed to have two identities.
Jenny/Jim approaches the biology/gender issue in a slightly different way – arguing a case against society’s stereotypes: ‘there’s plenty of other people going around with short skirts and high heels on, just they’re probably born as female rather than as male’.

There is a certain amount of effort that needs to go into shaping what is biologically male into ‘portraying this illusion of a female’ (Helen/Howard).

**Theme 4: Sexuality**

After the interviews, several of the interviewees commented that they were surprised that the interview did not question them as much about sex, as part of the definition of transvestism is that it involves some sexual elements. Although the interview did not directly address this issue, the theme of sexuality did emerge.

Three of the participants talked about how they enjoyed dressing up. Early memories of dressing up in stockings as a child were of sexual enjoyment: ‘it gave me a little buzz in the nether regions’ (Carol/Carl). But the sexual element is not necessarily an issue: ‘I don’t get turned on by doing this, but there is a kind of weird attraction’ (Diane/David). Jenny/Jim found that an attraction to high heels and short skirts meant that ‘when I found I could wear the high heels and a short skirt… it was a buzz, it was a real … adrenaline rush’. In fact dressing as Jenny for the afternoon ‘is like having sex for five hours’.

Other elements of sexuality were issues regarding sexual orientation. Two participants mentioned how they had questioned their own sexuality when they began dressing up.
Carol/Carl said – ‘I asked myself, ‘hey hold on a minute am I gay?’ The conclusion was not, but whereas one saw the natural progression of dressing as a women would lead her/him to sleep with a man, the other does not particularly find men attractive, but does find men dressed as women attractive.

**Theme 5: Spectrum (of gender and sexuality)**

Participants seemed keen to stress a spectrum of gender and sexuality. Diane/David and Carol/Carl concentrated more on this theme. Diane/David – ‘You would probably class yourself as female, I don’t know, at one end of that gender spectrum and that there are men that would class themselves as male and at quite the other end, then there are a whole spectrum of things in between the two and personally I believe it’s the same as sexuality’; Carol/Carl describes it as being a ‘sort of fluid sexual diversity’. If nothing else this ‘opens up your perspectives’ (Carol/Carl).

He also has definite ideas on how possible it is to change biological aspects. Despite having friends who are taking hormones and planning to undergo surgery, she/he does not think it is possible to change. She/he recounts telling one friend ‘but you’re not a girl, you never will be a girl’. ‘Even if you change the physical aspects you’re still going to think along certain lines’.

The spectrum of gender also includes the issue of transexualism. Carol/Carl was aware of those transvestites who approach dressing up from a more ‘psychological’ perspective. ‘It becomes more threatening. If you were somebody and you’re with a guy who’s dressed as a woman, ... who wants to become a woman, that’s quite
A threatening for those who ... aren’t interested, and don’t want to understand, for them it’s a sort of psychological problem’ (Carol/Carl). Jenny/Jim also makes the distinction between wanting to be a woman and enjoying dressing up from time to time: ‘I’m just doing this as a hobby that I like doing’. Diane/David agrees ‘I don’t want to be a woman, I just want to express a part of myself’. Carol/Carl puts it aptly ‘I’m not a woman, I’m a glamour puss’.

**Discussion**

The five themes discussed in this paper appeared in all four interviews. The goal in using an intensive, multiple case study approach was to gain a better understanding of transvestites’ perceptions of gender. The reader must make up their own mind as to whether the themes, sub-domains and domains assist in this understanding and form a coherent account (Elliott et al., 1999).

The themes discussed fell under two sub-domains *Gender within society* and *Biology, gender and sexuality*. Themes were ‘inequality and equality’, ‘awareness of society’, ‘biology vs gender’, ‘sexuality’ and ‘spectrum (of gender and sexuality)’.

Caution must be taken when attempting to generalise from these findings as the sample was drawn from a network of transvestites who knew each other. It also needs to be stressed that while they may be unrepresentative of ‘closeted’ transvestites, they may also be unrepresentative in terms of their sexuality. Three quarters described themselves as bisexual, while the majority of transvestites are heterosexual (Docter,
1988, cited in Dzelme & Jones, 2001). If further studies were to be carried out, it would be useful to tap into other networks of transvestites.

Care needs to be taken regarding the speaking position of the researchers. As educated women the researchers were perhaps less likely to accept more ‘traditional’ gender roles (please see appendix for a more detailed discussion). Some participants were a generation above the researchers, so these may have influenced interpretation. Interestingly, three participants dressed up for the interview, while one chose to come in his male persona. One researcher was in the interesting position of feeling that she was interviewing a woman, but that when she came to transcribe the tape was in no doubt of the maleness of the participant.

Arguably by asking participants about their views of gender the researchers were implying that such an entity exists in a format that is possible to discuss. As Wetherell (1996) suggests, by trying to find a masculine/feminine divide, perhaps we were contributing to the assumptions that underlie much research in social psychology – that an entity exists and it is possible to place individuals on a scale (e.g. Bem’s 1974 Sex Role Inventory – cited in Wetherell, 1996). Using a qualitative approach it was possible to see that as far as these participants were concerned concepts such as masculinity and femininity are elastic. Cross-dressing was not so much about becoming a woman, but a way of expressing a different aspect of their personality.
References


Appendix I
Interview schedule and information sheet
Interview Schedule

Study of transvestites and gender.

Aim: This research aims to explore male transvestites' perceptions of women.

Introduction blurb:
I am a Trainee Clinical Psychologist. This means I have a psychology degree, have some work experience and am now on a doctorate training course. All of my work is supervised by qualified professionals. Just to let you know what to expect today, I have several questions about your views of gender. You can say as much or as little as you feel comfortable with. The whole interview should take about an hour.

I will be tape recording our discussion. This is to make sure we don’t miss anything in the flow of conversation. Once I have transcribed the interview, the tape will be wiped clean.

Everything you say will be treated as confidential information. The transcript will be anonymised before it is shared with the other researchers. The only time I would break confidentiality and share what you say with anyone else, is if I was concerned about your safety, or the safety of somebody else. In that case, I am duty bound to let someone know about the risk. Does that make sense?

Do you have any questions before we start?

1. When I say the word ‘woman’ what comes to mind?
2. When I say the word ‘man’ what comes to mind?
3. What are your personal views of the main differences between men and women?
4. What similarities do you think there are?
5. We are all subject to various messages of how men and women are – where do you think your ideas came from?

6. What do you call yourself when you dress as a woman?

7. How long have you been dressing as ...........?

8. How would you describe ..............? For example looks, character, behaviour?

9. What do you think has influenced this? Where do you think this came from?

10. We all experience various challenges and difficulties. Do you think there are any particular difficulties that women face, or that men face or do you think men and women face the same difficulties?

11. Can you describe to me your ideal woman? You may choose to talk about a real person, or attributes that you find appealing.

12. Can you describe to me your ideal man? You may choose to talk about a real person, or attributes that you find appealing.
Information Sheet

Study of Gender

What is the study about?
Thank you for considering taking part in this study. We are a group of four researchers (Anna Gosling, Sheila Gould, Sharon Green and Vicky Laute) from the University of Surrey, currently undertaking a doctorate in Clinical Psychology. The study looks at views about gender. Everyone’s view is important in this research.

This study does not evaluate you as a person in any way. All the information you give will be confidential.

Am I eligible to join the study?
You are eligible to take part in this study if
• You are over 18 years old.
• You are fluent in English.
• You are biologically male.
• You would describe yourself as being a transvestite (rather than transsexual).
• You are not currently being treated for a psychiatric problem.
• You are willing to spend about an hour talking with one of the above researchers.
• You are willing to have the interview recorded. PLEASE NOTE this will be destroyed once the tape has been transcribed.

What will I have to do?
This study will involve meeting with a researcher at an agreed date, time and place. The interview will last approximately one hour. It will be recorded, so that we have an accurate record of what was discussed.

Although we are trainee Clinical Psychologists, the aim of the interview is for research, rather than therapeutic purposes. The interview will take the form of several questions asking your thoughts and ideas about gender.

What happens with my answers?
All your responses are strictly confidential and will be used only for the purpose of this study. Once the interviews have been transcribed all identifying characteristics will be removed. Some of your actual words will be used in the report, as it is important to accurately reflect your views. It will not be possible to identify individuals in the report. The tapes will be wiped when the research is completed.

What happens if I decide that I want to withdraw?
You are free to withdraw from this study at any time. If you have any questions about this research please feel free to contact Sheila Gould on 07958 653 427. If you would like a copy of the final report, please contact Sheila (as above).
Appendix II
Consent form and background information
**PsychD in Clinical Psychology**  
Department of Psychology

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**Consent Form**

Qualitative Research Project investigating perceptions of gender

I agree to participate in the research investigating perceptions of gender. I understand that participation will mean giving consent for the interview to be tape-recorded, transcribed and analysed by the research team conducting this research. I also understand that this information will remain confidential but will be included in an anonymised form in a written report and may be submitted for publication. This consent form will be kept separate from the information gathered during the interview in order to preserve anonymity.

Signature of participant: ________________________________

Name of participant (CAPITALS): ________________________________

Signature of interviewer: ________________________________

Name of interviewer (CAPITALS): ________________________________

Date: ________________________________

Thank you very much for your time and help in conducting this research.
**Background Information**

To begin, I’d like to get some basic information about you (such as age, education and occupation). The reason that I’d like this information is so that I can show those people who read my research report that I managed to obtain the views of a cross section of people. The information that you give will never be used to identify you in any way because this research is entirely confidential. However, if you don’t want to answer some of these questions, please don’t feel that you have to.

1. How old are you [ ] years

2. How would you describe your ethnic origins? (the format of this question is taken from the 2001 census). Choose one section from (a) to (e) and then tick the appropriate category to indicate your ethnic background

   (a) **White**
       British
       Irish
       Any other White background, please write in below

   (b) **Mixed**
       White and Black Caribbean
       White and Black African
       White and Asian
       Any other mixed background, please write in below

   (c) **Asian or Asian British**
       Indian
       Pakistani
       Bangladeshi
       Any other Asian background, please write in below

   (d) **Black of Black British**
       Caribbean
       African
       Any other Black background, please write in below

   (e) **Chinese or other ethnic group**
       Chinese
       Any other, please write below
3. What is your highest educational qualification?  
(tick the appropriate answer)  
None  
GCSE(s) / O-levels(s)/CSE(s)  
A-level(s) / AS-levels(s)  
Diploma (HND, SRN, etc)  
Degree  
Postgraduate degree / diploma

4. What is your current occupation (or, if you are no longer working, what was your last occupation?)

5. What is your current legal marital status?  
(tick the appropriate answer)  
Single  
Married  
Divorced / separated  
Widowed

6. How would you describe your current relationship status?  
Single  
In a relationship (but not living with)  
Living with a partner  
Other, please write below

7. How would you describe your sexual orientation?  
Heterosexual  
Gay / Homosexual  
Bisexual  
Unsure  
Other, please write below

8. Do you have children?  
(tick the appropriate answer)  
Yes  (go to part b)  
No  (end of questionnaire, thank you)  
(b) How many children do you have?  
[  ]  
(end of questionnaire, thank you)
Appendix III
Researchers' standpoints

Researcher 1
During the process of deciding research topics I found this by far the most interesting suggestion – not least because it was an area that I had little or no previous experience of. I have to admit a curiosity as to why transvestites dressed up. I think there was also a slight indignance too – that as far as I was concerned the women I knew did not look like how I imagined transvestites would dress up. I wanted to find out who they were modelling themselves on.

I was glad to have a fellow researcher with me during the interview – and have to admit to being a little taken aback when I met the participant I was interviewing. I had given some thought to what I wore that day, but had gone straight from college, so any make-up had worn off and I was fairly casually dressed in trousers and a shirt. Carl was dressed as Carol, in heels, full make up and leather trousers. I instantly felt very short, rather scruffy and very young.

Despite any initial apprehension, as the interview progressed I felt at ease interviewing Carol/Carl. Although dressed as Carol – there was never any doubt that I was interviewing a man. He seemed to have a great insight and understanding of himself, and presented himself as a man with an unusual hobby.

During the transcription and later looking over other transcripts I did learn that I still have a certain amount of indignation about the notion that clothing can alter gender in some way. I think perhaps I have more feminist perspective than I realised and actually feel quite angry. I suppose it boils down to the essence of what it means to be a woman and I’m not sure I had given this much personal thought before this research. For me, being a woman is much more than just appearance. Although my experience of the interviews was that on the whole that was not what the participants were getting at, it still feels that to ‘dress up’ as a girl you are in some way reducing what it means to be a woman down to appearance.

Again it is important to remember, I suppose, that I am a relatively well-educated woman. Although I’m not well-read in the area of gender, or feminism, I have been exposed to a number of ideas along the way. I also have a very strong sense of pushing against ‘traditional’ gender roles and stereotypes – the look of surprise on my mother-in-law’s face when she learnt who ironed her son’s shirts is testament to that.

Researcher 2
I came to the research because, having had experience of transvestites in my social network I was curious to find out more about their identities. As a group (four women) we talked about some of my experiences and it appeared that we were curious to know more about transvestite’s views of ‘women’ – this initially seemed to focus upon physical appearance. Although through my social network I had a small amount of knowledge about one person’s experiences, I entered the research unclear about transvestites in general, their experience of this label and how they differed from people that call themselves ‘transsexual’, ‘transgender’.
The interview schedule was devised with the question about transvestites’ views of women in mind. The schedule was created through a brain-storming process, enabling the group to develop an array of topics about which we were curious to know more. This centred around ideas of transvestites views of womanliness. However, having discussed the ideas for the schedule with our (male) supervisor, he suggested that we might was to include transvestites’ views of men in the interview schedule.

We also discussed finding out where transvestites’ ideas came from / how and why they decided to become transvestites, an area that I was keen to learn more about. However, we queried whether this would help us find out more about transvestites views of women or whether it would be engaging in a different area of curiosity. We did however feel that it would be appropriate to include an area of enquiry that explored ‘where transvestites’ views of women and men came from’.

I had observed several colleagues interview transvestites and was surprised how much each transvestite had to say in response to each question. However, when I undertook the interviewing myself I found the respondent was not so forthcoming with information as the previous interviewees I had observed. It felt very difficult to elicit responses and even prompts requesting elaboration did not appear to expand the knowledge already gained. Interestingly, when reflecting upon this there was the realisation that I had interviewed a transvestite in ‘male mode’ whereas all the other interviews that took place involved interviewing transvestites in their ‘female mode’. It therefore left me wondering whether this had made a difference and as a ‘man’ he was less forthcoming with his ideas.

Having had the privileged position of hearing the stories of the transvestites that were interviewed I am left with some uncertainties about transvestism, but the stories show (and I therefore have learnt), that despite their label of ‘transvestite’, this group of people often have very different experiences, views and values.

Researcher 3

I was the last researcher to join the group. I approached the topic with enthusiasm, as it seemed far removed from any of my previous experience, in both research and therapeutic contexts. I was keen to explore transvestites’ perceptions of women, as I felt that the ‘typical’ image they portrayed was not reflective of my own preferences. This applied to both physical appearance and behaviour.

Initially the interview schedule focussed on appearance of transvestites in female dress. Following discussion with our (male) research supervisor, the questions were widened to include perceptions of both men and women. Questions about other aspects of masculinity and femininity were also added. This broader schedule seemed to fit comfortably with the biopsychosocial model of individuals that I am familiar with.

During the interview with Jenny, I was very aware that I was talking with a man in women’s clothing. The conversation seemed to flow quite easily and Jenny was willing to talk very candidly about life as a transvestite, with little prompting. However, when I transcribed the interview, I began to feel angry about some
comments that I heard Jenny make. This applied to statements about physical appearance in particular. I started to view Jenny as quite an arrogant person. I reflected on this with the other researchers and questioned whether I would have had such a strong reaction to a woman making similar comments. I can't be sure.

Following the qualitative analysis, I was struck by the diversity within our small sample. I feel that our participants' individuality has challenged my views of a 'typical' transvestite. I was also surprised by how easily we agreed on themes within the research group. I was left with many more questions about unexplored aspects of our participants' lives.

**Researcher 4**

I approached the research topic with a large amount of curiosity regarding transvestites. My thoughts were initially centred only on their physical appearance and how this related to their understanding of how women dress and present themselves to the world in terms of appearance. I hadn't given much thought to their understanding of gender or sexuality. As a result the starting point for our interview schedule begun from physical appearance. However with greater discussion with the other researchers I was presented with possible aspects of identity and personality that I had not considered.

During the interview stage I initially found meeting Diane very intimidating. I think this was partly due to her bold and dramatic appearance. I also felt daunted by the prospect of trying to build rapport and gain an understanding of her beyond the layers used to disguise David's identity. However, once the interview begun I felt very comfortable in Diane's company. Despite expressing some views that as a woman I personally did not necessarily agree with, I did feel as if I was in discussion with another woman. This surprised me as in terms of appearance, Diane presented in a feminine way, but was clearly a transvestite and not a woman, but I did not feel conscious of this at the time.

My perception of Diane changes considerably when I came to transcribe the interview. I was clearly confronted with the voices of a female researcher interviewing a male about his perceptions of gender. I began to think of the interview in terms of David not Diane.

The analysis and interpretation stage threw out many more questions than answers for me. It became apparent that although sharing some views, there were such noticeable differences between the transvestites in our study. Despite this continuing confusion I was left with some sense familiarity for transvestites with a decrease in my initial intimidation.
Posttraumatic stress after childbirth: A qualitative account of the impact on relationships.
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Abstract

Title: Posttraumatic stress after childbirth: a qualitative account of the impact on relationships.

Objective: To gain an account of women’s experiences of traumatic birth and their understanding of the impact of the experiences on their relationships with their partners and their new babies.

Design: This study used semi-structured interview techniques, to gather information retrospectively.

Participants: Ten women, who had experienced a traumatic birth were interviewed.

Main outcome measures: Transcripts of the interviews were analysed using Interpretative Phenomenological Analysis. Two women’s interviews were excluded from the analysis as they scored well below the cut-off point for PTSD on a self-report measure.

Results: Four superordinate themes emerged under the headings: birth experience; role of expectations; impact of birth experience; and coping and changes for others. Participants described the importance of autonomy and control in the birth experience and how the trauma was more than pain. Health professionals’ attitudes were
perceived to contribute to the traumatic nature of the birth experience. Participants expected a particular type of birth experience and they spoke of the difficulty coming to terms with the loss of the expected birth. Women spoke of the impact of the experience on their partners, and described how this also impacted on partners’ relationships with the new baby. Although not explicitly asked, all women described how the symptoms of PTSD impacted on their relationships with their partner, baby and friends. Participants acknowledged the need to make sense of their experiences, either in a formal or informal way and gave suggestions of how to improve services to help other women.

Conclusions: Women experienced symptoms of posttraumatic stress following childbirth. The role of control, autonomy and health professionals’ attitudes in their experiences is discussed. The impact of their experiences on their relationships is discussed. Implications for practice are discussed, specifically the importance of keeping women informed as much as possible before and during birth. The role of clinical psychologists in providing direct input after the birth and through supervision of midwives and health visitors is highlighted. Suggestions are made for further research looking at comparisons between birth experiences of women who develop PTSD with those that do not.
Introduction

Background

The psychological consequences of traumatic experiences have been described for centuries. Six months after the Great Fire of London, in 1666, Samuel Pepys recorded how he continued to experience vivid dreams and had difficulty sleeping due to intrusive thoughts of the fire (Saigh, 1992). Symptoms of avoidance, ‘flashbacks’ and nightmares in ‘war neurosis’ have been described in case studies and psychoanalytic literature since World War I (Blank, 1993). Studies of World War II and Korean War Veterans describe similar symptoms of restlessness, combat related nightmares, memory difficulties, impaired concentration, phobias and sympathetic over-activity (Saigh, 1992). Similar symptoms have been found in individuals following the aftermath of floods, fires and earthquakes, in studies of civilians’ reactions to natural disasters (Saigh, 1992).

Despite the substantial literature it was not until the Diagnostic and Statistical Manual of Mental Disorders Third Edition (DSM-III, American Psychiatric Association, 1980) that posttraumatic stress disorder (PTSD) was included in the psychiatric diagnostic criteria (Hansson, 2002). PTSD was recognised in those exposed to traumatic experiences, for example war veterans or victims of major disasters (Ballard, Stanley & Brockington, 1995). PTSD was defined as a syndrome that followed ‘an event beyond the usual range of human experience’ (DSM-III-R, APA, 1987). The removal of this in the subsequent edition (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; DSM-IV, American Psychiatric Association, 1994) has led to an increased acknowledgement that symptoms can occur
following circumstances that may be within the 'usual range' of experience. It is now widely acknowledged that PTSD might follow more commonly occurring trauma, such as road traffic accidents, physical assault, medical illness and treatment and childbirth (Fones, 1996; Mayou & Smith, 1997; Shalev, Schreiber & Galai, 1993; Ballard et al., 1995).

This introduction will begin by outlining the symptoms of PTSD and the definition will be discussed. Psychological theories of the causes of PTSD will be introduced and discussed. The evidence supporting posttraumatic stress symptoms after childbirth will be presented and a discussion of the methodology used to assess the incidence. The impact of PTSD symptoms on relationships will be introduced, looking at evidence from previous studies, such as war veterans, holocaust survivors and motor vehicle accident victims. Evidence that PTSD symptoms after childbirth can influence relationships will be presented and discussed. Finally the rationale for this study will be presented and the decision to use qualitative methods will be discussed.

Symptoms of posttraumatic stress disorder

The International Classification of Diseases (10th revision, 1992), of the World Health Organisation is commonly used for the diagnosis of mental disorders in the United Kingdom. However, the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV, 1994) is most commonly referred to in the literature on posttraumatic stress disorder (PTSD) so this convention will be followed (e.g. Bailham & Joseph, 2003).
The DSM-IV criteria for posttraumatic stress disorder state that the stressor should be an event that involves actual or threatened death or serious injury, or damage to self or others (American Psychiatric Association, APA, 1994). The person’s response should involve perceptions of intense helplessness, fear or horror. Main symptoms of posttraumatic stress disorder include: persistent re-experiencing of the event, including dreams, intrusions and re-experiencing emotions associated with the event. Persistent avoidance of stimuli associated with the trauma and emotional numbing; meaning a reduced ability to feel emotions, especially those associated with tenderness, intimacy and sexuality. Symptoms of increased physiological arousal, examples of these include difficulty sleeping, concentrating and irritability. For a diagnosis to be made symptoms must be present for at least one month and must cause significant distress or impairment in daily life (APA, 1994). The full criteria can be found in the table below.

**Table 1: Diagnostic criteria for Posttraumatic Stress Disorder (APA, 1994, p427-429)**

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<td><strong>A.</strong> The person has been exposed to a traumatic event in which both of the following were present:</td>
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<td>(1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others</td>
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<td>(2) the person’s response involved intense fear, helplessness, or horror.</td>
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<td><strong>B.</strong> The traumatic event is persistently reexperienced in one (or more) of the following ways:</td>
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<td>(1) recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions.</td>
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<td>(2) recurrent distressing dreams of the event.</td>
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<td>(3) acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated).</td>
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<td>(4) Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.</td>
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(5) Physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma) as indicated by three or more of the following:
   (1) efforts to avoid thoughts, feelings, or conversations associated with the trauma.
   (2) efforts to avoid activities, places, or people that arouse recollections of the trauma.
   (3) inability to recall an important aspect of the trauma.
   (4) markedly diminished interested or participation in significant activities
   (5) feeling of detachment or estrangement from others
   (6) restricted range of affect (e.g. unable to have loving feelings)
   (7) sense of a foreshortened future (e.g. does not expect to have a career, marriage, children or a normal life span)

D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:
   (1) difficulty falling or staying asleep
   (2) irritability or outbursts of anger
   (3) difficulty concentrating
   (4) hypervigilance
   (5) exaggerated startle response

E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than one month.

F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Acute: if duration of symptoms is less than 3 months
Chronic: if duration of symptoms is more than 3 months
Delayed onset: if onset of symptoms is at least 6 months after the stressor.

The diagnostic criteria (APA, 1994) state that in order for a diagnosis of PTSD to be made an individual needs to experience one of the symptom clusters in each of the criteria B, C and D. Although an objective assessment of the events might satisfy criterion A, increasingly it is being acknowledged that it also contains a subjective element, so that not all events are experienced in the same way (Yule, Williams & Joseph, 1999).
The ‘gold standard’ for diagnosing clinical PTSD is an interview by a trained clinician (Ayers, 2001). Symptom checklists, such as the Reaction Index (Frederick, 1985) or the Impact of Event Scale (Horowitz, Wilner & Alvarez, 1989) provide some indication of the presence of symptoms, but are often seen as a compromise when assessing for clinical levels of PTSD (Ayers, 2001). For this reason, questionnaire measures that relate specifically to DSM-IV diagnostic criteria are seen as better tools for assessing PTSD than symptom checklists (Ayers, 2001).

Psychological theories of PTSD

Various psychological conceptualisations of the aetiology of PTSD have gone some way to increasing our understanding of why some individuals exposed to trauma develop symptoms of posttraumatic stress, while others do not. Any theory of PTSD must also explain why some individuals who show stress reactions immediately after the trauma go on to develop a chronic problem, while others do not (Dalgleish, 1999). Models discussed are a psychodynamic account, a learning model and cognitive models.

Psychodynamic account of PTSD

Freud (1920/1955) discussed ‘traumatic neurosis’, as a condition long described following railway disasters and other accidents in which life is at risk. He associated this with the war neurosis seen after World War I. In terms of symptoms, Freud highlighted the impact of nightmares on those with such a condition. He wrote ‘I am not aware, however, that patients suffering from traumatic neurosis are much occupied in their waking lives with memories of their accident. Perhaps they are more concerned with not thinking of it’ (page 13, 1920). This relates to current definitions
of PTSD in terms of the symptom of avoidance, but might exclude symptoms of intrusions such as ‘flashbacks’.

Psychodynamic thinking has moved on considerably, current schools, for example, object-relations theorists might conceptualise reactions to current traumatic experiences in relation to events in the past, specifically in terms of the unconscious ‘phantasies’ and fear the infant had about its main caregiver (e.g. Garland, 1998). Object-relations theorists suggest that infants internalise early relationships (known as ‘objects’) (Lemma, 2003). In the event of a trauma the internal and external containers are lost, so the world becomes a frightening and dangerous place to be and the internal representation of a ‘good’ early relationship is powerless to prevent the worst (Garland, 1998). Treatment of trauma using this model would be to restore the function of the internal container, the internalised part of the mother that is able to hold the infant’s anxieties, process them and return them to the infant in an easily manageable form (Garland, 1998).

Treatment efficacy is one way of evaluating a theoretical model, although some psychodynamic psychotherapists would argue against this link (e.g. Fonagy, 1999). There have been few studies looking at efficacy of psychodynamic approaches to treatment of PTSD, but studies that have been conducted have not tended to show decreases in symptoms of PTSD using a psychodynamic approach (Van der Kolk, McFarlane & Van der Hart, 1996). Therefore, support for a psychodynamic approach to understanding PTSD is limited.
Another model that attempts to explain PTSD is based on Mowrer’s (1947) two-factor theory of learning (cited in Foy, Osato, Houskamp & Neumann, 1992). The model postulates that both classical and instrumental (or operant) conditioning contribute to the development of avoidance behaviour. The first factor is the classical conditioning of the fear response. A neutral stimulus is paired with a noxious unconditioned stimulus, resulting in a fear response (unconditioned response). The previously neutral stimulus becomes the conditioned stimulus and results in the conditioned response of fear. An example of this would be the victim of a road traffic accident who was listening to a particular song on the radio (a neutral stimulus) at the time of the accident. When they listen to that song subsequently it results in the conditioned response of fear as it has been paired with the noxious unconditioned stimulus (the car crash). Through processes such as higher order conditioning and stimulus generation the conditioned fear response is generalised to similar stimuli to the conditioned stimulus, or to other neutral stimuli that are paired with the conditioned stimuli.

The second factor of the two-factor theory refers to the instrumental learning of avoidance responses to decrease or escape the fear elicited by the conditioned stimulus. Once the avoidance behaviour is associated with the conditioned stimulus, the behaviour is reinforced by a reduction in the fear response (Foy, Osato, Houskamp & Neumann, 1992).

Keane, Zimmerling & Caddell (1985) used this two-factor learning theory to conceptualise the causes of PTSD in war veterans. They suggested that the theory accounted for the conditioned startle responses, avoidance behaviour and stimulus
generalisation found in combat veterans (Foy et al., 1992). The two-factor learning theory has also been used to understand fear and anxiety in victims of sexual assault. For example Kilpatrick, Veronen & Resick (1982) suggest that exposure to the life-threatening sexual assault elicits intense fear, which is then elicited by similar stimuli or other stimuli associated with the traumatic event (Foy et al., 1992).

However, learning theory cannot account for individual differences in response to events, nor does it adequately explain symptoms such as re-experiencing the event (Foa, Steketee & Rothbaum, 1989). It cannot explain why some individuals go on to develop posttraumatic stress symptoms, while others exposed to the same stimulus do not (Smith, Perrin & Yule, 1999). There is not a clear relationship between severity of exposure and severity of symptoms, which suggests that stressors cannot be seen objectively (Smith et al., 1999)

Cognitive models

Cognitive models of posttraumatic stress disorder have included the cognitive element of meaning of the traumatic event (Foy et al., 1992). Cognitive factors go some way to explaining why it is some individuals go on to develop PTSD while others do not. Such models take into account individual differences in threat appraisal, attributions and the meaning of a particular event (Smith, Perrin & Yule, 1999). An example of the role that meaning plays in the development of trauma symptoms is given by Foa, Steketee & Rothbaum, (1989) who described the case of a rape victim developing symptoms of traumatic stress only after she had learnt that the next victim of the rapist had been killed.
It is not possible to discuss all cognitive models of PTSD, four will be discussed here. Horowitz’s (e.g. 1986, cited in Dalgleish, 1999) formulation of stress response syndromes is one of the most influential cognitive theories of PTSD (Dalgleish, 1999). He proposed a sequence of reactions following a traumatic event. Initially there is a ‘crying out’, or stunned reaction phase, followed by information overload, when thoughts, images and memories of the trauma cannot be reconciled with meaning. There follows a phase of oscillation between intrusion and avoidance, when the completion tendency (or need to understand information about the trauma in relation to past understanding of the world) means that trauma-related information is kept in the active memory, causing it to break through into consciousness in nightmares and flashbacks. The tension between the completion tendency and the processes of defence means individuals oscillate between intrusions and avoidance/numbing. Incomplete processing of the traumatic information leads to it being maintained in active memory and thus to development of chronic PTSD symptoms (Dalgleish, 1999).

Although Horowitz’s model is able to explain a great deal about the processes of PTSD, a major criticism is that it fails to explain why some people develop PTSD when others do not (Dalgleish, 1999). The model also struggles to account for the development of late-onset PTSD (Dalgleish, 1999).

Janoff-Bulman (e.g. 1992) presents a cognitive-appraisal model of PTSD that argues that it is the content of pre-existing beliefs that an individual carries into a traumatic experience that are important. Janoff-Bulman (1992) presents the notion of ‘shattered assumptions’, that basic assumptions about the world that individuals hold are not
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supported in the light of the traumatic experience, such assumptions might include beliefs about the self as being invulnerable, perception of the world as an understandable, meaningful place, a view of oneself in a positive way. Although this model highlights the importance of pre-existing beliefs, there are problems, in that it assumes that if an individual does not hold such positive beliefs about themselves then they will not be 'shattered' when faced with a traumatic situation (Dalgleish, 1999). This has not been supported by research findings that individuals with a history of psychological problems (and hence less intact assumptions of personal invulnerability) are more likely to develop PTSD after a traumatic experience (Kilpatrick, Veronen & Best, 1985).

Foa and colleagues (e.g. Foa, Steketee & Rothbaum, 1989) have proposed a ‘fear network’, an information-processing model of PTSD. Fear structures are developed in long-term memory, following a traumatic event, these fear structures include: stimulus information about the traumatic event; information about physiological, behavioural and cognitive reactions to the event; and information that links these stimulus and response memories together (Dalgleish, 1999). This goes a long way to understanding the role of meaning and attributions about the traumatic event in PTSD, but can still be criticised for not explaining why some individuals develop fear networks and others do not (Dalgleish, 1999).

More recently Ehlers & Clark (2000) have proposed a cognitive model of PTSD that draws on previous models (e.g. Janoff-Bulman, 1992; Foa et al., 1989). The model proposes two key processes in PTSD that lead to a sense of current threat. These processes are: (1) individual differences in the appraisal of the trauma and/or its
sequelae and (2) individual differences in the memory for the event and its link with other autobiographical memories (Ehlers & Clark, 2000). Individual differences in how a traumatic event is appraised can lead to a sense of current threat, such a threat can be external (for example the world is unsafe) or internal (for example a threat to the sense that one is a capable human being). Types of appraisal of the event that can lead to sense of current threat include (1) overgeneralization, exaggerating the possibility that the trauma may reoccur, or that other traumas are likely to happen, this may lead to avoiding situations that could result in exposure to trauma; (2) appraisal of how an individual felt or behaved during the event may have longer term impact, for example arousal during a sexual assault led one woman to interpret this as having secret desires that were repulsive to her.

Appraisals of the trauma sequelae can contribute to the development of symptoms of PTSD. For example misunderstanding symptoms of PTSD, or interpretation of others’ reactions and how the impact on other areas of life is understood can all contribute to the development of symptoms. The range of possible appraisals impacts on the range of emotions people may subsequently feel, for example if appraisals were related to continued danger (e.g. nowhere is safe), then fear may be the emotional response; while anger may dominate if appraisals were concerned with a sense of unfairness (e.g. others have not treated me ‘right’).

According to Ehlers & Clark (2000) models of PTSD need to be able to explain the difficulty often experienced in purposefully recalling an event, with the frequent involuntary re-experiencing that people often complain of. Ehlers & Clark (2000) suggest that the problem with trauma related memories is that they are inadequate
integrated into autobiographical memory, hence the difficulty retrieving them intentionally. However, they highlight a second way in which autobiographical memories are stored, via triggering stimuli associated with the event (such as smells or music). Memories are usually ordered into meaningful themes, and such organisation generally inhibits the second way of retrieval (so that autobiographical memories are not unintentionally retrieved during everyday tasks). The incomplete processing of trauma memories into autobiographical memory explains why they are difficult to recall intentionally, but are easily triggered by similar physical cues.

Other studies have demonstrated support for aspects of the model. Dunmore, Clark & Ehlers (1999) found that cognitive factors were associated with the onset and maintenance of PTSD in their study of 92 assault victims. Factors included: appraisal of aspects of the assault, appraisal of the sequelae of the assault, dysfunctional strategies and global beliefs impacted by the assault. However, further work needs to be done to investigate the model further (Ehlers & Clark, 2000).

**PTSD and childbirth**

One major methodological consideration of studying PTSD is the retrospective nature of the research (e.g. McQuaid, Pedrelli, McCahill & Stein, 2001). Present emotional state may influence reports and memories of the experience. One way of avoiding this difficulty, suggest McQuaid et al. (2001), is to interview people before they undergo a traumatic experience. Obviously there are difficulties in predicting who will have a traumatic experience and when. However, childbirth is emerging as a useful paradigm for investigating several types of psychopathology. As a predictable event it can be used prospectively to study various psychopathologies, for example dysfunctional...
attitudes and life events on depression (e.g. Grazioli & Terry, 2000). It is possible to measure psychological characteristics prior to the birth, and thus help to identify possible contributions to cause. Thus, increasingly, childbirth is being seen as a useful paradigm for understanding contributory factors associated with PTSD.

Epidemiology

PTSD symptoms following childbirth have been recognised by several researchers. Bydlowski & Raoul-Duval (1978, cited in Ballard et al., 1995) reported symptoms of avoidance and nightmares after long, hard labours in ten women. Beech & Robinson (1985) drew attention to the issue of women suffering from extreme nightmares for over a year following traumatic and painful births. Ballard et al. (1995) reported four cases of stress reactions after childbirth and related these to PTSD symptoms. All four deliveries were emotionally traumatic and all four women experienced symptoms consistent with DSM-III-R (APA, 1987) criteria for PTSD.

Studies using different methodologies have produced a range of incidence rates for PTSD symptoms after childbirth. For example, Menage (1993) estimated that one-third of women with gynaecological complications go on to develop symptoms of PTSD. However, this retrospective cross-sectional study used a highly self-selected sample of 500 volunteers from newspaper and magazine advertisements making it difficult to generalise findings to the general population. The cross-sectional nature of the study means it is not possible to assess level of trauma prior to the birth. This is important when considering causation as pre-existing symptoms of posttraumatic stress can be triggered following childbirth (Ayers, 2003). Other cross-sectional studies have reduced the impact of self-selection by surveying all women giving birth
at a particular hospital. For example Wijma, Söderquist & Wijma (1997) sent questionnaires to all women who had given birth over a year at one hospital in Sweden. They found that 28 of the 1640 women (1.7%) screened had a PTSD profile on the Traumatic Event Scale. The Traumatic Event Scale (Wijma, Wijma & Söderquist, 1997, cited in Wijma et al., 1997) is based upon the DSM-IV criteria for PTSD. Women who had a PTSD profile reported contact with the staff during delivery as being less adequate than women who did not have a PTSD profile.

Prospective studies of incidence of PTSD, such as Czarnocka & Slade (2000) found that 3% (n=8) of women with ‘normal’ births had symptoms of PTSD at six weeks. Czarnocka & Slade (2000) were assessing PTSD symptoms, but diagnosis of chronic PTSD is only possible after three months (e.g. Rothbaum & Foa, 1993). Creedy, Shochet & Horsfall (2000) interviewed women four to six weeks after their birth and found an incidence rate of 5.6% (n=28). Creedy et al. (2000) give the incidence for acute posttraumatic stress, which is diagnosed if symptoms persist for a month.

Another study, Soet, Brack & Dilorio (2003) found that at four weeks after childbirth 1.9% of the 103 women they interviewed (n=2) had developed all the symptoms of posttraumatic stress disorder to meet the diagnostic criteria. Again, at four weeks this could only be acute posttraumatic stress. Soet et al., (2003) did assess for past trauma, but not levels of PTSD in pregnancy, so again were unable to draw conclusions about the causative nature of the traumatic birth.

Other studies have controlled for posttraumatic stress symptoms and depression in pregnancy. For example, Ayers & Pickering (2001) found that at six weeks 2.8% of
women fulfilled the criteria for PTSD (when women with PTSD and depression in pregnancy were removed), this reduced to 1.5% at six months. Again this underlines the importance of when PTSD screening occurs. Although this study took into account PTSD symptoms in pregnancy, it did not screen for life-time PTSD.

In summary, there are numerous methodological complications when measuring incidence of PTSD after childbirth. These include: the population sampled (‘normal’ vs. ‘complicated’ births), the time of assessment, cross-sectional vs. prospective nature of studies to ascertain the causative nature of childbirth. However, despite these complications there is support for the conclusion that some women do experience symptoms of chronic PTSD following childbirth. The best estimate at the moment appears to be about 1.5% of women.

**Impact of PTSD on relationships**

This next section will discuss the impact of PTSD on relationships. Initially research into the impact of PTSD on relationships after other traumatic experiences will be discussed. Then current research into PTSD after childbirth will be outlined.

Studies of individuals with PTSD following other traumatic experiences suggest that symptoms of PTSD can impact on relationships. Studies of war veterans with PTSD have shown that PTSD symptoms often exert a strong negative influence on those around the sufferer (Jordan, Marmar, Fairbank, et al., 1992). In their study of Vietnam veterans Jordan et al. (1992) found that those with PTSD had more marital, parental and family adjustment problems than Vietnam veterans without PTSD. Those men with PTSD who had been married prior to the war, were twice as likely to be divorced.
than those without PTSD. Other studies of war veterans have found partners of veterans with PTSD have higher levels of somatic symptoms, depression, anxiety and insomnia, as well as higher levels of social dysfunction (e.g. Westerink & Giarratano, 1999).

Children of war veterans have also been found to be affected by PTSD symptoms in a parent (Westerink & Giarratano, 1999). Although not significantly more psychologically distressed compared with controls, children rated their family living environment as being significantly higher in conflict. Other studies have suggested that some children may experience secondary trauma as a result of witnessing a parent’s nightmares and flashbacks (Rosenheck & Nathan, 1985).

There are some difficulties using studies of PTSD in war veterans to help understand the impact of PTSD on relationships in other populations. For example in the majority of studies war veterans are male and of a similarly aged cohort (Kuhn, Blanchard & Hickling, 2003). When looking at the impact on children of war veterans, the children are often older and it is likely that mothers may act as a buffer to shield their children from the worst of the PTSD symptoms (Westerink & Giarrantano, 1999). Studies of war veterans do not shed light on the impact on younger children, or of their primary carer having symptoms of posttraumatic stress.

Studies of children of holocaust survivors suggest that there may be intergenerational factors pointing to a vulnerability to PTSD, leading some individuals to be more vulnerable than others (e.g. Yehuda, Schmeidler, Wainberg, et al., 1998). Although in such studies holocaust survivors are both male and female, there remain retrospective
difficulties in studying events that occurred many years prior to the study taking place (Kuhn et al., 2003).

Research into PTSD following motor vehicle accidents is also conducted retrospectively, but it is possible to assess individuals within a matter of days or weeks after the traumatic event. Some studies of motor vehicle accidents have investigated the impact of PTSD symptoms on psychosocial relationships. For example Kuhn et al. (2003) looked at the impact PTSD had on three areas of psychosocial functioning: major roles (e.g. school, work, homemaking); relations with family and friends; and use of leisure time. They found motor vehicle accident survivors with PTSD to be worse off than those without PTSD at 12 months, in all areas of functioning except their relationships with friends. Despite these findings, this study does not give information about the quality of relationships with family and friends. It suggests that the PTSD symptom of numbing was a significant factor in psychosocial functioning.

In summary, studies of war veterans, holocaust survivors and motor vehicle accidents suggest that PTSD symptoms do have an impact on family members and partners. However, it is difficult to draw conclusions from other populations due to cohort effects and the age of children. PTSD after motor vehicle accidents suggest that symptoms such as emotional numbing are important factors in psychosocial functioning, however, it is yet to be seen whether this can be generalised to PTSD after childbirth.
Impact of PTSD following childbirth on relationships

As this is a relatively new area of investigation there is limited research into the effects of PTSD after childbirth on relationships. Bailham & Joseph's (2003) review of the literature speculates that as avoidance is a key feature of PTSD, that avoidance in PTSD after childbirth can manifest itself in sexual avoidance and fear of childbirth.

There are some case studies and a qualitative study that support the development of sexual avoidance. For example Fones (1996) reports the case of a woman who, following a labour she described as a "long, horrifying torture" (page 195) could not resume a sexual relationship with her partner for a year after the birth. Although sexual relations did resume, she continued to be extremely anxious about accidentally conceiving until she underwent surgery to prevent further pregnancy. O'Driscoll (1994) also presents a woman who could not resume a sexual relationship with her partner following a traumatic birth. Any sexual activity led to her re-living and re-experiencing the distress and pain of labour. Avoidance of intimacy of any kind is amongst the DSM-IV criteria for PTSD, but it may be that these women are more likely to experience these types of difficulties due to re-living the trauma associated with the birth.

PTSD symptoms following childbirth have been shown to affect the relationship with the partner in general. In her qualitative study of 20 women who experienced traumatic birth, Allen (1998) found that eight women had clinically significant scores on a measure of posttraumatic stress (the Impact of Event Scale, Horowitz, Wilner & Alvarez, 1979). All eight reported that the closeness of their relationship with their partner had been negatively affected. Many reported that their partners showed
irritation that they were continuing to feel distressed and in return six women were angry with their partners for not understanding their distress. Two women stated that their sex lives had been affected and two felt that they were so emotionally drained that they could not offer any support to their partner (Allen, 1998).

There is qualitative evidence to suggest that PTSD symptoms can also impact on women’s relationships with their new babies. Women may avoid their babies, with other family members taking on responsibility for the care of the baby (e.g. Ballard et al., 1995). They may experience feelings that the baby is not their own (Ballard et al., 1995). Attachment difficulties may stem from re-experiencing the trauma, as the infant reminds the mother of the difficult birth (Bailham & Joseph, 2003). Although some mothers may avoid their new babies, other studies also suggest that mothers with PTSD symptoms following childbirth become over-protective because of the experiences the baby has been through (e.g. Allen, 1998). The evidence of the impact on attachment is limited and further research is needed to examine the impact of PTSD on the mother-infant relationship (Bailham & Joseph, 2003).

There is some evidence to suggest that PTSD symptoms after childbirth may impact on relationships, but there have been limited studies in the area. It is an important area to study as psychopathology in mothers has been associated with abnormal development in their children (Dodge, 1990). For example, depressed mothers have been shown to be less responsive, have less emotional involvement with their baby and have impaired communication (Field, Healy, Goldstein & Guthertz, 1990). This can have a longer term impact in terms of behavioural disturbances and may lead to difficulties developing attachment (Bailham & Joseph, 2003). To date, there have
been no published studies looking at the effects of the mother's posttraumatic stress disorder on the baby (Bailham & Joseph, 2003). However, qualitative studies and case reports found that some mothers had difficulty in developing attachments with their babies following their traumatic births (Allen, 1998; Ballard et al., 1995).

Studies of postnatal depression have shown that partners of women who are depressed in their first year of parenthood, are more likely to be depressed (Ballard, Davis, Cullen, Mohan & Dean, 1994). They have also shown an association between depression and difficulties in relationships, although it is not possible to ascertain causation (Sullivan-Lyons, 1998).

**Rationale for present study**

Despite the methodological problems in studies of incidence, there is evidence that supports qualitative descriptions of women experiencing symptoms of PTSD after childbirth. Studies of other populations have suggested that symptoms of PTSD have far-reaching impact, in that partners and family members are also affected. Studies of postnatal depression have suggested that psychopathology in a mother can impact on child development and relationships in partners. Some studies investigating PTSD after childbirth have suggested that this may be the case. However, there is little evidence for the effects of symptoms of PTSD on relationships with partners or babies.

Due to the potentially sensitive nature of many of the issues relating to this area a semi-structured, in-depth interview was considered to be the most appropriate form of data collection (Langley, 1994, in Neale, 1999). Semi-structured interviews allow the researcher and participant to engage in dialogue that enables the interview to change
in the light of the responses given. This is a relatively new area of inquiry, so it also allows the researcher to investigate further areas of interest that may arise (Smith & Osborn, 2003).

The aim of the research was not to develop a new theory of PTSD after childbirth, nor to analyse the way in which the account was constructed, but to gain an account of women’s experiences and their understanding of the impact on their relationships. Therefore, due to its assumption that there is an underlying reality and its emphasis on gaining insight into individuals’ experiences, interpretative phenomenological analysis (IPA, Smith & Osborn, 2003) was used to analyse the data. The IPA approach is committed to the theoretical assumption that the person is a linguistic, cognitive, physical and affective being and that there is a connection between what people say and what they think and feel (emotionally) (Smith & Osborn, 2003). It also acknowledges that as a thinking, feeling, being, the researcher has an impact on that process, through the interview and data analysis. While IPA tries to gain as great an understanding of the participants’ perceptions of the world as possible, it acknowledges that this is not possible to do completely, and that the researcher’s perceptions must be taken into account too.

**Summary**

There is evidence to suggest that some women develop posttraumatic stress disorder following childbirth. The impact of this on their relationships with their new baby and other family members has yet to be fully investigated. Studies of other populations have shown that PTSD in parents can impact on a child’s mental health and may lead to increased vulnerability to PTSD in later life. Studies looking at the impact on
children of other psychological difficulties in mothers, suggest that PTSD symptoms may impact on child development. Social support may mediate psychological difficulties in mothers, but if PTSD is impacting on key relationships this may have important implications. There is limited research looking at women's experiences and due to the potentially sensitive nature of the study qualitative research methods were used.

Aim

This study aimed to gain an account of the experiences of women who had undergone a difficult or traumatic childbirth. It looked specifically at their perceptions of the impact of their experiences on their relationship with their baby, other children and partners.
Method

Ethics

Ethical approval was applied for and received from the South East Multi-Centre Research Ethics Committee and the University of Surrey Ethics Committee (copies of ethical approval can be found in appendix I).

Participants

Participants were recruited through on-line websites and through the use of snowballing techniques. It is important to bear in mind when regarding the findings that the participants were a self-selected group who had identified themselves as having had traumatic birth experiences.

Participants were eligible to take part in the study if they identified themselves as having experienced a traumatic birth, the birth had occurred more than three months ago and they were over 18 years old. Participants also had to be able to speak and read English fluently; this was due to the nature of the analytic procedure, which relied on the researcher engaging with and interpreting data within the transcripts. As the researcher was unable to speak or read another language, participants had to be fluent in English.

Fourteen women contacted the researcher following the advertisement placed on the internet website ‘mumsnet.com’ (appendix II) and were sent information sheets (appendix III). Of those women who were sent an information sheet eight agreed to participate. Nine women were e-mailed through ‘birthtrauma.com’ website, four of
whom replied, received a copy of the information sheet and were keen to participate. Three other women were sent copies of the information sheet and were contacts known to the researcher who had expressed interest in participating in research in the past, two of these women agreed to participate. Twenty one women received copies of the information sheet, of those fourteen agreed to participate, indicating a response rate of 67%. Four women did not participate, due to practical factors, specifically their location (one lived on the Isle of Man, another North Wales and another in Lancashire), the computer of one woman stopped working and she lost contact with the researcher until after the study had been completed.

Ten women were interviewed in total. Demographic information can be found in the results section.

Measures

Interview Schedule

The interview schedule looked at aspects of the experiences of women who have had a traumatic birth experience. The schedule contained questions relating to women’s experiences of childbirth, specifically what it was that made it traumatic, how they coped afterwards, the impact on their partner, the impact on their relationship with their partner, the impact on their relationship with their baby and the impact on other important relationships. Women were also asked questions about coping strategies and what changes they would like to see made for the future so that it would not happen to other women. A copy of the full schedule can be found in appendix (IV). In line with Smith & Osborn (2003) questions were open and there was the option of following up particular areas of interest.
The schedule had been used in a similar study by another researcher (Waring & Ayers, unpublished) and was found to be acceptable to participants and to elicit rich verbal information. In this study, the researcher altered three questions by extending them, to allow more examination of the impact of the experience on relationships. Question 2 was expanded to ask what the partner was told, question 7 was expanded to ask about the impact of the experience on the partner's relationship with the baby and question 11 was expanded to include decisions about having more children. The researcher also added another question (question 13). This extended the original schedule from 16 questions to 17. The previous question 13 became question 14 (and so on). Following the initial interviews the schedule was found to elicit sufficient information regarding participants' experiences of traumatic birth and their relationships with their children and partner.

**Traumatic Birth Symptom Scale**

This measure highlights symptoms of posttraumatic stress after childbirth. It is adapted from the PTSD Symptom Scale – Self Report (PSS-SR; Foa, Riggs, Dancu & Rothbaum, 1993). The PSS-SR contains seventeen items relating to the traumatic experience, these items relate to the criteria for PTSD outlined in DSM-IV (4 re-experiencing, 7 avoidance, and 6 arousal items). Total scores of 17 or more are considered cases (Foa et al., 1993).

The PSS-SR has been shown to have high levels of internal consistency, with an $\alpha$ of 0.91. The alpha coefficients for individual subscales are 0.78 for re-experiencing, 0.80 for avoidance and 0.82 for arousal (Foa et al., 1993). It also has good levels of test-retest reliability, with an overall level of 0.74, with individual scales ranging from
0.56 to 0.71 (Foa et al., 1993). Foa et al. (1993) assessed convergent validity using the Structured Clinical Interview for DSM-IIR (SCID, Spitzer, Williams & Gibbon, 1987). Using the SCID, the PSS-SR has 100% specificity (no false positives) and a sensitivity of 62%. Overall it correctly identified the PTSD status of 86% of the subjects. Foa et al. conclude that due to its relatively low sensitivity, the PSS-SR is a more conservative measure of PTSD than its interview counterpart the PSS-I.

The PSS-SR items are easily related to childbirth experiences and having been developed with a female sample following assault is ideal for use with women postpartum (Ayers, 2001). The adapted version of the PSS-SR (the Traumatic Birth Symptom Scale, TBSS), used for this study, relates items specifically to the birth experience. So where the PSS-SR asks ‘have you had upsetting thoughts or images about the assault that came into your head when you didn’t want them to?’, the TBSS asks about this in relation to ‘the birth’. Respondents are asked to rate on a scale of 0-4 how frequently they have experienced the symptoms in a ‘typical’ month since the birth. The TBSS also contains a disability scale, which relates to the DSM-IV disability criteria and asks respondents to rate on a scale of 0-4 how disabling the symptoms they experienced were. Scores of 2 or higher on the disability scale are suggested for cases of posttraumatic stress disorder (Ayers & Pickering, 2001). A copy of the TBSS can be found in appendix V.

The TBSS has been used in previous studies of women after childbirth (e.g. Ayers & Pickering, 2001) and has been identified as the preferred measure of PTSD to use with women after childbirth (Ayers, 2001). No formal reliability and validity studies have been conducted using the TBSS.
Procedure

Would-be participants were sent a copy of the ‘Information Sheet’ (see appendix III) and were asked if they were interested in participating to contact the researcher via e-mail or mobile telephone. Women who expressed an interest in participating were contacted, their GP details taken and a time and place was arranged to meet. The GP was contacted prior to the interview, by a brief letter informing them that their patient was participating in the study and requesting that they contact the researcher if they knew of any reason why the women should not participate. A copy of the letter can be found in appendix VI. Women were offered travel expenses, but none requested any. They were offered no other payment.

A time and place for the interview to take place was arranged. Seven participants were interviewed in their own home, one was interviewed at work, another in a café and one came to the University of Surrey to be interviewed. Before the interview took place they were also asked to fill in a consent form and to agree to their interview being tape-recorded (the consent form can be found in appendix VII). They also completed a demographic information form (appendix VIII).

Participants were interviewed using the semi-structured interview described previously. The researcher used non-directive counselling skills of reflection, summarising and open-ended questions to enable participants to give their own accounts of their experiences (e.g. Allen, 1998). It is interesting to note that participants were keen to discuss their experiences of childbirth and that this was sometimes a little overwhelming. On occasion it was difficult to turn the interviews to focus on the impact of this on relationships.
Analysis

Audiotapes were transcribed verbatim and the data analysed using interpretative phenomenological analysis (IPA, e.g. Smith & Osborn, 2003). The researcher primarily analysed the data, although three transcripts were analysed separately by a colleague to allow verification that the analysis had been systematically conducted and that themes were supported by the data. A group discussion of themes emerging from the first transcript took place with seven fellow researchers. During this discussion emerging themes were highlighted and evidence in the data identified. Further discussion of validity and reliability can be found in the discussion.

Smith and Osborn (2003) suggest an approach to using IPA analysis, they state that their suggestions are not prescriptive and can be altered by individual researchers. In this study their suggestions were followed. Coyle and Rafalin (2000) outline the importance of qualitative research being transparent about its analysis, therefore a detailed description of the analytic process follows.

Looking for themes in the first case

The transcript of the first interview was examined in detail then each other transcript was examined. Transcript one was read a number of times and notes were made in the left-hand margin about what was interesting or significant about the responses. The transcript was read and re-read to enable the researcher to become as familiar with the account as possible. Comments made in the left-hand margin ranged from summarising or paraphrasing elements of the text, to making associations and beginning to make interpretations. Other comments were about the use of language and similarities and contradictions within the text. This process continued throughout
the whole transcript of interview one. Then the researcher returned to the beginning of
the transcript and began to document emerging themes in the right-hand column.
Emerging themes aim to draw together initial notes into more concise phrases that still
encapsulate the meaning in the text. Emerging themes may be on a more abstract level
and use psychological terminology. As more general themes emerged, theoretical
connections could be made with other cases, but these were still specific and grounded
in the text. The process continued until initial notes were transformed into themes for
all of transcript one.

Connecting themes
The next step of the process involved listing all the emerging themes onto a piece of
paper and looking for connections between them. The initial list was chronological, as
it was presented in the order in which it appeared in the transcript. The next part of the
analysis involved ordering the themes in terms of their meaning. Some themes
clustered together and superordinate concepts emerged, while others simply clustered
together. Throughout this process the text was continually referred to, to ensure that
any clusters made sense when referred to the text. Alongside this, a directory was
developed to allow participant’s phrases that supported a particular cluster, to be
stored together.

A table of themes was produced for case one, in which some themes were clustered,
and given names to represent the superordinate theme. Some themes, which were not
relevant or particularly richly supported in the text, were dropped at this stage of
analysis.
Continuing analysis with other cases

Subsequent transcripts were analysed in a similar way to the first interview. The themes from case one assisted in orientating the analysis of the other transcripts. Similarities and differences in accounts between participants were noted.

Once all the transcripts had been analysed a table of superordinate themes was constructed (see results section). The numbers of participants who expressed each theme is noted in the results section, to enable the reader to assess the support for each theme.

To avoid being able to identify participants, husbands/partners will be referred to as partner. As part of ethical approval, it was stipulated that it would be preferable if participants were referred to using an ID number, rather than a pseudonym. To comply with this requirement, participants will be referred to by letters of the alphabet. Letters of the alphabet in no way relate to participants' real names, or the order in which the interviews were conducted.

Who is the interviewer?

The author conducted the interviews and analysed the data. Part of the process of the research has been to consider how to refer to myself in the writing up process. Generally I have referred to myself as 'the researcher', but for this section I will use the first person singular, as 'the researcher' sounds too removed.

Like the participants I am female, White European and live in my own home. I am married and in my early thirties. As a trainee clinical psychologist my identity lies somewhere between student researcher and mental health professional. My study and
work commitments dictate that I switch between the two roles regularly. I interviewed
the participants wearing my ‘work’ clothes, rather than the more casual clothes I tend
to wear on university days.

My familial culture is to praise and reward educational achievement, but there is an
underlying assumption that getting married and having a family is equally important.
My generation was the first to attend university (although previous generations
achieved degree-level diplomas). I am the first female member of my immediate
family to reach thirty without having had a child. A number of my friends and peers
have children.

My interest in childbirth began during my MSc in Health Psychology, which I
completed prior to clinical training. I conducted research into postnatal depression and
found a significantly neglected area of psychopathology post childbirth. One
supervisor for this research also supervised my previous research and her area of
expertise is in posttraumatic stress after childbirth. My other supervisor’s research
interests lie mainly in health psychology and she has expertise in qualitative analysis.
My preconceptions prior to this study were that childbirth can be a difficult time and
that some women do experience it as traumatic. My clinical experience of working
with people with posttraumatic stress is limited, although I have worked clinically
with a range of people with anxiety related disorders.
Results

Ten women were interviewed about their experiences of childbirth and their perceptions of the impact of the experience on their relationships with their families.

The table below shows the demographic data for all ten participants.

Table 2: Demographic information

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Parity</th>
<th>Level of education</th>
<th>Time since birth</th>
<th>Total symptom score on TBSS</th>
<th>Score on disability scale of TBSS</th>
<th>Case for PTSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>31</td>
<td>1</td>
<td>degree</td>
<td>9mths</td>
<td>26</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>34</td>
<td>2</td>
<td>degree</td>
<td>54mths</td>
<td>36</td>
<td>2</td>
<td>*</td>
</tr>
<tr>
<td>C</td>
<td>36</td>
<td>2</td>
<td>prof. qual</td>
<td>54mths</td>
<td>30</td>
<td>2</td>
<td>*</td>
</tr>
<tr>
<td>D</td>
<td>32</td>
<td>1</td>
<td>degree</td>
<td>27mths</td>
<td>14</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>29</td>
<td>1</td>
<td>A-level</td>
<td>3mths</td>
<td>35</td>
<td>2</td>
<td>*</td>
</tr>
<tr>
<td>F</td>
<td>34</td>
<td>1</td>
<td>diploma</td>
<td>30mths</td>
<td>36</td>
<td>2</td>
<td>*</td>
</tr>
<tr>
<td>G</td>
<td>27</td>
<td>2</td>
<td>degree</td>
<td>22mths</td>
<td>20</td>
<td>2</td>
<td>*</td>
</tr>
<tr>
<td>H</td>
<td>38</td>
<td>2</td>
<td>degree</td>
<td>42mths</td>
<td>41</td>
<td>3</td>
<td>*</td>
</tr>
<tr>
<td>I</td>
<td>37</td>
<td>1</td>
<td>A-level</td>
<td>18mths</td>
<td>6</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>J</td>
<td>38</td>
<td>2</td>
<td>prof. qual</td>
<td>54mths</td>
<td>7</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

*TBSS – Traumatic Birth Symptom Scale*

All the women described their ethnic origin as being White European and they all lived in their own home. Nine women lived with their children and partner, one lived with her children. The mean (and standard deviation) length of time since the birth was 31.3 months (17.9).
Results from Traumatic Birth Symptom Scale

All women interviewed completed the Traumatic Birth Symptom Scale (TBSS). Of the ten women interviewed six women scored 17 or more on the symptom scale and two items on the disability scores, indicating that these are cases for PTSD. Two women scored one on the disability item, with one of those scoring just below the PTSD score. These women are included in the analyses, as during the interviews it became clear that they had been suffering from the impact of symptoms of PTSD.

Participants I and J had low scores on the symptom scale and during the interview did not report significant ongoing effects of the traumatic birth experience. These experiences are therefore excluded from the analysis.

Women had diverse experiences associated with different aspects of the birth. For example some women had relatively straightforward vaginal deliveries, with no obstetric intervention, but which were followed by concerns about the welfare of their baby, or themselves, while others found aspects of the labour itself traumatic. Therefore respondents’ experiences are referred to as the birth experience to encompass this range.

Themes for all participants

The table below (figure 1) shows the themes for all participants. These will be discussed in detail below.
Figure 1: Superordinate themes and themes

<table>
<thead>
<tr>
<th>Birth experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Loss of autonomy</td>
</tr>
<tr>
<td>2. Loss of control</td>
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<tr>
<td>3. Beyond pain</td>
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<tr>
<td>4. Reactions of health professionals</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Role of expectations</th>
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</thead>
<tbody>
<tr>
<td>5. Not what I expected (the ‘wrong birth’)</td>
</tr>
<tr>
<td>6. Emotional impact of the ‘wrong birth’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Impact of birth experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Impact of the experience on the partner</td>
</tr>
<tr>
<td>8. Impact on partner’s relationship with baby</td>
</tr>
<tr>
<td>9. Impact of PTSD symptoms:</td>
</tr>
<tr>
<td>a) intrusions</td>
</tr>
<tr>
<td>b) avoidance and numbing</td>
</tr>
<tr>
<td>c) hyperarousal</td>
</tr>
<tr>
<td>10. Blame</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coping and changes for others</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Developing an understanding of what happened</td>
</tr>
<tr>
<td>12. How to make things better for others</td>
</tr>
</tbody>
</table>

Birth experience

Women’s recollections of their birth experiences provided rich verbal accounts and several themes emerged, these will be discussed initially.

Theme 1. Loss of autonomy

Participants expressed a sense that they were not involved in the birth experience, that they were not involved in making key decisions during the birth and therefore felt a loss of freedom to make their own decisions. All eight women with PTSD symptoms had a loss of autonomy. For example C said:

‘...at that point I felt completely it was being done to me. I wasn’t part of it. It was all, you know, nobody seemed to be that interested in what I thought, and by that point
I was so doped up as to not really be able to say what I thought and yet in my notes everywhere it just said I wanted a natural birth

E also said she felt as if 'I lost all my autonomy the minute I walked in'.

G had a similar experience 'I think I felt that everybody was in authority and I was just this little person and I couldn't do much about it'.

Theme 2. Loss of control

Linked in with a sense of loss of autonomy was a sense of loss of control, six women highlighted this area (A, C, D, E, F and G). Some women described how the process seemed to be taken out of their hands 'I was on this kind of runaway train, so I wasn't in control' (D). There was a sense that people had an altered sense of consciousness and so this led to a loss of control 'at the time you're just so blurred you just don't think' (F).

E describes how being out of control was part of the experience that remained with her. E: 'that's the only time I can honestly remember when I've been absolutely totally and utterly out of control, not knowing what's happened, needing so much but not knowing how to ask for it. And um, you know I think that still stayed.'

Being out of control seemed to have numerous consequences. For example, for some women screaming and being out of control of their emotions led to shame and embarrassment, G: 'I was screaming my head off, which was very embarrassing for me cos it wasn't like I wanted to scream'. E explained how this made her feel 'I felt
stupid I'd made noises, I felt stupid I'd shouted'. This again seemed linked in with a loss of autonomy and 'others' taking over, as A explained 'they just came in and wanted to inject me all over the place... and they just started doing it, and that's what freaked me out'.

Theme 3. Beyond pain

Women made it clear that the trauma was not simply related to the experience of pain, that in some ways it was beyond pain. For example C explained 'And I wasn't that bothered about the pain. I mean it was excruciatingly painful but I don't think it was ever the pain that really bothered me'. Pain was experienced as a 'normal' part of childbirth 'I was in huge amounts of pain, I really was, which I think is perfectly normal' (H).

G also stated that it was more that just the pain, or being left alone that made the experience so traumatic. When the interviewer asked whether the pain contributed to the trauma of birth, G replied: 'No, the pain, because it is painful, having children is painful. Being left on my own, it wasn't so much that. It was the way I was treated.'

E echoed these sentiments that there were other factors despite the pain that appeared to make the experience so difficult '...it was never the pain of it that I could remember. It was always the panic and fear'.

For some women though, the pain did play a large part in making the experience traumatic. For B the pain was 'so ferocious' that it made her vomit, which she described as 'a hideous thing'.
This woman associated the pain with vomiting (many women vomit in labour and it is not necessarily caused by pain). Vomiting can also be linked with a sense of loss of control, as it is another aspect of the experience that they have no control over, which again leads to embarrassment and distress ‘I just remember it was so humiliating and I was vomiting at the same time’ (B).

Theme 4. Reactions of health professionals

Women’s perceptions of how they were treated by the health professionals during the birth seemed to impact on how they felt about the experience. All eight women experienced health professionals in a negative way at some point during their birth experience. Health professionals were seen as unsympathetic, unsupportive, uncommunicative or simply absent.

All women described the way they felt that the health professionals were unsympathetic, or seemed to have an unhelpful attitude. B said ‘I was examined by a midwife and she was blisteringly unsympathetic’. Other women explain how they felt chastised by staff ‘...this woman who’d taken over the night shift, sort of telling me off for not trying hard enough and stuff’ (D). B had a similar experience ‘...and the anaesthetist was shouting at me to be still and not behaving myself or something like this’. H had a similar experience of being criticised ‘she was obviously getting very irritated with me and thought I was being quite dramatic and was criticising me to the anaesthetist who got at me and my husband, which we found a bit shocking.’ Another woman described how this made her feel about the midwife F: ‘I hate her for everything. She was shouting at me and I was saying I want to go home and she said we want to go home as well so just get on with it. She wasn’t very supportive at all.’
There was a sense that some of the health professionals did not appreciate the situation the women were in, for example not physically being able to move to the correct position for an epidural 'she said you need to sit up. I couldn't ... And the woman turns round and says well if she's not going to co-operate I'm not doing it' (E). C had a similar experience 'And she was trying to make me lie in a certain position that really hurt and I kept saying I can't do it and she was like 'lie down'.

For one woman it was the way they suggested she had an unwanted procedure that was the problem. It was not until the shift changed and a midwife came on duty whom she respected, that the situation changed. 'and it was the midwife that I'd seen the night before who I'd really liked. And she was like what's all this, and she really dealt with me really well. And I did let them do it' (A). The reverse also happened, for example D experienced a shift change and lost her 'lovely midwife and student midwife... and then there was a shift change and another midwife came on and I was being left for an hour'.

Three women describe being left alone, and experiencing the health professionals as being absent. For example G described how she and her husband were left alone on the ward: 'There was nobody in there. No patients, no nothing, in another part [of the hospital] even further away from anybody else'. F had a similar experience of being left alone 'the midwife just kept going in and out of the room and leaving me, telling me to push and then disappearing'. Although all three women had their partners with them, F admits 'I was thinking how useless he would be there in case I pushed'.
Some women described a lack of information from the professionals involved in their care, which again led to a lack of autonomy and a feeling of not being in control. For example D explained it in this way 'there was just this culture, this atmosphere, where you just weren't able to say things and nobody asked you'. One woman described how her baby was moved from one area to another in the Special Care Baby Unit without her being told:

'F: ...And they moved her in special care to the back side of the room, she was like high dependency, without telling me.

Interviewer: So you went up to see her and she wasn't there?

F: Yeh. And I just went 'where is she? Where is she?' I just freaked'.

Other women experienced lack of information about the procedures they were having. For example, a woman who was being induced later heard that another woman had been advised differently:

'E: ...another lady who was induced and the first thing they said before they put the drip in was we advise you to have an epidural. And I said well they didn't advise me of that.'

There was a sense that people did not receive full explanations D: 'It's not having it explained.' 'No-one explained to me what the difference is between like an induced labour and a normal labour' (E). Lack of information was a key part of the experience for C too, 'And then when they pulled him out they didn't really say anything. I then still didn't know if he was alive and I was imagining the worst'. So lack of information seems to be linked to loss of autonomy and a sense that others were in control.
However, although all participants recounted difficult experiences with health professionals, there were positive experiences too, 'I also remember very nice people, like the anaesthetist in theatre being very nice and making a real effort to, almost she was being there for me' (D). E also had a positive experience of a midwife 'she was fantastic and afterwards she was the only person who came out with any great positive comments. Those comments stuck and they helped and I think without those comments I think it would have been a lot worse'.

The experiences the participants describe seem to go beyond pain, they describe a loss of autonomy and of feeling out of control. These experiences seemed linked to the attitudes of the health professionals involved in their care. Women who were kept uninformed of what was going on, who felt that others were in charge, felt a loss of autonomy. There seemed to be a dichotomy between health professionals taking charge and not allowing women to be part of the process, and health professionals being absent, leaving women panicking that no-one was in control.

Role of expectations

Theme 5. Not what I expected – the ‘wrong birth’

For many women the role of expectations was key to how they perceived the traumatic birth experience.

All the women had some idea about how the birth might be for example although E had not finished her birth plan she had expected a 'nice pleasant, well not pleasant, but nice idea of natural childbirth'. G had a baby before, she had a plan 'My only plan with both of them [her children] was not to have Pethidine, to try and do it without an epidural'. However, G was also very realistic 'the less forceps, ventouse, all that sort
of thing, I didn't really want all that again, but that's emergencies. If it needs to be
done, it needs to be done'.

Some women had very definite ideas about the type of birth they wanted. For example
D: 'I definitely had a strong perception of what childbirth was going to be, which is
probably why it was such an extreme shock for me'. D found that preconceptions of
the birth, from antenatal classes, also impacted on the shock of the actual experience.
'I certainly came away from those classes and from my reading about home birth, was
that if you've got a positive mental attitude it'll all be fine [laughing]. You know, and I
just think God, utterly ridiculous'. Other women wanted to do it naturally as well 'I
really wanted to do it totally naturally. I went along to the active birth sessions and
everything' (C). Again, when things did not go to plan 'I suppose you have a higher
disappointment level' (C).

There were aspects of the birth that women felt completely unprepared for 'Nobody
said that I'd feel rough afterwards. I had this thought that I would give birth and then
go skipping off down the road ... and it never occurred to me that it would hurt
afterwards, let alone it would hurt this bloody much afterwards' (A).

Theme 6. Emotional impact of 'wrong birth'

All eight women described how the impact of not having the birth they expected left
them with a number of emotional reactions. For example A said 'I just felt so hard
done by and sorry for myself'. B had a similar reaction to the 'wrong birth' she said 'I
think life's so unfair... but I feel, I feel cheated that's how I feel, I feel cheated.
Because I had such a ghastly experience'.
For C there was a sense that time needed to be taken to adjust to the loss of the ‘good birth’. ‘You should be allowed to grieve for the birth you didn’t have. The birth that you’d worked yourself up to for 9 months, you know, having done the exercises and gone along to the classes and all that’. Again for F the experience she had was compared with how it ‘should’ be ‘It was the most miserable time of my life that was. It’s supposed to be the happiest and it certainly wasn’t that’.

For E there was a sense of failing that was associated with the birth ‘It’s still there and it’s a sense of failure, and I think there’s nothing worse than looking at your daughter and everybody saying oh isn’t she lovely, isn’t she wonderful, and you’re thinking well I bollocks that one up didn’t I?’. That she had ‘failed’ to recover from the experience led to a loss of confidence for D ‘I didn’t trust my instincts any more, because there is so much written in your preparation for childbirth about female instincts and you know the whole lot went out the bloody window. So I had no confidence at all about anything’. Other women talk about losing confidence after their experience, but also regaining it G says ‘I think possibly knocked my self-confidence a little bit and I felt, I don’t know, I think now I’m possibly stronger because of it, because I think to myself I would never let myself be put in that situation again’.

All the women had expectations about their birth, while this may not always have been definite they had ideas and thoughts about what giving birth might involve. Not having the birth expected, or hoped for, had an emotional impact on women, who felt cheated, miserable or a failure. One expressed a need to grieve for the loss of the ‘good birth’.
**Impact of birth experience**

Initially partners’ experiences of the birth (as reported by the women) will be discussed, followed by participants’ understanding of the impact on their partners’ ability to bond with the baby. Then the impact of PTSD symptoms will be outlined. The theme of blame will then be discussed.

**Theme 7: Impact of the experience on the partner**

All the women’s partners were present at the birth. Depending on the experience some women reported that their partners seemed to find the birth traumatic as well. However, others did not seem to have been affected by the experience. For example D explained her partner did not seem traumatised by the birth experience at all ‘he’s said for him, no, it was an event that happened, it wasn’t a nice event but it’s just an event that happened and it stayed there’. Other women had the sense that their partners found the experience quite positive ‘[partner] was on some massive high. You know, there he was, first born son and he’s like fantastic’ (B).

Three women said their partners did find the experience difficult. For example G explained that ‘he felt quite traumatised because he hadn’t been able to deal with things. And didn’t really know what to do, you know, standing there feeling a bit helpless’. F described her partner’s reactions ‘I think he felt a bit shell-shocked as well with it all to be honest’. Others found it extremely traumatic, H described her partner as being ‘really really depressed about this thing about me dying. He really thought they were coming to say I was dead and that really affected him profoundly.’
Theme 8: Impact on partner’s relationship with baby

For some partners it seemed as though their experiences of the birth impacted on their relationship with the baby. For example H describes how her partner withdrew after their child was born, during the experience he thought she would die, ‘He said to my dad that he felt so depressed about it, everything that happened, and how awful he felt about that because everybody was saying to him ‘oh did you cry when he was born’ and ‘isn’t it amazing when you look at them’ and all that. So yeh it did, it really affected him what happened’. This is similar to expectations about birth and parenthood discussed earlier in relation to the women.

Other women thought that the experience had a positive impact on their partner’s relationship with the baby. For D the fact that she had a caesarean meant her partner had to look after the new baby and was ‘hands on much more than he might have been’, and ‘for him it was actually quite positive because he took charge really’. Others recognised that their partner’s were pushed out and C recalls ‘he practically pretended he hadn’t got a son. And I think if you talk to him about it... he was really upset but neither of us knew what to do.’ Again this seems to relate to the emotional impact of the birth on the partner and the mother being unable to help with that.

Some women described how their partners found the birth experience difficult, while others did not. For some fathers, their experiences seemed to impact on their relationship with the baby.
Theme 9. Symptoms of PTSD

All eight of the women described symptoms following the birth that can be related to the DSM-IV (APA, 1994) criteria for PTSD. The next section will explain how these symptoms impacted on relationships after the birth. The following themes relate to three main areas of symptoms of PTSD, intrusions, avoidance and hyperarousal.

Intrusions

Re-experiencing traumatic experiences in the form of nightmares or ‘flashbacks’ are symptoms of PTSD (criterion B). Four women gave examples of re-experiencing the event (A, B, D, E,) for example B described having intrusions ‘I was still waking up crying and sweating and re-living this wretched birth like some kind of colour video over and over in my head’.

For some women, these intrusions impacted on their relationship with their partner. Their partner’s lack of understanding of effects of this caused difficulty. E: ‘I kept saying you know, I’m getting flashbacks, I keep seeing stuff and did this happen and did that happen. He’d just say why are you thinking about it, it’s done’. E described how her partner did not want to discuss what happened at all ‘he won’t talk about it at all. He won’t tell me anything, he won’t talk about that day at all. He’s not a great talker anyway but he just, I’ve never heard any of his opinions of the day, he’s never wanted, he’s never once said any of it’. B had a similar experience of feeling that her partner did not understand ‘I did feel he was completely oblivious to my suffering’. Although D and her partner talked about the experience, he still found it difficult to understand ‘I think to some extent he’s found it quite hard to understand the depth of my reaction’.
A describes how talking to her partner about the experience was important ‘every time I closed my eyes I’d get flashes of it and then I’d have to get up in the morning and ask [partner] you know, why did they do this and why did they do that?’ However, there were still aspects of how she felt that she could not share with him, for example not being able to turn the light off for fear of nightmares ‘It was really embarrassing and I didn’t really talk to [partner] about it cos I was thinking he’d think I was silly’.

Another aspect of re-experiencing is experiencing intense psychological distress when exposed to stimuli that symbolizes or acts as a reminder of the traumatic experience (Criterion B, 4). One woman described how her baby reminded her of the experience ‘every time I look at her I was thinking back to when she turned up and that was a big problem’ (E). Another woman describes how revisiting the hospital where the birth had happened was difficult, when talking about future births she explained ‘if there’s another hospital nearer I could go to I would’ (F).

Avoidance and numbing

All eight women described how they avoided thinking about the experience, or felt emotionally numb. These impacted on the relationships with their baby, partner, family and friends.

For example, in an attempt to avoid their baby, some women described how they became almost emotionally detached. Three participants described how they did not feel as though they bonded with their babies. F describes how it was for her ‘when we eventually got out [of hospital] I just found it really, really hard to bond with her’. B describes how she felt ‘some people say oh you know they fall in love with their baby instantly. I definitely didn’t fall in love with him’. All three mothers explained how
they felt they cared for their babies’ physical needs, but there was a sense of emotional detachment. E explains ‘I knew she was having the right feeds and she was being changed but I didn’t think she was getting any kind of niceness from me or any kind of love from me.’ For one mother the sense that she was not providing her child with any more than physical care led to her feeling that she was not needed ‘the amount of times I just got in my car and just drove off and left [partner] and said ‘here you are, you can deal with her. I can’t bear it. She’ll be better off with you, not me’’ (F).

So though they were not physically avoiding their new babies, some of the women were avoiding them emotionally.

Some women described how their relationships with their partners went through particularly difficult times in the months after the birth experience. This can be understood in terms of numbing or withdrawal from others, or restricted range of affect (Criterion C). C described how she and her partner drifted apart ‘With me withdrawing and him opting out and us not talking and not being able to find any common ground so we very much went off and did our own things’. For C, this led to further difficulties in the relationship ‘[Partner] wasn’t very helpful. He got very friendly with a girl at work ... But that was as a result of it really’. The impact of the experience and the consequences of the trauma seemed to impact on the relationship ‘You know he’d got this wife who’d been through this horrible experience and was obsessed about her baby dying, and he was worried as well’. However, C found that she was not able to offer her partner any support, restricted affect, ‘At that point I really felt like I couldn’t do any more emotion, so we sort of, it was a very difficult year for us’.
H also had a difficult first year. It was ‘\textit{without question the worst year we've ever had}’ (H). For H and her partner this was associated with inability to express a range of emotions ‘\textit{I completely lost my sense of humour}’, also a sense of foreshortened future (Criterion C), ‘\textit{fearful of the future ...I didn't know whether I was going to be able to go back to work and would I be able to manage it and would I be competent and things like that}’.

For some women the impact of avoidance and numbing led to difficulties in their sexual relationships. This initially seemed to be a result of the ongoing physical impact of the experience, B explains ‘\textit{And they say you get the green light, and he was all excited and I'd say you've got to be joking, you know. I felt like a horse came out from inside me, not a baby}’. But the problems of intimacy continued after the physical discomfort had gone, ‘\textit{well it's not painful any more but it's a bit of a, a don't feel like sexy}’ (A). D described feeling ‘\textit{numb}’ from the waist down and not ‘\textit{loving myself enough for sex}’. The ongoing difficulties of negotiating the sexual part of the relationship was described by A ‘\textit{to start with he was kind of very like he is when I'm ill... very sort of kid gloves, are you alright all the time. It was quite tricky for him to know how to be with me or what I wanted, and I don't think I really knew either}’.

There were also examples of the impact of avoidance on other relationships. For example avoiding seeing friends who are pregnant ‘\textit{the hardest part is seeing them pregnant because it's really, it still stirs up for me, oh my God, what's going to happen to you... and it makes it quite hard to actually see them really}’ (D).

For some talking about the birth was difficult, another example of avoidance. G had not spoken to her mother about the experience until just before the interview, it
seemed difficult to broach the subject with her 'I didn’t really know how to talk about
it with her. Yeh, I think she felt quite bad that we hadn’t spoken about it before’. D
also explained she had not fully shared the impact of the experience with her mother
for some time and had found it difficult to ‘I hadn’t been articulating it, I didn’t really
have the words’.

Another example of avoiding reminders of the traumatic event was avoiding childbirth
in the future. All the women described how the experience impacted on their decision
and thoughts about having another child. A described how nine months after the
experience she was beginning to be able to hold the idea of having another child in her
head ‘I can now just hold the thought in my head that maybe one day’. D explained
that ‘for quite a while I thought I don’t think I can ever do this again. So she was very
much of a last baby’. After more than two years this had begun to change ‘It’s
changing. It’s not definite.’

Other women were clear that if they did have another child, they would want the
experience to be different F: ‘I don’t want to be in the hospital where I had her. My
friend’s a midwife so I’ll just let her get on with it, come round here with me.’ G also
wanted a different experience ‘after that experience I’d quite like a home birth next
time’.

This impacted on relationships with partners, for example G’s partner was protective
about future pregnancies after the last experience ‘he doesn’t want me to have to go
through that again, and he doesn’t want to go through that again’. H also explained
that her partner was reluctant to think about another child ‘I think he would have been
quite happy for me just having one because of what happened. Yeh, we had to have a big chat about it'.

For women who had gone on to have other children, the first experience made the decision to have more, difficult as B explains 'For a long time afterwards I said I'd never have another, ... I think if I hadn't had the post traumatic stress counselling I wouldn't have had another'. Not wanting her child to be an only child, B had investigated alternatives 'I really was talking about adoption... I'd looked into it and got the brochures and all sorts of stuff'.

Again for H the first experience impacted on her feelings before the birth of her second child, for a start the gap between the two children was larger than she imagined, 'I just thought I will eventually, but I just couldn't face it, yeh. And there's a 3½ year gap and I always imagined it would be about two years'. H describes how in the later stages of pregnancy with her second child she began to think more about her previous experience, 'I literally used to go over and over and over in my mind what had happened and get really upset about it. And really really worried'. C felt less worried, 'I wasn't that worried about trying for [second baby] because she'd [the consultant] also said that if I felt badly about it I could have an elective caesarean, and having a caesarean was never something that bothered me because my mum had all three of us through caesareans'. Although the prospect of a caesarean made H even more concerned 'once I made the decision with the consultant that I was definitely going to have a caesarean, then I started panicking about the caesarean and trying to find out how many women had died whilst having a caesarean'. So women's
perceptions were not only coloured by their previous experiences of childbirth, but also other people’s experiences.

**Hyperarousal**

Criterion D of the diagnostic criteria for PTSD includes symptoms of increased arousal, hypervigilance and over alertness.

Symptoms of hyperarousal seemed to impact on some women’s relationships with their children. Although five women said they did not have any difficulty bonding with their baby, three of the five explained how they almost ‘overly bonded’. This led to over compensation, for example C described how she was very protective of her new baby ‘I wouldn’t let him out of my sight. Wouldn’t let anybody else touch him, change his nappy’. Although H felt as though she bonded with her baby, she felt as though the difficult birth experience impacted on how she felt about his safety ‘I’m much more neurotic about my little boy dying...I would wake up in the middle of the night, practically every night, and check if he was still alive. I became obsessed with cot death’. Her birth experience involved fear for her own safety, not her child’s, but it seems the state of over alertness may have generalised to concern about her baby.

Two women described having difficulty sleeping following the traumatic experience, ‘I was afraid of the dark. I mean all through my pregnancy I’d been getting up six times a night to go for a wee in the dark, you know without turning the lights on and now I couldn’t get out of bed, I couldn’t have the light off’ (A).
Interestingly, two women had been diagnosed with postnatal depression following their traumatic birth experience (D and G). Both had been prescribed anti-depressant medication by their family doctors. D explained 'he [the doctor] said postnatal depression, and I had Prozac for six months. I think it did make a difference, but not a significant one, this other stuff didn’t go away’.

The impact of the birth experience can be seen in terms of symptoms of posttraumatic stress disorder. These symptoms impacted on relationships with the baby and partner and influenced decisions to have further children. They also impacted on relationships with other important people such as friends and parents.

Theme 10: Blame

Some women describe a need to blame someone for their experiences. Seven women were able to split the birth experience from the baby, but as they needed to blame someone, it was usually themselves. For example B said 'I almost felt it was my fault that I was doing something, I did something you know, I had an inadequate birth, I didn’t breath through the contractions like these serene women do on the NCT [Natural Childbirth Trust]videos they show you. I felt that I was at fault and not, I never felt anger towards him [her baby]’.

C was also able to separate the experience from her child ‘it was never about him. It was my worries’. A was extremely conscious that she had split the experience from her baby. Indeed for A the birth experience had involved her being torn by her baby’s fingernails as she was born, this caused difficulties when trying to lay blame. As A explains ‘what I had to get my head round was that she had caused it but it wasn’t her
responsibility and that's a difficult one. Cos normally when someone hurts you or something like that happens you know where and how to put it together. It was her but it wasn't her, you know'.

D blamed the system for leaving her with ongoing concerns, she did not receive a diagnosis or opportunities to debrief for several months after the birth. She felt that a change in the system may have meant she did not have to suffer for as long. 'I still actually feel quite angry that that's how the system is'.

F, however, was not able to split the experience from the baby and found that her baby's ongoing medical problems did little to help this, 'when she's ill I get ratty with her cos I think God you're making it difficult for me ... and that's really awful. I think God what am I saying, she doesn't know'.

Thus, not all women blamed, but some participants blamed themselves, rather than their baby, others blamed the system, while one blamed her baby, although this led to feelings of guilt.

**Coping and changes for others**

**Theme 11. Developing an understanding of what happened**

Women described how important it was to develop an understanding of their experiences. For those women who had worked through the experience there was a need to talk about what had happened and in some way seek acknowledgement and recognition that what had happened was not 'right'. Sometimes this was a formal
process, using debriefing services or counselling, but more informal ways of doing this were also mentioned as important.

Having a ‘debrief’ with midwives and having her condition (PTSD) recognised was really important for D. She explains how the fact that other people knew that the condition existed leaves her feeling angry ‘having it recognised... having the debrief. But I also as a result of that, I experience a lot of anger about the fact that they knew. But some women do get this, you know, that you’re not some sort of random freak, but quite a group of women that do experience long term feelings of trauma’. Several women were offered a debrief by the midwife service, but some found that there was no clear explanation, about what happened, on offer. For example H hoped for a clear explanation six weeks after her birth experience but was faced with a doctor who ‘had obviously not even read my notes and I was just being seen as routine and I was asking all these questions and I just didn’t get any proper answers and I felt really upset about that.’ In contrast to this C found that her visit to the hospital was more constructive ‘I saw a really nice consultant about it. She was lovely. She’d obviously read my notes beforehand and was really helpful. Talked me through it and explained that obviously the drip shouldn’t have come out and that the fact I was there for so long didn’t help because I had three shift changes while I was there so I had no continuity of care really’. Confirmation and acknowledgement of the problem seems a key part of making sense of what has happened D explains ‘the debrief just helped me to make sense of so much, and I wish to goodness that they’d offered it [sooner after the birth]).
However, F found that while the debrief with the midwife helped, it only helped on one level:

‘Interviewer: Did going through the birth with [the midwife listening service] help?
F: It did, to make things clearer. Only to answer the questions. From an emotional level, no. To a level, to find out why things happened. Why did this happen, why didn’t this happen.’

F had been referred to the midwife counsellors and was waiting for her first appointment. Other women had seen counsellors and had found it very helpful. For example B said ‘I had three sessions with her and it was fantastic. It was very, very helpful and just what I needed’. D also had a positive experience of counselling ‘it was brilliant. It was really, really good’.

For other women using their partner as a way of debriefing was important, A: ‘If [partner] hadn’t been there and if I didn’t have him to say why did they do this, when did they do that... if I didn’t have constant access to him to say that, I don’t know where I’d put all those questions.’

This was not the case for everyone, for example F said ‘He says you go through the same things again, same things. I think he just, so I don’t bother telling him things or how I feel any more cos he says I’ve heard it all before, how I feel, and nothing’s, I’ve just got to get on with it’.

Four women described how they found it useful to talk it through with other family members, especially mothers or sisters. ‘I went to see her [sister] for a couple of
weeks and that really helped. To go and spend time with someone who really knew what I was on about' (C). This changed the quality of some of these relationships, for example D 'It brought us closer together. Well, we were always friends really as much as a mother and daughter could be, but it brought us closer together as adult friends’.

One woman had a chance meeting with someone who had a similar experience and discussing this helped ‘sitting down and talking to her and realising the different situations that could, the things that could have happened, then that started to help’ (E).

One woman had not discussed her experiences with anyone. She felt that ‘there’s nothing that talking about it can actually do. It sounds stupid, but because it’s in the past and it’s gone, nothing that can be said will make it any better’ (G). However, she did think that this might change with future pregnancies ‘I think maybe if we do have another one then I will talk about it’. She also felt that the interview would be an opportunity to begin to talk about it.

So women had different experiences of making sense of what had happened to them, either using formal means, such as debriefing with individuals involved, or using a counselling service, or more informally. Some women used a combination of these, one woman was still avoiding talking about it.

**Theme 12. How to make things better for others**

As a final question women were asked what they would like to see change, to ensure other women might have better experiences. This final theme is devoted to their ideas.
on the subject. Participants had many suggestions and there is not space to discuss them in great depth, but some examples are below.

There were suggestions about what people should be told before the birth. Some women mentioned a difference in what they had learnt about at the classes and the actual experience B: *the disparity between the hospital classes that I went to and the NCT [Natural Childbirth Trust] classes and the actual experience was enormous*. Other women suggested better preparation for particular procedures, for instance what might happen if you have to have a caesarean (C). A also felt it was important for people to know what to expect, but was not sure how to do this *without making everybody scared*.

There were suggestions made about how health care professionals should behave during the birth, for example A said that *everybody in that room should have empathy injections*. G suggests that health professionals should be aware that just because people are having second babies does not necessarily mean that they are confident, she had limited contact with the midwives during her birth experience and does not think this is right. *We have an expectation that we should have a midwife, we should be helped*.

Other women suggested that care needs to be more tailored to the individual, for example F: *You feel like a conveyor belt. You need to be more individualised*. Associated with the type of care offered was the idea of continuity of care, B suggests having a team of midwives caring for you throughout pregnancy and for the labour *I do think a team who know you would be really good. So at least you'd met once before*. 
Many women suggested the opportunity to talk about it afterwards would be useful. The timing of this was a consideration, but a leaflet handed out on the postnatal ward letting people know of its availability was suggested by A. D suggested ‘a poster in the baby clinic’ with information listing symptoms and saying ‘are you feeling any of these’.

E suggested that someone should offer to ‘sit down and go through it with you in hindsight, afterwards’. However, she also said that due to the subjective nature of the experience, ‘it should be offered to everybody, cos what I perceive as traumatic, someone might just find the normal way traumatic’. H also suggested a proper opportunity to discuss with someone what had happened ‘a clear explanation almost immediately to the family as to what happened’.

The participants made a number of useful suggestions about how their experiences might not be repeated, how clinical psychologists may fit into that is discussed later.
Discussion

The following section will be used to discuss the main findings of this study and relate them to psychological literature. Each superordinate theme will be taken in turn and discussed. Following this, implications for practice and limitations and strengths of this study will be highlighted. Suggestions for further research will be made before drawing final conclusions.

Birth Experience

Although the participant’s actual birth experiences were very different, common elements emerged in their accounts. All the women in this study reported that childbirth was more than simply a painful experience. The themes of loss of control, loss of autonomy and being treated in particular ways by health professionals all contributed to the experience of the birth as traumatic. This is similar to findings by Lyons (1998) who found that high scores on a measure of PTSD (the Impact of Events Scale, Horowitz et al., 1979) were associated with feelings of being out of control during the delivery, but not with pain scores. This supports findings from research into non-traumatic birth experiences. For example Green, Coupland & Kitzinger (1990) found that feeling in control during labour and being kept informed were associated with positive psychological outcomes.

Control, specifically the need for events to be predictable and controllable is a key aspect of attribution theory (e.g. Kelley, 1967, cited in Joseph, 1999). Attribution theory suggests that attributions about causes are structured around certain criteria, for
example: internal vs. external attributions, stable vs. unstable attributions, global vs. specific attributions and controllable vs. uncontrollable attributions (Ogden, 1996).

Control, or at least the perception that control is available, is a key contributory factor in the reporting of acute pain (Williams, Golding, Phillips & Towell, 2004). A reduction in perceived control is often associated with the 'patient role' that people tend to adopt once they enter a hospital environment. The patient role is also associated with lack of self-efficacy and depersonalisation (Williams et al., 2004).

The adoption of the patient role is often facilitated by the reactions of health professionals, whose language and behaviour can impact on that of the 'patient' (Williams et al., 2004). In this study all participants reported some negative experience related to their appraisals of the behaviour or language used by health professionals involved in their care. For some this was associated with their perceptions of the health professionals' negative attitude. Wijma, Soderquist & Wijma (1997) also found that rating the delivery staff negatively was associated with a PTSD profile after childbirth. They suggest several reasons for this negative evaluation of staff. Firstly they suggest it may be the process of selective attention, associated with high anxiety levels (i.e. a greater chance of interpreting neutral or minor threats as more serious than they are) (e.g. Beck & Emery, 1985, cited in Wijma et al., 1997). Secondly they suggest such negative evaluation may be associated with greater levels of external attributions in people with PTSD. This is supported by studies into war veterans (Mikulincer & Soloman, 1988, cited in Wijma et al., 1997), although interestingly some women reported feelings of self-blame in this study (as discussed later). Thirdly, Wijma et al. (1997) suggest that the women who had a PTSD profile
may have had insufficient contact with staff and that may have contributed to the stress of childbirth. Women in this study also experienced health professionals as absent.

That people need to be able to explain and understand events is associated with the general theoretical view that individuals need to predict the future and feel in control of events. Feeling out of control, loss of autonomy and negative evaluations of support from important others (health professionals) were important aspects of these women’s experiences.

*Role of expectations*

Another theme that emerged in this study was that the experience of childbirth differed from what women expected. For these women the role of expectations appeared to be important. Prior beliefs about oneself are particularly pertinent to the development of PTSD, according to Ehlers & Clark’s (2000) cognitive model. They suggest that those with negative beliefs about themselves are likely to see the traumatic experience as confirmation of these beliefs. In this study it seemed that positive beliefs, or expectations about the nature of the experience and the role of others (health professionals), were shattered, lending some support to the shattered belief aspect of the theory. This is contrary to findings from studies of childbirth in general, that suggest positive expectations of childbirth were associated with positive outcomes, while negative expectations were associated with negative outcomes (e.g. Green et al., 1990).
Unlike investigating PTSD after other types of trauma, most women had an expectation about what their birth would be like. Even if women do not attend antenatal classes, they have usually developed a sense of what childbirth will be like, either from their social network, through books, television, magazines or the internet (Weaver, 1998). People may have pre-existing beliefs about how they will behave in other traumatic experiences (Ehlers & Clark, 2000) and beliefs about themselves may be shaken by the traumatic experience. It would be interesting to investigate the role of beliefs and expectations about childbirth in the development of PTSD symptoms, perhaps in a prospective study comparing expectations during pregnancy and experiences in the postpartum period between women who go on to develop PTSD and those who do not.

Women in this study experienced the emotional consequences of not having the birth they expected. Some felt this as a loss and needed to grieve for the birth they had planned for and expected. Others felt they had failed as the birth had not gone to plan. This suggests that expectations about the birth experience may be an important factor in the development of psychopathology.

*Impact of the birth experience*

Research into PTSD in other populations suggests that partners’ mental health can be affected by the PTSD symptoms of their partners (Jordan, Marmar, Fairbank, Schelnger, Kulka, Hough & Weiss, 1992). One limitation of using childbirth as a paradigm for assessing the impact of PTSD on relationships is that partners are often part of the experience. Unlike PTSD after other traumas, such as sexual assault or
motor vehicle accidents where partners are not necessarily present, it is becoming the
norm for fathers to be present at the birth (Sullivan-Lyons, 1998).

In this study all the partners were present and involved in the birth experience, and
some may have been suffering from the impact of the trauma. This is worth
consideration when investigating the impact of PTSD on relationships in future
studies as partners' psychopathology may act as a confounding variable.

Women's reports of the impact on their partners were mixed. Some women reported
their partners did not seem particularly affected by the experience, while others
reported that their partner seemed to find it equally distressing. Although not included
in the analysis, participant I described her partner as being highly traumatised by the
experience and was concerned that he may have been exhibiting symptoms of
posttraumatic stress. Other participants said their partners were upset and distressed
after the birth and some described symptoms of avoidance. It seems likely that for
some fathers, feelings of helplessness and concern that their partners would die might
act as triggers for developing PTSD symptoms. This is an important area for further
investigation, as the impact of two parents with PTSD symptoms could be significant
in a child's early development. Certainly non-depressed fathers have been shown to
act as a buffer for babies against the impact of mothers' depression (Sullivan-Lyons,
1998).

The impact of the experience on father's relationships with their children was
highlighted in this study, as some mothers reported that their partners found it difficult
to bond with the baby, again demonstrating the need for more research in this area.
Those women who were assessed as having symptoms of PTSD using the Traumatic Birth Symptom Scale also spontaneously recounted symptoms during the interviews that can be related to the DSM-IV criteria of PTSD, thus giving support to the notion that women were experiencing symptoms of PTSD, rather than other forms of psychological distress. Participants mentioned symptoms of intrusions, avoidance and hyperarousal, although they were not explicitly asked about these symptoms. In line with other studies (e.g. Ayers & Pickering, 2001) there was evidence of co-morbidity with postnatal depression. Those women also diagnosed with postnatal depression were prescribed medication, which may not always be appropriate. Postnatal depression is routinely screened for after childbirth, but despite the co-morbidity with depression, postnatal PTSD can remain undetected as not all women who experience PTSD have postnatal depression (Bailham & Joseph, 2003).

The symptoms of PTSD were shown to impact on relationships in a number of ways. For instance symptoms of hyperarousal, avoidance and intrusions impacted on some women’s experiences of the mother-baby bond. However, participants were split as to whether there was an impact on the mother-baby bond. These findings are similar to Allen (1998), who also found that mothers’ reactions to their new babies differed. Allen (1998) found that some mothers who experienced a traumatic birth and had symptoms of PTSD were detached from the infant, some resented their baby, while others felt over-protective. Some women in this study described how their baby reminded them of the trauma. This is similar to Bailham & Joseph’s (2003) suggestion that this is what might contribute to attachment difficulties. The impact of avoidance and numbing symptoms on relationships is in line with previous findings from other populations experiencing PTSD (e.g. motor vehicle accidents, Kuhn et al., 2003).
Participants reported how symptoms of numbing and avoidance impacted on their relationships with their partners. Emotional and physical avoidance impacted on sexual and emotional aspects of their relationships. This is similar to previous studies (e.g. Allen, 1998) who found relationships to be affected by the traumatic birth experience. Avoidance and numbing symptoms also impacted on mothers’ desires to go on and have other children. For many women the traumatic experience had to be dealt with before they could consider further children. This supports previous findings associated with fear of further pregnancy (e.g. Fones, 1996).

The final theme under the superordinate theme of impact of experience was the theme of blame. Ehlers & Clark’s (2000) model suggests that appraisals of the traumatic event associated with personal responsibility can lead to guilt. Certainly mothers in this study felt the need to blame someone, often themselves. Self-blame is often associated with the need to maintain a sense of controllability, whereas other-blame is associated with the need to maintain self-esteem (Joseph, 1999). These processes are complex and more research is needed, but it is suspected that those who do better at adapting to an event, are those able to maintain a balance with the need to maintain self-esteem and control. Self-blame is associated with higher levels of depression and psychopathology (Joseph, 1999).

Coping and changes for others

Women found opportunities to discuss their experiences useful. Only one woman said that she had not found it helpful to talk about her experiences. Ehlers & Clark (2000) suggest that it is ‘the way’ (p. 335, their italics) in which experiences are discussed that can be unhelpful. If events are reported in an unemotional way or important, but
distressing aspects, are omitted, proper access to the meaning of the event can be prevented (Ehlers & Clark, 2000). All other participants found informal and formal methods of talking about their experiences helpful. Ehlers and Clark (2000) use the term ‘therapeutic reliving’ to describe how people need to discuss their experiences. As predicted by attribution theory, the drive for understanding is an attempt to re-establish the world as a predictable and controllable place (Janoff-Bulman, 1985, cited in Joseph, 1999).

Research into the effectiveness of psychological debriefing following major traumatic events is fraught with methodological problems such as small sample size, absence of randomisation, absence of control group, varying degrees of trauma and low response rates (among others) and there is limited evidence to suggest that formal psychological debriefing has an impact on psychological outcome (Bisson, McFarlane & Rose, 2000). However, evidence suggests that, on the whole, psychological debriefing is well received by participants (Bisson et al., 2000). For women in this study, information about what had happened and the chance to process it emotionally were highlighted as important. Recognition and prompt diagnosis of their PTSD were also considered important.

Participants had many suggestions about what could be changed to ensure other women did not experience similar difficulties. However, none of these suggestions are particularly radical and are not beyond reasonable expectations of care during and after childbirth.
Implications for practice and conclusions

The following section will outline implications for practice, for health professionals involved in childbirth and for clinical psychologists. Conclusions from the study will also be outlined.

It is not possible to make large generalisations from this study, due to its qualitative nature. However, the finding that lack of autonomy and lack of control contributed to the experience as being traumatic is supported by previous research. This has implications for health professionals involved in childbirth. Keeping women informed as much as possible throughout the experience could help to prevent these feelings in the future. There seemed a lack of information prior to the birth about what to expect if things went wrong, although there is a fine line between scaring pregnant women and helping provide clear information. Studies looking at providing information about other potentially painful procedures generally support the provision of prior information (Williams, et al., 2004).

This study found that some fathers were affected by the birth experience. The experience and lifestyle changes associated with a new baby have an impact on fathers too, but this is often given little attention in the research (Sullivan-Lyons, 1998). Psychopathology in fathers is likely to impact on the support they are able to provide and whether they can buffer the impact of the mother with PTSD, so further research is needed.

For this group of women symptoms of PTSD were shown to relate to difficulties in relationships, in developing a baby bond, in relationships with partners and in
relationships with friends. This indicates that further research is needed to assess the nature of the impact on the relationship with the baby and to find effective ways of intervening.

Implications for clinical psychologists working with women following traumatic experiences are outlined in the Division of Clinical Psychology of the British Psychological Society’s ‘guidelines for clinical psychology services to obstetrics and gynaecology’ (1995). These guidelines state that clinical psychologists can provide a range of psychological services at all levels, from working directly with women, to working with health professionals in obstetrics and gynaecology and to advising purchasers and services planners. Implications from this research support a role for clinical psychologists working with women and their partners after their traumatic birth experience. There are also opportunities for clinical psychologists to become more involved in supervision, for example of midwife services providing support to women after traumatic birth experiences. Also for clinical psychologists’ involvement in teaching/training in communication and in the application of biopsychosocial approaches to obstetrics and gynaecology to health professionals such as midwives, doctors, health visitors.

It may also be that clinical psychologists have a role in ensuring PTSD is screened for routinely in baby clinics. There is also a role for dissemination of information about PTSD after childbirth, to ensure it has a higher profile, so women do not continue to suffer in silence. Therefore clinical psychology has a valuable role to play in further research into postnatal PTSD.
In summary the main conclusions from this study are that women reported experiencing a loss of control and a loss of autonomy during the birth experience. Sometimes this was associated with the behaviour of health professionals, either taking away control, or not being in control. The impact of the traumatic birth experience can be understood in terms of the symptoms of PTSD, these were demonstrated to impact on baby’s relationship, partner’s relationship and the relationships with other important people. Women suggested a number of ways in which practice could improve.

Strengths and limitations of the study

This following section will outline some of the strengths and limitations of the study.

One possible criticism of the study is the relatively small sample size. However, the validity of the study is not compromised by the sample size, due to different assumptions that underlie qualitative work (Holt & Slade, 2003). Smith & Osborn (2003) suggest that there is no definitive answer to the question of sample size, but suggest that five or six participants are a ‘reasonable sample size for a student project using IPA’ (page 54). There are published examples of qualitative studies using sample sizes of one, four, nine (Smith & Osborn, 2003) and seven (e.g. Holt & Slade, 2003).

There were difficulties recruiting participants, as fortunately posttraumatic symptoms following childbirth are relatively rare (e.g. Ayers & Pickering, 2001), so access to women with PTSD symptoms was limited. Recruitment was planned to take place via a telephone helpline for women with symptoms of PTSD. Unfortunately this could not
proceed, as the helpline withdrew from the study following the ethics committee’s recommendations that participants’ General Practitioners (GPs) were contacted prior to the interview commencing. This study was reviewed by the Multicentre Research Ethics Committee (MREC), part of the National Health Service (NHS) as participants were considered under the remit of MREC as they had their baby in an NHS facility. The ethics committee were concerned that if participants became distressed during the interview there would be no access to health professionals for the researcher to report any concerns to, so made contacting the GP a prerequisite of participating. GPs were informed that their patient was participating and asked to inform the researcher if they had any concerns about this. Unfortunately the telephone helpline co-ordinator felt that it would be unethical to inform the GP of women’s participation, even with their consent, so withdrew from the study. Therefore alternative sources of recruitment were followed. Fortunately ethical approval also covered recruitment via Internet websites.

A strength of this study was that it accessed women who were not necessarily known to medical services, other than the fact that they had given birth. Some participants were not able to express their distress at the time of the birth experience, so statutory services were not necessarily aware of their difficulties. Recruitment via medical services might have missed some of these participants, as their birth experience may not have been seen as objectively traumatic. This research highlighted the subjective nature of the birth experience as all participants felt they had experienced a traumatic event. However, it also meant that it was not possible to check whether women had symptoms of PTSD before interviewing them. It would have been unethical to recruit women for an interview study, and then not interview them following a screen.
Recruitment via the Internet restricted participants to being computer literate and to having regular access to Internet websites. However, recruitment via this method did bring a fairly homogenous sample in terms of education, ethnicity and home ownership status. As with other qualitative studies, it is important not to draw general conclusions from the findings of this study, as findings are only pertinent to this specific group of women. Future studies might wish to access a different sector of the population, perhaps by advertising in parenting magazines or via parent and toddler groups.

Another aspect of the study design that may have influenced the findings is the fact that the researcher was also a trainee clinical psychologist. In many ways this could be seen as an advantage, in that developing rapport and sensitively engaging people in discussions of difficult emotions are an aspect of a clinical psychologist’s professional role. However, although the interviews appeared to provide good verbal accounts, some women may have been reluctant to mention some of their feelings to a mental health professional. It may be that despite best efforts on the part of the researcher to develop a rapport with the participants that some women felt evaluated as a parent. New mothers are often acutely aware of evaluation and comparisons with other new parents and not least by their own preconceptions about what it means to be a ‘good mother’ and bond with their baby (Kitzinger, 1992). It may be that some mothers were concerned that they may be accused of not coping and threatened with the removal of their baby, or simply be bowing to the pressures of social desirability and want to present themselves to the researcher in a positive light (e.g. Fife-Schaw, 2000). Although this may have impacted on some women’s accounts, generally rich verbal
accounts were given and women were open about their negative emotions, implying
this was not the case for all women.

There is an issue relating to the nature of the experiences participants recounted.
While the goal in a research interview is to elicit rich, verbal information, this was not
always possible, as participants often showed signs of upset and distress. While
probing questions may have elicited more detailed descriptions, consideration had to
be given to the participant’s emotional state. Some women became upset while
recounting their stories, and so it was not possible to probe too deeply. There were
also aspects of the interview that it was difficult to probe, for example where women
were not forthcoming about certain aspects of their personal relationships with their
partners. An important point to note is the difficulty in concentrating on the impact of
the experience on relationships, as participants generally wanted to recount their
experiences. IPA allows researchers to follow participants and use their stories, but
this generally meant that the main area of relationships was relatively neglected.
Further research in this area may need to consider alternative methodology, perhaps
more quantitative methods might enable a more focussed study.

Women who volunteered to participate in research about their experiences are likely
to have been sufficiently recovered from that experience to be able to talk about it.
Some women expressed an interest in participating, but felt unable to. This may have
contributed to the finding that some women did not have particularly high levels of
PTSD symptoms as measured by the TBSS. There are difficulties in the self-report
aspect of the TBSS. Although the TBSS was not used to diagnose PTSD, it did
highlight the presence of symptoms and level of disability associated with these.
Although other studies have shown good levels of agreement between self-report measures and the 'gold standard' diagnostic interview (e.g. O'Reilly, Grubb & O'Carroll, 2004) there are difficulties using the measures with patient populations. The retrospective nature of the self-report may also have impacted on the accuracy of the self-report data. Women were asked to report how they felt in a 'typical' month after the birth. Memories and reports of past events are often coloured by current emotional states (e.g. McQuaid, Pedrelli, McCahill & Stein, 2001).

The retrospective nature also impacts on the causative implications of the effects of PTSD on childbirth. Interviews were conducted after the traumatic experience. Therefore it is not possible to know what women's relationships with their partners and families were like prior to the birth. Women's relationships with their babies often form while they are pregnant, and again the retrospective nature of the study meant it was not possible to examine this. However, this was an exploratory study to see if further research in this area is warranted. Clearly future studies may want to consider investigating the nature of relationships prior to the birth experience and again afterwards to look at any changes that may be associated with the impact of PTSD symptoms.

An important point to note is the impact that the research had on the interviewer. During the process of analysis some transcripts were read and analysed by colleagues, some of whom found it reasonably distressing or upsetting to read the accounts. It is interesting to note that I had no strong feelings during the interviews, or the analysis. Perhaps the analytic process means that being so close to the material its impact is not so striking, or perhaps the women presented their stories to me in a manageable form.
during the interviews. The one colleague who found reading the transcript traumatic joked that it reminded him of his daughter’s birth. Perhaps not having experienced childbirth, either as myself or with someone else, I was not able to fully empathise with the experiences. Alternatively it could be argued that because I do not have my own experience, I can engage better with the information presented by the participants without being reminded of my personal experiences. The reader can perhaps decide for themselves about the impact of their own experiences on reading these accounts.

**Issues of reliability and validity in qualitative research**

In comparison with qualitative research, the criteria for judging research using quantitative methods are well established (Yardley, 2000). For instance, representative sampling, adequate sample size, reliable and valid measures and designs limiting the impact of confounding variables are all acknowledged as important factors in assessing quantitative research. Qualitative research methods are still relatively new to psychology, so standards and conventions for assessing validity are not well defined. Research using qualitative methods is often at risk of being assessed using criteria that can be seen as ‘irrelevant’ to their approach (Yardley, 2000). Yardley (2000) suggests that a particular difficulty in assessing the integrity of qualitative methods is the broad range of epistemologies and techniques that fall under the heading qualitative methods. Such is the range of theoretical orientations that devising a checklist or specific criteria to assess validity could be seen as being as unhelpful as using quantitative criteria (Smith, 2003). Two papers have been published that have gone some way to addressing issues of validity, while acknowledging the differences in orientation (Smith, 2003). These are Elliott, Fischer & Rennie (1999) and Yardley (2000). Elliott et al. (1999) suggest seven guidelines pertinent to qualitative research,
including owning one’s perspective, situating the sample and providing grounding in examples. It is for the reader to decide the coherence of the account and the extent to which it resonates with their experiences.

The aim of this research was to gain women’s views of the impact of their traumatic birth experiences on their relationships with their babies and partners. A brief summary of the results of the project will be posted on the websites used for recruitment, and summaries will be e-mailed to all those who participated. Participants will be encouraged to comment on the findings, which will act as a credibility check.

Understanding more about the nature of relationships from the point of view of the partner (or the child) was beyond the scope of this research. Therefore, the use of ‘triangulation’ (for example data gathering from various sources), would not have been appropriate (Yardley, 2000). Further research, using other research methods, such as observation or interviewing family members, would add to the understanding of the impact of PTSD in this area, but not specifically to women’s experiences.

**Future research**

Throughout this discussion directions for future research and further investigation have been highlighted. Further research may want to compare the experiences of women who do not have PTSD after childbirth, with those who do. It would be interesting to see whether some of the themes that have emerged in this study, would also be important to women who do not develop PTSD symptoms. Such comparison might begin to highlight particular factors that contribute to the development of PTSD.
Concluding remarks

This study aimed to investigate women's experiences of traumatic childbirth and their perceptions of the impact of these experiences on relationships. It found that important elements in the experience were the loss of control and autonomy, the attitude of the health professionals. The impact of the experience and subsequent symptoms of PTSD were also highlighted. The role that clinical psychologists can play in supporting women after traumatic experiences and in supervision and teaching to health professionals was discussed. As an exploratory study it highlighted a need for further research in this area.
References


Appendix I
Ethics approval letters
16 February 2004

Ms Anna-Louise Gosling
Department of Psychology
School of Human Sciences

Dear Ms Gosling

Posttraumatic stress after childbirth: A qualitative account of the impact on relationships (EC/2003/99/Psych)

I am writing to inform you that, following approval of your above submission by the South East Multi-Centre Research Ethics Committee, the University Ethics Committee has approved this protocol on the understanding that the Ethical Guidelines for Teaching and Research are observed. For your information, and future reference, the Guidelines can be downloaded from the Committee's website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (EC/2003/99/Psych). The Committee should be notified of any changes to the proposal, any adverse reactions, and if the study is terminated earlier than expected, with reasons.

Date of approval by the Ethics Committee: 16 February 2004
Date of expiry of approval by the Ethics Committee: 15 February 2009

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
Dr V Senior, Supervisor, Psychology
Ms Anna-Louise Gosling  
Trainee Clinical Psychologist  
School of Human Sciences  
Department of Psychology  
University of Surrey Guildford  
Surrey GU2 7XH

6th February 2004  

Dear Ms Gosling  

MREC 04/01/007  Post-traumatic stress after childbirth: A qualitative account of the impact on relationships

Thank you for your letter dated 26th January 2004 addressing the issues raised by the South East MREC at the review of the above named study at their meeting on 14th January 2004.

I would like to congratulate you on the high standard of your response to the issues raised; your response was clear, concise and well presented.

Yours sincerely

[Signature]  

DR J M Lambert  
CHAIRMAN, SOUTH EAST MREC
Ms Anna-Louise Gosling  
Trainee Clinical Psychologist  
School of Human Sciences  
Department of Psychology  
University of Surrey Guildford  
Surrey GU2 7XH

6th February 2004

Dear Ms Gosling

MREC 04/01/007 Post-traumatic stress after childbirth: A qualitative account of the impact on relationships

The South East MREC reviewed your application on 14th January 2004. The documents reviewed were as follows:

Application form dated 26 01 04  
Protocol January 04 version 2  
Research Summary January 04 version 2  
Curriculum vitae – Anna Louise Gosling and Dr Victoria Senior  
Interview Schedule – December 03 version 1  
Traumatic Birth Symptom Scale – December 2003  
Advertisement – December 2003 version 1  
Information Sheet – January 04 version 2  
Consent form – January 04 version 2  
Letter to GP January 04 version 1  
University's insurance information

The members of the committee present gave approval for your research on ethical grounds.

The committee is happy to give you approval on the understanding that you will follow the conditions of approval set down below. A record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the use of an existing database collected for previous research or other purposes with
limited patient contact through the central research team. For this reason you are not required to notify any LRECs when undertaking this research.

MREC Conditions of Approval

- The protocol approved by the MREC is followed and any changes to the protocol are undertaken only after MREC approval.

- If projects are approved before funding is received, the MREC must see, and approve, any major changes made by the funding body. The MREC would expect to see a copy of the final questionnaire before it is used.

- You must complete and return to the MREC the annual review form that will be sent to you once a year, and the final report form when your research is completed.

Legal and Regulatory Requirements

It remains your responsibility to ensure in the subsequent collection, storage or use of data or research sample you are not contravening the legal or regulatory requirements of any part of the UK in which the research material is collected, stored or used. If data is transferred outside the UK you should be aware of the requirements of the Data Protection Act 1998.

ICH GCP Compliance

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request or on the Internet at www.corec.org.uk

Yours sincerely

DR J M LAMBERTY
CHAIRMAN, SOUTH EAST MREC

Enclosures MREC Response Form dated 06 02 04
MULTI-CENTRE RESEARCH ETHICS COMMITTEE
RESPONSE FORM

DETAILS OF APPLICANT

1. Name and address of Principal Researcher:

Ms Anna-Louise Gosling
Trainee Clinical Psychologist
School of Human Sciences
Department of Psychology
University of Surrey Guildford
Surrey GU2 7XH

2. Title of Project

Post-traumatic stress after childbirth: A qualitative account of the impact on relationships

3. Name and address of Sponsor:

N/A

DETAILS OF MREC:

4. Name and address of MREC:

South East MREC
Room 76 B Block
40 Eastbourne Terrace
London W2 3QR

5. MREC Reference Number:

MREC 04/01/007
Listed below is a complete record of the review undertaken by the MREC with the decisions made, dates of decisions and the requirement at each stage of the review:

14\textsuperscript{th} January 2004 \hspace{1cm} Approved subject to amendment

a) Further details are required regarding the other web-based organisations which may be used as part of the study. If it becomes necessary for these organisations to be accessed to aid recruitment to the study, the applicant is reminded that a copy of the advertisement will be required for review by the MREC.

b) The application mentions in the response to question B4 that the co-ordinator will ask members if they are interested in participating in the study. The applicant is reminded that subject’s being interested in participating in the study does not necessarily mean that they will be suitable to participate.

c) The Committee questions how well the co-ordinator will know the potential subjects.

d) It was agreed that consent should be sought from the subjects for the applicant to inform their GP of their participation in the study. Failure to give consent for the applicant to contact their GP should exclude the subject from entering the study.

e) The subject’s GP should be asked whether they are aware of any reason why the subject should be excluded from participating in the study. A copy of the GP letter is required for review.

f) Clarification is required that the Traumatic Birth Symptom Scale is being used to assess subjects, but not for excluding subjects from the study.

g) The applicant is asked to explain how she will deal with the variation of responses due to the different periods of time since the birth trauma; members agreed that subjects’ responses may be different depending on how long ago the birth trauma occurred.

h) The tapes should be incinerated, not just wiped.

i) Evidence is required regarding the responses to A18 and A19.

j) The responses to B10 and B11 are incorrect and should be amended. These should relate to the questions being asked in the survey.
k) The Committee question whether there are enough questions relating to relationships with partners in order to provide data to answer the research question.
l) The applicant is asked to consider including a control group, for example, those who have experienced a traumatic birth but not PTSD.
m) Full reimbursement of travelling expenses should be offered to subjects and detailed in the information sheet and the response to question B7.
n) Consent for the interviews to be taped should be sought from the subjects.
o) The applicant is asked to consider seeking the views of the subjects’ partners on whether or not their relationship has changed since the birth event.
p) The applicant is asked to clarify, in the application form and associated paperwork, that she is studying the symptoms of Post Traumatic Stress Disorder.
q) The applicant is asked to explain what she would do should a subject present with another depressive illness.

Subject Information Sheet

r) The results of the study should be offered to subjects.
s) The word “major” should be omitted from the section entitled “What will happen to the results of the research study?”

THE FINAL DOCUMENTS AND ARRANGEMENTS APPROVED BY THE MREC

The following items have been approved by the South East MREC:

Application form dated 26 01 04
Protocol January 04 version 2
Research Summary January 04 version 2
Curriculum vitae – Anna Louise Gosling and Dr Victoria Senior
Interview Schedule – December 03 version 1
Traumatic Birth Symptom Scale – December 2003
Advertisement – December 2003 version 1
Information Sheet – January 04 version 2
Consent form – January 04 version 2
Letter to GP January 04 version 1
University's insurance information
Methods of initial recruitment of study -
Compensation arrangements for subjects -
Payments to researcher -
Provision of expenses for subjects - √

Date of approval: 6th February 2004

Signature of Chairman/Administrator: Jane Martin

Date: 6th February 2004

Name: MRS JANE MARTIN
Appendix II
Copy of advertisement placed on website
Study Of The Effect Of Traumatic Birth On Families

This study is part of ongoing research into the effects of traumatic birth. At the University of Surrey we are interested in finding out more about how traumatic birth affects family life and what it is like to live with. This may help us to think about the kind of help mothers and their families might need.

You can take part in the study if you are over 18 years old, have experienced a traumatic birth at least three months ago and are able to read and speak English fluently. The study involves being interviewed for about 45 minutes about your experiences and you will be asked to complete a short questionnaire.

If you are interested in taking part and would like further information please contact Anna Gosling (Trainee Clinical Psychologist) on 0794 168 4043 or e-mail: anna@aptd2000.freeserve.co.uk. We will send you an information leaflet.
Appendix III
Information for Participants Sheet
Study Of The Effect Of Traumatic Birth On Families

Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?
This interview study is part of ongoing research into traumatic childbirth by Dr Susan Ayers of the Psychology Department, University of Sussex, Brighton. It is in collaboration with Anna Gosling and Dr Victoria Senior at the University of Surrey. We are interested in finding out more about how traumatic birth affects family life and what it is like to live with. This may help us to think about the kind of help mothers and their families might need. This study does not evaluate you as a person or as a parent in any way.

Why have I been chosen?
You have been chosen to take part because you are over 18 years old, have experienced a traumatic birth over three months ago and are able to read and speak English fluently.

Do I have to take part?
It is up to you whether or not you decide to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You will also be asked for your consent to contact your family doctor, to let them know you are taking part in the research. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?
The study involves being interviewed once for about 45 minutes and completing a short questionnaire. During the interview you will be asked about your birth experience and how you feel it affects/affected your family life. The interview can take place at University of Surrey or at your home - whichever is most convenient for you. You will receive any expenses back in full.
What are the possible disadvantages and risks of taking part?
Talking about a difficult experience can be upsetting. If you do become upset during the interview you can ask to stop at any time. You have the option of continuing later, at another time or finishing the interview altogether. The researcher may discuss with you whether it might be helpful for you to visit your family doctor.

Will my taking part in this study be kept confidential?
All information which is collected about you during the course of this study will be kept strictly confidential and will be handled in accordance with the Data Protection Act 1998. All your answers are confidential and will be used only for the purpose of this study. The interviews will be transcribed and examined for general themes. Any report on this research will use identification numbers so that you cannot be identified.

What will happen to the results of the research study?
The results of the study will be used for a research project as part of a PsychD in Clinical Psychology. It is likely that the research will be submitted for publication in a research journal. Anyone who chooses to take part will not be identifiable in any way. You will have the chance to see the results, if you wish.

Who is organising the research?
The research is being organised by a Trainee Clinical Psychologist as part of a PsychD in Clinical Psychology. The research is being supervised by Dr Susan Ayers, Department of Psychology, University of Sussex and by Dr Victoria Senior, Research Tutor at the University of Surrey.

Contact for further information
If you have any questions please contact Anna Gosling Trainee Clinical Psychologist on 0794 168 4043 or Susan Ayers Research Supervisor on 01273 678990

Thank you for taking the time to consider taking part in this research
Appendix IV
Interview schedule
Introduction - Thank you for agreeing to talk to me about your experience of childbirth. I am going to ask you some questions about your experience of birth, how it has affected your life, and your family. If you don’t feel comfortable answering any of the questions, just say so. We can leave them out or come back to them later. You are also free to stop the interview at any time.

General background

First of all, I’d like to ask a few general questions:

1. How many children do you have?
2. Have you had any other pregnancies?
3. If more than one child, which of these births did you find traumatic or difficult?
4. How long ago did you have this experience?
5. Do you have a partner?
   If yes, are you currently married/living together/living separately?

Experience of childbirth

First of all, I’d like to know something about your birth experience and what made it traumatic.

1. Would you mind talking me through what happened during your birth? OR

   Can you think back to when your labour first started and talk me through what happened from there onwards?

2. Was there one particular aspect that made your birth traumatic?
   If yes,
   • It sounds very difficult. In our research we are interested in finding out what things make an event like that particularly traumatic (e.g. attitude of staff, pain, loss of control, fear of dying).
   • Could you tell me what things made that event particularly traumatic for you?
   • What was your partner told? If anything?

Affects of traumatic birth on personal life

3. How did your experience make you feel afterwards?
   a. In the first few weeks
   b. In the first few months
   c. Present day

4. Has your experience changed how you feel about yourself?

5. Do you think your behaviour changed after your experience?
   If yes- Can you tell me more about this?

6. Has your experience affected the way you live your life? (e.g. socialising, employment, future plans)?

Affects of traumatic birth on relationship with partner (where relevant)

7. Do you think your experience affected your partner in any way?
If yes- Can you tell me more about this? His relationship with the baby?

8. Do you think your experience affected your relationship with your partner?
   d. In the first few weeks after labour (if yes – in what way?)
   e. In the first few months (if yes – in what way?)
   f. Present day (if yes – in what way?)

Affects of traumatic birth on the mother-baby bond

9. Do you think your experience affected the way you felt about your baby?
   a. In the first few weeks after labour (if yes, in what way?)
   b. In the first few months (if yes, in what way?)
   c. Present day (if yes - in what way?)

10. Do you think you behaved differently with your baby because of your experiences in birth?
    a. In the first few weeks after labour (if yes, in what way?)
    b. In the first few months (if yes, in what way?)
    c. Present day (if yes - in what way?)

Affects of traumatic birth on other children (where relevant)

11. Do you think your experience affected your other child/children in anyway?/Decision to have more children?
    If yes – in what way?

12. Do you think your experience affected your relationship with your other children?
    a. In the first few weeks after labour (if yes - in what way?)
    b. In the first few months (if yes - in what way?)
    c. Present day (if yes - in what way?)

13. Do you think your experience had an impact on other important people in your life? Friends?/ parents?

Coping strategies

14. What things do you think were important in helping you cope with your experience?

Recovery & change

15. Do you feel you have recovered from your experience now?

16. What [helped you/didn't help you] get over your experience?

17. What changes would you like to see to stop this happening to other women?
Appendix V
Traumatic Birth Symptom Scale
Below are a few questions about your experience of birth:

How long ago was the birth? ___________________________________________________________________

During your birth:

Yes  No  Were you physically injured?
Yes  No  Was someone else physically injured?
Yes  No  Did you think that your life was in danger?
Yes  No  Did you think someone else’s life was in danger?
Yes  No  Did you feel helpless?
Yes  No  Did you feel terrified?

Below is a list of problems that people sometimes have after a traumatic birth. Read each one carefully and circle the number (0-3) that best describes how often that problem bothered you in a typical MONTH after birth.

0  Not at all or only one time
1  Once a week or less / once in a while
2  2 to 4 times a week / half the time
3  5 or more times a week / almost always

0 1 2 3  Having upsetting thoughts or images about birth that came into your head when you didn’t want them to.
0 1 2 3  Having bad dreams or nightmares about the birth.
0 1 2 3  Reliving the birth, acting or feeling as if it was happening again.
0 1 2 3  Feeling emotionally upset when you were reminded of the birth (for example, feeling scared, angry, sad, guilty, etc)
0 1 2 3  Experiencing physical reactions when you were reminded of the birth (for example, breaking out in a sweat, heart beating fast)
0 1 2 3  Trying not to think about, talk about, or have feelings about the birth.
0 1 2 3  Trying to avoid activities, people, or places that remind you of the birth.
0 1 2 3  Not being able to remember an important part of the birth.
0 1 2 3  Having much less interest or participating much less often in important activities.
0 1 2 3  Feeling distant or cut off from people around you.
0 1 2 3  Feeling emotionally numb (for example, being unable to cry or unable to have loving feelings).
0 1 2 3  Feeling as if your future plans or hopes will not come true (for example, you will not have a career, marriage, children, or a long life)
0 1 2 3  Having trouble falling or staying asleep.
0 1 2 3  Feeling irritable or having fits of anger.
0 1 2 3  Having trouble concentrating (for example, drifting in and out of conversations, losing track of a story on television, forgetting what you read)
0 1 2 3  Being overly alert (for example, checking to see who is around you, being uncomfortable with your back to a door etc)
0 1 2 3  Being jumpy or easily startled (for example when someone walks up behind you)
How long did you experience the problems that you reported above?
1  Less than 1 month
2  1 to 3 months
3  more than 3 months

How long after the birth did these problems begin?
1  less than 6 months
2  6 or more months

How disabling were these reactions?
0  not at all disabling
1  slightly disabling
2  definitely disabling
3  markedly disabling
4  severely disabling

Please indicate below if the problems you rated on the previous page interfered with any of the following areas of your life:

Yes  No  n/a  Work
Yes  No  n/a  Household chores and duties
Yes  No  n/a  Relationships with friends
Yes  No  n/a  Fun and leisure activities
Yes  No  n/a  Schoolwork
Yes  No  n/a  Relationships with your family
Yes  No  n/a  Sex life
Yes  No  n/a  General satisfaction with life
Yes  No  n/a  Overall level of functioning in all areas of your life

Finally, please indicate whether any of the following traumatic events have happened to you or you have witnessed them:

Yes  No  Serious accident, fire, or explosion (for example an industrial, farm, car, plane or boating accident)
Yes  No  Natural disaster (for example, tornado, hurricane, flood, or major earthquake)
Yes  No  Non-sexual assault by someone you know (for example being mugged, physically attacked, shot, stabbed or held at gunpoint)
Yes  No  Non-sexual assault by a stranger (for example being mugged, physically attacked, shot, stabbed or held at gunpoint)
Yes  No  Sexual assault by someone you know (for example, rape or attempted rape)
Yes  No  Sexual assault by a stranger
Yes  No  Military combat or experience of a war zone
Yes  No  Sexual contact when you were younger than 18 with someone who was 5 or more years older than you (for example, contact with genitals, breasts)
Yes  No  Imprisonment (for example prison inmate, prisoner of war, hostage)
Yes  No  Torture
Yes  No  Life-threatening illness
Yes  No  Other traumatic event (please specify ____________________________)

THANK YOU VERY MUCH FOR YOUR HELP
Dr
The Surgery,
Town
County

Dear Dr

NOTIFICATION TO GP OF PATIENT’S PARTICIPATION IN A RESEARCH PROJECT

Patient’s Name: [name] – DOB: [address]

Title of Project: Posttraumatic stress symptoms after childbirth:
a qualitative account of the impact on relationships

Name of Researcher: Anna Gosling

As you will know, this patient has experienced a difficult or traumatic birth. I am writing to let you know that we have asked her to take part in a research study looking at the impact of difficult birth experiences on family life and relationships. Your patient will be asked to take part in a semi-structured interview (lasting about ¾ hour) asking her about her experiences of the birth and the effect she feels it has had on her and her family’s life. Please find enclosed a participant information sheet.

It is not anticipated that there will be any side effects from this investigation but if you have any concerns about your patient participating in this study please contact me by (2 weeks before interview). If I have not heard from you within this time I will assume it is acceptable to continue with the interview.

If you would like more information on this research (or would like details of the outcome of the study), please contact me at the Department of Psychology, University of Surrey, Guildford, Surrey GU2 7XH, telephone number 01483 689441.

Yours sincerely

Anna Gosling
Trainee Clinical Psychologist
Appendix VII
Consent form
Unis
University of Surrey

Study number: 04/1/007
Participant number:

Consent Form

Title of project:
*Study of the effect of traumatic birth on families*

Name of researcher: Anna Gosling

1. I confirm that I have read and understand the information sheet dated_______ (version_______) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I agree to my family doctor being contacted before I take part in the study

4. I agree to the interview being tape-recorded

5. I agree to take part in the above study.

Please initial box

Participant name
(please print) Date Signature

Researcher name
(please print) Date Signature
Appendix VIII
Demographic questionnaire
It would be very helpful if you could supply us with the following details:

Your date of birth ............................................... Age last birthday ..............................................

What is your marital status? Who do you live with?
[ ] married [ ] husband/partner
[ ] living with your partner [ ] husband/partner & children
[ ] separated [ ] parents
[ ] divorced [ ] friends
[ ] single [ ] just your children
[ ] widowed [ ] alone

Where do you live? What ethnic group do you consider you belong to?
[ ] council rented [ ] African
[ ] own home [ ] Afro-Caribbean
[ ] private rented [ ] Bangladeshi
[ ] hostel [ ] Chinese
[ ] bed & breakfast [ ] Indian
[ ] live in job [ ] Pakistani
[ ] White European
[ ] Other (please specify) ____________________________

What educational qualifications do you have? At what age did you leave full time education?
[ ] none [ ] 15 or under
[ ] CSE's / O levels / GCSE's [ ] 16 (O level or GCSE stage)
[ ] A levels [ ] 18 (A level or other diploma stage)
[ ] City & Guilds [ ] 18+(Further education stage)
[ ] Diploma
[ ] Degree
[ ] Higher degree
[ ] Professional qualification (please specify) ..............................................................................................

What job do you do, or if you are not currently working, what was your last job?
(please state job title and type of business) ..............................................................................................

If you have a partner, what is your partner's occupation?
(please state job title and type of business) ..............................................................................................
Appendix IX
Sample transcript
Sample transcript

I: Thank you for agreeing to come along and be interviewed about your experiences. As you know, I'm going to ask you a little bit about your experience of the birth itself and then I'm going to ask you little bits about how you feel it affected you and your family and life in general a bit really. Right, if you don't feel comfortable answering any of the questions just let me know, alright, and we can stop and I can turn the tape machine off and whatever. And also you can stop and leave if you want to at any moment.

First of all, I'd just like to ask you a few general questions. Have you any other children apart from [baby's name]?

P: I've got a stepson who's 5.

I: Okay.

P: None of my own.

I: Okay. And have you had any other pregnancies apart from [baby's name]?

P: Had one other pregnancy. It was terminated a few years ago.

I: Okay. And obviously we're talking about [baby's name]'s birth today. How old is [baby's name]?

P: 3 months.

I: It was a few months ago that it all ...

P: Yeh.

I: Okay. And you mentioned that you're stepmum so you have a partner.

P: Yeh.

I: Are you currently living together?

P: Yeh, yeh.

I: ... Married?

P: No. Haven't got to that point yet. Doing it all the wrong way round.

I: Okay, so if we start off. I'd like to know a little bit about your birth experience. So if you can just tell me what it was like.

P: Well [baby's name] was 5 weeks early. I finished work on the Monday, well actually I was due to finish work a week on Monday but I had a cyst in rather a nasty place and I couldn't walk, I couldn't do anything and I had a lot of trouble with doctors pumping me full of antibiotics - I was very unwell. And then on the Friday they decided that finally they'd do something about it and they tried to, they wanted to operate but they couldn't give me an anaesthetic because of her, so they did what they could under gas and air.

I: So it wasn't very pleasant?

P: No, not very pleasant at all. So basically the whole what I call the hell of the two weeks started at the beginning of that week because up until then everything wasn't too bad and then becoming more and more ill and then pumped with all these antibiotics and everything else, no-one quite sure what was going on. So they did this
operation on the Friday and then, so I went home on the Friday night, due to start
maternity leave on the Monday, and thought oh lovely I can walk around, I feel great,
beautiful, went to sleep. 12 hours sleep for the first time in 3 weeks. Woke up
Saturday morning, got out of bed and my waters went.

I: Oh gosh.
P: My other half and I basically sat there and went maybe it’s a side effect of the cyst.
No it’s not is it, no. So we had breakfast, I had a shower
I: Very sensible.
P: Did everything you’re not supposed to do and thought I’m not coming home, cos it
was so early and I thought you know this isn’t good, by which point I’m starting to get
a little bit concerned because I hadn’t got to the section in the book yet that told you
about – I’d done the ante natal class but I’d still been hiding from the videos, you
know. Quietly watching them on Discovery at home on my own but couldn’t watch it
in front of the group, you know. At that point up until the Friday you know my
biggest fear was the fact that my other half was going to be in the room and see me
naked. He’s seen me naked for 5 years but I was, you know, it’s a very different kind
of naked. You know, so that was a baptism by fire on the Friday and sort of realising
that gas and air wasn’t too crashed out, I was thinking oh dear, this isn’t good. And
then the concerns as to what was happening with her kicked in. So went off to [Town]
name and they had a bit of a bed crisis as well as every other kind of crisis and the
next three days it was just me getting progressively iller and knowing that the waters
had gone, not knowing what had happened to her was getting worse and worse as in is
it a problem with her, is it a problem with me. And I knew it was me, but not
knowing what was going on inside was making it very difficult. And then eventually
they decided to induce me on the Tuesday and I spent the night throwing up blood,
which wasn’t very pleasant, and I rang my other half at midnight and we lived in
[Other town name] at the time so we were commuting between the two. We were due
to move actually, well end of that month, when she was in hospital, so he was
commuting sort of backwards and forwards. He’d just gone home and I rang him at
midnight and said look I’m really unhappy here and they wouldn’t let him in the ward,
so I got into a bit of an argument about the big sign that said partners anytime.
Everyone else had their other halves there and there I am with a bowl of blood of blood
and they wouldn’t let him in so, they let him in and in the end they said in the morning
that they would induce me. Which I thought well that’s a great idea, let’s just get this
over and done with, but no-one really told me what that involved. So I sort of got
down to the delivery room, walked down. I thought great, she’s going to turn up and
got down there. They sort of started things and nothing was really happening. They
said I’ll tell you what – that was 3 o’clock in the afternoon, they said we’ll bring you
back in the morning.
I: So you had to ...
P: So I said no. You don’t start something and then put me back on the ward and then tell me you’re gonna start again in the morning. And they said oh well you don’t want to labour through the night. And I said, look I’m not being funny, I haven’t slept for 10 days now, this is getting stupid. I just want this done now. I had drips and everything going on and ... but for some reason I couldn’t say that to the midwife. I could say it to my other half. She said I’ll put you back on the ward and I said oh okay that’s fine. She walked out and I blew a gasket, and [partner’s name]’s like just tell them that. I lost all my autonomy the minute I walked in and as luck would have it the minute I started to kick off the rest of my waters went and they had no choice but to keep me there and carry on with the process. So after about 4 or 5 hours eventually they put up the drip on top of all the other drips and um filled me full of the oxytosin stuff that they do, and carried on with the induction, which just took off. Um, because no-one explained to me what the difference is between like an induced labour and a normal labour, I think for a start all my expectations went out the window the minute I got there because I had wanted a water birth. I wanted water, I wanted baths, I hadn’t been able to have a shower for 3 days, I hadn’t been able to do anything. I couldn’t have a water birth, I couldn’t have this, couldn’t have that, couldn’t be examined half the time either because she was premature. So we didn’t even know how far, I mean it was like the blind leading the blind for a little while. Also, being completely unaware that if you put on your birth plan I do not wish to have an epidural, they don’t offer it to you.

I: Even if you change, on the way your circumstances change.

P: If you ask for it fine.

I: Right.

P: What I subsequently have now found out, which actually made me feel a lot better, was another lady who was induced and the first thing they said before they put the drip in was we advise you have an epidural. And I said well they didn’t advise me of that. And she said well did you have it in your birth plan. I said it was the only sentence on it because I’d just started to write it. I just put on it, you know, as a last resort unless necessary because I was terrified of needles and stuff and just didn’t like the idea of that. But, so no-one had sort of explained how it was going to be and maybe if someone had said at the time, you know, you need to rethink this now it might have been easier. But no-one said that at the time. So it just took off from there and she was born in 5½/6 hours from start to finish, really quickly.

I: Quite quickly then, the actual

P: Yeh, I think it just flew, she unfortunately, well I sort of struggled through because at the beginning it was all rather amusing. You know, like we’re in the delivery room ringing people from the phone and this kind of stuff. Until I heard one of the ladies next door, at which point I lose about 10 minutes, I don’t remember a hell of a lot, I just remember seeing my other half at the end of my bed rubbing my foot and I’m thinking what are you doing, oh you’re back are you. And that’s when terror sets in
and so it started, we just didn’t have a choice because I couldn’t get off the bed because I was monitored all the time. I couldn’t do any of the things that I was told would help.

I: Walking around and
P: Couldn’t walk around. Every hour I was allowed to go to the loo, that was it. I was unplugged to go to the toilet and that was it. So all the things that I knew would make it better I couldn’t do. We didn’t have a TENS Machine, we didn’t have this, everything I sort of thought was going out the window and then in the back of my mind I was thinking, I’ve seen the odd thing on Discovery, I’ll be fine. Plumped for some pethadine after a while, which cos the midwife said have a sleep, have some pethadine. That didn’t work and then turn on the gas and air, at which point I found it far too much. So I started to panic and the more I started to panic the worse it got, and at that point they were saying things like, oh she’s under stress. They took the gas and air off me cos I was thinking oh it’s lovely, I’m floating, this is great. I remember hearing my other half say look you’ve got to hand it over. You’re going purple. And I’d just completely overdone it. And whether it was a response or whatever, but [baby’s name] stopped breathing for a little while as well. So all I could hear in the back of my mind, I could hear people saying things like distress and all this kind of stuff but no-one was really telling me what was going on. I wasn’t really compus mentus to understand it. And then the more that kicked in the more scared I got and the worse everything got and you know my idea of this nice pleasant, well not pleasant, but nice idea of natural childbirth suddenly you know, and I vowed I would not be that woman next door. And the thing I remember the most through it was that each stage thinking, apparently I apologised through the whole thing, I did nothing but say sorry, I swore twice but I did nothing but say sorry to everybody. I mean apparently I even shouted through the wall I’m really sorry, ignore me, I’m a wuss. You know, anything to try and make these poor women feel better, but I just felt like every stage I was failing, it was horrible. It was really really horrible and honestly because she was early they were all saying you know paediatricians are on standby, I could hear them calling them. I could see out of the corner of my eye every so often I could see them bringing equipment through, so I didn’t know what was going on at all as to whether she was okay or not, or what, and she was, and then eventually that was when the midwife actually said look because she had turned back to back as well, she was pressing on the nerves in my legs and they couldn’t, because I couldn’t stand I couldn’t go anywhere, there was no way they could put me in any position that didn’t sit on this nerve.

I: Right.

P: And the pain was just getting ridiculous. The contractions fine, but the pain from this nerve was just horrific and so the midwife said look, you know, would you consider an epidural, at which point I was like yes, fine, give it to me.

I: Yeh, yeh.
P: And the anaesthetist turned up and we got, we got into an argument there. It was just in hindsight it was a mess because she came in and she said you need to sit up. I couldn’t physically get my brain to talk to the rest of me because I couldn’t get this muscle to move and I was saying in this groggy haze and telling my best friend and my other half you’ve just got to lift me, I can’t do it, you’ve got to lift me. And the woman turns round and says well if she’s not going to co-operate I’m not doing it. And I just remember trying to get the words out look I’m co-operating, I just physically cannot do this, you know. I wanted to do it but someone was just going to have to drag me. In the end I said that to my other half and he got it sorted. But the thing was, as soon as they started the epidural that was it, they couldn’t actually administer anything and she was born 45 minutes later.

I: Oh right.

P: The minute the woman put the epidural in, that was it, I was ready to have her.

I: Right.

P: So, sort of 45 minutes later she was there so that actually you know it didn’t help.

I: It didn’t help.

P: I lost out, it was too late, yeh. Which in the long run isn’t ideal because it put me off ever having one again, cos for a long time I was thinking well if that’s the benefit you get from it then what’s the point, you know, so I’d managed to have this whole day of everything that I’d not wanted and having the one thing that I’ve always said I’d never have which was an epidural. She was born, I don’t remember seeing her, I just remember being so bloody glad it was all over, um, she got taken off by the paediatricians who brought her back about half an hour later, so I’m told but I’d lost track. She was all bundled up and given to me, at which point I was like well what do you want me to do with her. You know, you’re going to put her in the special care unit, so you might as well do that. So none of that either, none of that sort of oh wow you know I’ve got a baby thing.

I: It was completely, you didn’t really feel

P: I felt nothing. I felt absolutely nothing. I mean the last 15 minutes and it’s, it’s one of the things that’s caused the most problems is I was just so desperate for it to be over. All I wanted was for them to just get her out. You know, all I wanted, just you know because they were saying that she wasn’t right and I was getting scared and so I spent the last 15-20 minutes you know yelling at the top of my lungs get her out sort of thing. And I felt so bad that when she came I didn’t, my other half he put her on me, you know what do you think and I’m like

I: Great

P: What do you want me to say. You know, lovely, now just put her where she’s gotta go. So they took her and put her in special care. My other half went with her, and I ended up just sitting there wondering quite what had happened really. I think the best part was I was then sick and I felt …. I was sick and I just thought oh that’s what I need, that’s what I want, all I want is to be sick. You know, so it was just, and
it was just the weirdest thing. I mean it just, and then everyone says well your bath’s ready. I have my bath. Walk back to the ward, which shows epidurals don’t work. Walk myself back and sat myself down on the bed and that was it, and you’re just sitting there thinking this is surreal, this is, and you know, all the other mums are there with their babies in their cots and she’s not. No-one will talk to me, the other women don’t.

I: No.

P: I mean it’s, 7, I think when I walked back to the bed it’s 7 in the morning so everyone’s just waking up. And nobody will talk because they obviously didn’t know

I: What had happened

P: Why is yours not there, we won’t say anything just in case. And you know, my other half went home, everyone went home and I’m just sort of sitting there. I ended up pacing the wards, I left that afternoon, I didn’t stay.

I: Did they let you go and see her?

P: They took a photo of her, my other half came back with a photo. But there was a lack of communication between the special care unit and the ward. I mean when I, I said I wanted to leave and they said fine, go when you like. And it was only sort of about lunchtime, I went down to see her, and then at lunchtime, because they were lovely in the special care, and I went back to the ward and someone says to me oh yes, how are you. I said fine. How’s the baby getting on, is she feeding well? I’m like no, you know. And then eventually it dawned upon people that she was in special care, at which point it was very different. They were saying I did wonder why you were walking around. Cos I did nothing but just walk around, I couldn’t stop, I couldn’t sit down. I mean whether it was the adrenalin or what it was, but I just, and it was like that for the next 24 hours.

I: You just ....

P: We ended up going and seeing people on the way home, I was still in my pyjamas and we were sitting having cups of tea with people and chatting away, and it was like a completely different – I didn’t know what it was. So in the end they said well you can go to special care when you like, so I sort of popped back there a couple of times and she was in the incubator, you couldn’t actually pick her up or do anything. And then that evening I sort of went home.

I: Without her?

P: Yes. I went home without her. With the special care unit handing me the humungus generator and said you know make sure you start expressing every 2 hours.

I: Right.

P: So I’m sitting in the flat, no curtains at the window, a blanket wrapped round me, attached to this milking pump. No baby and no sleep for days and just wondering what the hell I’d done. It made no sense to me. I didn’t, I mean there were flowers and cards but it didn’t compute at all. I knew something was missing but on the other hand had anything actually happened or was it, it was a very very strange set-up. It
was like that, I mean she was in there for 2½ weeks. It was like that for the next week, where I’d get up in the morning, drive there, pump through the night and after about 5 or 6 days I couldn’t do it any more. I couldn’t keep driving and being up all night. So I actually stopped. And gave her formula which she loves. But it was, every day was is she coming home today and they’re saying well it should be. If she has this 1oz. If she doesn’t have it then you think here we go, another day. And on the other hand, you’re going out. I’m going home and I’m packing up a flat to move in and we went and had a curry one night and it’s like I’ve got a newborn. But I haven’t, you know, and within 2 days of her being born we had my stepson, whose mum isn’t very helpful, and we had him so we had nowhere to take him as we had no flat so I was at [.....] bowling after a couple of days. And I’m standing there thinking this is very very strange. One, it’s amazing I’m up and about and everything’s working, but two, what’s this all about. And it was like that for the first couple of weeks. It was really, and I started to get, I got flashbacks. I’d start driving the car, but stupid things like you can park in the traffic lights on my way home, sitting in the traffic on the A[road] which is notorious for traffic. It can take anything up to 2 hours to get home some nights. Sitting there and thinking I’ve got to be home in time to pump for this, and do the next pump in that one. I had bottles and bottles of this milk everywhere. I could have supplied everybody in the special care unit but I couldn’t breast feed because she couldn’t, she was too young to know how to do it. So again, another falling down, and it was just like a knock on card effect that everything just going.

I: All the expectations you had from beforehand, not lived up to.

P: And I always said I had no expectations. I always said all along I’ve got no expectations, I just want a healthy, happy. I always knew she’d come early. I don’t know why but I always knew she’d be early. I just never knew how early. And she was 6lb 1oz, 5 weeks early, 5½ weeks early.

I: Not bad going for an early baby. If she’d have stayed on any longer she would have been ..

P: Yeh, I mean she was 10lb on her due date, I looked to see. But I always knew she felt big and I always thought she might come along early, and I was early as well.

I: Right.

P: So I just thought it was a possibility. But you know I just didn’t, you know I thought well maybe things won’t work out and I was prepared that you know I might need to have a caesarian. I wasn’t prepared for the way everything was ... I think I found it very very difficult. No-one really appreciated what it was like. People who didn’t really realise what it was like to drive up to special care every day, see her. I would sit there. She was on a 3 hourly feed. She’d just have a little bit of milk through a tube, then special care would desperately try and get her to breast feed but she wouldn’t. And then I’d have to pump, and then, so I’d just sit there all day because I wouldn’t be allowed to take her out, wouldn’t be able to play with her, do
anything. And then I’d get in the car and drive home. But I’ve never been so mentally exhausted. And you get back and nobody would have a clue as to what that was like. I’m on the half with the visitor right now. And the 2½ weeks she was up there, only once we took our stepson up to see her. It was the only time he went up there.

I: He couldn’t, work out what the fuss was about you think.

P: What he says now, he now thinks very different but at the time communication was appalling.

I: Between you and him?

P: Yeh. It involved communicating but not knowing what to say. He’s not the most sensitive guy. He is but he doesn’t, things always come out wrong with him. His first comment after she was born was fancy a shag. The midwife nearly hit him.

I: That wasn’t bright ....

P: It made me giggle because that’s what, that’s the kind of thing he’d say. My hopes and dreams were what a beautiful daughter, well done, haven’t you done well, but that’s what I got and had maybe it not been such an appalling run up and appalling sort of situation then maybe that would have been not too bad but the longer things like that stuck in my head, silly little details turn into really big deals. You know, he ended up in conversations, he didn’t go up to the hospital because he said when she comes home then I’ll be there. I see no point in going up and sitting there and looking at her in a cot. And knowing him I can see why he said it. But you know, all these dads are there and they’re saying to their girlfriends or their wives, have you expressed, have you done that, how many ounces of milk has she had. He wouldn’t have even had a clue.

I: Very much ....

P: And I felt really really, I felt so lonely up there it was horrendous. And I was surprised at how many dads took the time .... It’s this big deal, you know, whereas [partner’s name]’s just wandering around. Admittedly we were moving and you know he went home and made sure there was food on the table for when I got back. And somebody had to keep everything else running. But emotionally he didn’t have a clue. And I mean all the way through it’s been like that. Antenatal blokes, with their little notebooks. And they asked him, when they found out he had a child already it was like he became a God. You know, what was it like, was it amazing, and [partner’s name] sits there and says well actually it was just a sheer relief she was fine. No it wasn’t amazing. Amazing now, not on the day, and he upset a lot of people by being very honest. And me, cos I was sitting there thinking oh, this is the way you’re going to be with our daughter, great. This isn’t what I’d fantasised about since I was a kid. You know all this gushing is what I want, I don’t want you sitting there saying it’s relief and no I don’t feel anything until she grabs my finger or she does something. Although I’m glad he did say it because afterwards I started to think maybe something was wrong with me because I didn’t feel anything.
I: Right.
P: And I kept thinking I remember when he was with [stepson’s name] .... You know, he took a little while before he got to know him then you know that actually did help. But during pregnancy it was a bone of contention.
I: What that he wasn’t’ that interested?
P: You know, yeh all these other dads are running round, I mean when she was born we didn’t even have, we had nothing. He kept saying oh we’ll get it next week. Wait until we move and then we’ll decide whether we’re going to get a pram. I need a pram now. Well we’ve got nowhere to put it, wait until we’ve moved. And it was like that all the way down. It’s like I didn’t. And I worked, I mean she was actually born the day I was supposed to start maternity leave.
I: And you worked right up to the end as well.
P: Yeh.
I: You didn’t even have a bit of time at home to get excited about it.
P: I was just starting to get to that when the stupid lump came. And I was just thinking you know I’ll get to that point when I go and buy little bits and you know start complaining that I can’t move. I just sort of got to that point.
I: You passed the stage before
P: Yeh
I: Time off before the baby comes
P: And during the time afterwards there was no rest because I couldn’t sit at home, I was backwards and forwards. So whereas my friend had a baby sitting at home with a baby and getting to know it and lived in pyjamas all day. I was up and dressed by half six, getting in a car to get up to the hospital for the 7 o’clock feed you know. And it just
I: You were doing all that, the tough side of being a new mum but none of the fun bit.
P: None of the cuddles. There’s one sister up there who disagrees with babies being taken out and cuddled. And when she was on I mean everyone, she was ..... she’s onto that, she’s very good, she knows what she’s doing. No-ones allowed to have cuddles. And these dads looked really despondent you know. And the days that she’s not, you get more of a cuddle, you get up there and you think oh she’s on, shit.
I: No cuddles or not much of a cuddle.
P: But I wasn’t too, I felt very detached.
I: Funny.
P: Yeh, very, very detached. Just, um, I didn’t resent her, it wasn’t a case of resenting her but I was left with such a bad feeling about it all that I was still trying to work my way through that. Every 20 minutes or 15 minutes I’d sit down and something would come back into my head, something I’d said, something I did. That either I’d forgotten about or I wasn’t pleased about or, it was made worse by, it was mickey taking at home. Like some of the things that were said, that wasn’t very amusing.
I: It was harder for you in that in the sort of weeks after it all happened, the couple of
weeks after, to sort of go back to your jovial self if you like,
P: On the outside you know I was dressed, happy, in the sense I could have a giggle
with people, you know I looked after my stepson, ran around and looked after the
house, packed the house, moved house, rang the solicitors from the hospital. You
know, did all that kind of stuff. Inside, all I was completely obsessed about was just
how crap the whole thing had been. You know, I’d sit somewhere and all of a sudden
I’d start hearing myself shouting about getting her out and stuff. And I would be so,
feel so messed up over it and the problem is I’d then talk to my other half about it
who, being the treat he is sometimes, would come out with things like well just
because you didn’t cope, it’s not a big deal, you know she’s still here and well. And
that would then do it for another couple of weeks. That would just about put the nail
in the coffin. And then when you try and explain it, he just doesn’t see it. There was
some kind of, I mean his son was born in 20 minutes. His ex had 5 children so they
pretty much slid out, they knew what they were doing you know. And there was some
kind of, I did feel some kind of, not competition, I’m not sure what the right word is, I
felt that cos she had been able to do all that, you know, I wanted it to be a nice, I mean
lots of things, I mean in talking to her now she said he doesn’t tell you but not one of
them did I have naturally except for him. The only one that was natural was his
because he was too damn quick to have anything, otherwise I’d never have done what
you did. But again, it’s all the stuff that takes months to find out.
I: What was [partner’s name] told when all this was going on. Was he in the room
with you for most of the time. So it wasn’t as though he was kept away.
P: No, he, I mean throughout the whole thing I had got the impression through most
of it that he thought I was actually, what’s, not a hypochondriac but I think he thought
I was making most of it up. I think he thought I was making a big deal of all of these
things. Because of the week before, in and out of doctors, up to the hospital at 4 in the
morning because I was in so much pain, you know, I always felt like it was a case of
him thinking oh she’s moaning.
I: Right.
P: So I mean when we were in hospital he never asked the doctors what was
happening. He just put his trust in them basically.
I: Why?
P: I don’t’ think he actually wanted to know. My friend says yes he was quite
concerned, he was quite worried at the time, but I have very little memory of him
being in there. I just
I: Has your, do you think the experience has changed how you feel about yourself?
P: Um.
I: In what kind of way?
P: It’s still changing. If you’d asked me that a couple of months ago I would have
said I was, I felt I’d let myself down. I really thought, I thought I was stronger than
that, better than that. I thought I was more capable than that, I thought I was more of a natural mother than that. I went several rounds with myself for quite some time. Now it’s changing in the sense that I’ve, I think I’ve learnt, I’m learning a bit about how things bother me, that maybe they shouldn’t. She is here and she is well and we now get on. So to a certain extent it should still be, it’s becoming more irrelevant, but it isn’t in other ways. You know, some days I think oh well you know at least she’s here but on the whole, no, it’s still there. You know, it’s still there and it’s a sense of failure, and I think there’s nothing worse than looking at your daughter and everybody saying oh isn’t she lovely, isn’t she wonderful, and you’re thinking well I bollocksed that one up didn’t I, you know, and that’s exactly how I felt.

I: Right.
P: I just felt that, I felt stupid.
I: Why?
P: I felt stupid I’d made noises, I felt stupid I’d shouted, I felt stupid that I couldn’t cope, I felt all these kind of things you know. I wanted four children. Ha ha. Up until you turned up. It was just, I really felt like. I think it’s the one thing that I kind of wanted to go smoothly. Cos if there’s ever a problem, chances are I get it twice as bad as anybody else. So it was almost, everyone was like well of course yours wouldn’t have been easy would it?
I: Right.
P: You think, oh d’you know, I’d like to have been the one that you know. The other girl at work, you know, her first child, six hours labour, no pain relief, absolutely happy, beautiful 8lb baby, went home, sleeps all night, wonderful, you know. Me, no I have to have all this. And there was part of me just thought why is it always me. Um, and also I felt really bad about the distance it put between us. Between me and [baby’s name].
I: So you do feel as though it really affected your
P: Oh it did, there’s no doubt about it, it did. I don’t know the links why because I wasn’t conscious of resenting her, but it did put distance between us. Absolutely.
I: How do you think things are, or things have been since then. Obviously initially it was tough, but have things been changing over the last few weeks?
P: Yes, I think they are evolving a little bit. Obviously nature does seem to have this thing that you do lose, you do forget stuff, and I think even, the only thing that’s stayed true is from the day she was born until now it was never, the pain of it that I could ever remember. It was always the panic and the fear. It was always the panic and fear. Anything else, cos I’m quite good with the rest of it, but it was, I’ve never felt so completely and utterly panicked. I mean I’ve usually been able to talk myself through most things. Hated them, horrible, scared whatever, but I’ve usually been able to have the inner voice whereas that’s the only time I can honestly remember when I’ve been absolutely totally and utterly out of control, not knowing what’s
happened, needing so much but not knowing how to ask for it. And, um, you know I think that still stayed.

**I:** Do you think there was a particularly thing about the birth that made it, that made it like that, or was it just the whole, the whole thing?

**P:** I have to say it would probably have been made easier and there's a lot I think my other half could have done to have made it easier. And I think that's where the resentment came. Because the first couple of months, the first few weeks we were just so happy that we had her in that sense. You know, I mean he went back to normal living within a week. You know, within a week he sort of expected to go back to everything as normal. So the resentment creeps in. More and more I was looking at him and thinking you know you could have done something to make that better. And interestingly when we've been at the NCT stuff, all along I'd sort of said, he kept saying I don't need to be here cos all you've got to do is ask for what you want. I kept saying but if I'm ever in a situation when I can't ask, I want you to know what to do. And that was, I think that was the bit that got me the most because that's what I needed him to do that day. Because I couldn't ask and I wouldn't ask. And I think there is two times through the whole thing, one when the woman screamed next door and another time shortly before she was born where he actually, he got me to look at him and actually the first and only time I remember looking at him through the rest of it, and those were the only two things that helped.

**I:** Right. So him being there

**P:** And doing, and yeh, and I think I resented the fact that if he'd done that all the way through and talked to me and told me what was going on, because I trusted him more than anyone else in that room. My best friend was very good, she was fab, she picked up the bits that he was, I mean that's why she was there. Poor midwife, I mean after he left with [baby's name] she said I know why you had her in here and I was like yeh okay. She's a bit of a gore monster and she really just wanted to see the mess really.

**I:** Oh ugh.

**P:** I know, she was the first person to see you, cos your dad wouldn't. But you know I think that's the bit, that's what causes, still does. Still comes in from time to time. I mean he does, he just cannot get why I feel so bad about it. So we're out for drinks and somebody says something about why I need to get out of here and he says yeh get her out, get her out. And I just, I physically shrink and I just want to run and I get so upset when he does it, and I've told him it. And he just says oh don't be so silly. It's nothing to be, and he just doesn't, doesn't get it at all.

**I:** Do you think this is something that's changed since you've had [baby's name], do you think when he made, I mean I don't know whether you've had quite the same experience in the past but has it just been do you think around this particular experience that it's

**P:** Yeh, yeh. I mean he's always been like this. You know that's part of, unfortunately part of the part I liked was that he wasn't all gushy and silly and that I,
you know he’s always very genuine and got a bit of a laugh with him. He doesn’t take things too seriously. But, yeh, this particular, it’s just his usual way of working just doesn’t work. I mean, I, it was, I kept saying you know I’m getting flashbacks, I keep seeing stuff and did this happen and did that happen. He’d just say why are you thinking about it, it’s done. Because I can’t stop it, it just keeps turning up. You know, and that’s difficult cos he just doesn’t get it. He doesn’t, and he won’t talk about it at all. He won’t tell me anything, he won’t talk about that day at all. He’s not a great talker anyway but he just, I’ve never heard any of his opinions of the day, he’s never wanted, he’s never once said any of it.

I: Like wasn’t it scary, or anything like that.

P: Never, and even now over three months later I still crave for him to say it. But he’s never said it, and when I rang a friend of mine and her husband answered, he said oh, you know she had it, and oh she was so good, I was so proud of her, I couldn’t have done that. And that is all I ever wanted to hear from him. And I said that to him. And that’s when he came out with the cracking comment about well just cos you didn’t cope it doesn’t matter, you didn’t do too badly. You know, it’s just like

I: It’s not what I need.

P: It’s not what I need but unfortunately it’s starting, it creeps into everything now, now I’m like well you don’t say things like that. And it’s never bothered me before. I mean he comes out with, you know, he sits there and says oh look we’ve got her and it’s good isn’t it. You know, I know it’s not about, about the fact she’s not here, he just doesn’t sort of see that that could actually make things a lot better. I’ve almost sat there and written a script, said look please just read this out loud to me. It’s just the way it is.

I: How does he, what is his relationship like with [baby’s name]?

P: It’s good.

I: He’s not like the experience has really affected them at all?

P: Not at all. No, I mean when his son was born, he was born in a very different situation, it wasn’t as close as we are and not very stable, and I remember when he was born, I remember [partner’s name] feeling very confused, very aloof from it, not really into [stepson’s name] at all until he was quite a lot older. And I was always worried that that would be the case with her, but it’s not and he’s you know very good with her. They do get on fine. Even people say you know I can’t believe it, she was putting up fence panels the week before she had [baby’s name] and then a week later she was on the phone to solicitors, I can’t believe how she did it all. He doesn’t get it. He still doesn’t get it. I mean even when she came home he’d say could you do me a favour, could you just take that wallpaper off today whilst I’m at work so I can get that done this evening, and she was 3 weeks old. And in between feeds and being up all night, you know he’s telling me to go to B & Q at 8 o’clock. He just doesn’t get it, cos he can see you walking about and doing stuff. It just
doesn't, the answer is as you say no I don't want to do it, but I was so keen to make amends and show that I could cope

I: After having [baby's name]?

P: That I went way over the top. I mean, the only time I drew a line was when I was too tired to drive us, I was worried about driving, but other than that no I was at B & Q at 8 o'clock in the morning, I was carrying paint tables, her under one arm, because I just wanted to prove that I could do it and also because I didn’t feel that attached to [baby’s name], it was actually very easy just to lob her in somewhere and off we go. I’ve got to take all the stuff with me and got to do all that and in the end I did crumble, sort of late one night after one feed too many at about 3 o’clock in the morning I just sat down and just hollered. It was at that point I just said to [partner’s name] no I just don’t feel. I won’t do anything to harm her or hurt her but I just. This isn’t what I expected, you know, I didn’t have a year of broodiness, just sit here and look at this and think okay, you know. And every time I look at her I was thinking back to when she turned up and that was a big problem. That was a big problem, I mean even stupid things like I’d move in a certain way and it’d be like oh God I wish I hadn’t done that.

I: It brings you straight back to the birth?

P: It wasn’t very handy when daddy wanted to get friendly. It was like no, I don’t want to know. It is improving but I do wonder what would happen if I ever went for another one. And that’s where I’m getting to now, and now it’s a case of you know [partner’s name] saying you know we always said we wouldn’t have one. It can’t be as bad as the last one, but then you think oh dear, what if it is, you know, and what if your expectations are that much higher now because you’re thinking oh I’ve had that so I really want a normal happy, you know my water and all this kind of thing, and not give me drugs and do that. But on the other hand it’s helped in the sense that I kind of lost, lost that sort of, I should have just gone and got what I needed and, you know there isn’t a great competition to it all and you don’t have to do it and it would have been a lot easier and better if someone had said look induction is a funny way of having a baby, it’s not clever, it’s a lot faster, it’s a lot more nasty, especially seeing as they had a time limit they had to have her out by because she was premature. The midwife did keep coming in saying look I’m sorry, she just kept coming in turning this drip up. Now if I’d known what I know now, then it would have been very different and I think that’s, that’s the bit at the moment when I’m thinking you know, that’s the difference.

I: It might help you with the future.

P: In the future, if you always know what’s happening you shouldn’t be in that situation. Yeh, it wasn’t what I expected.

I: So you haven’t initially and also sort of in the first few weeks after she was born, did you feel attached to her? Do you think you behaved differently with her than perhaps you might have done had she come in this perfect way?
P: No, I didn’t apparently, I thought I was. I thought the night I sort of burst into tears and said oh no I’ve got to do this properly. I don’t know who she is or any of this stuff, [partner’s name] actually said but you don’t realise that she’s screaming and she’s crying and not once have you gone in there and shouted at her. You’ve come downstairs and screamed and shouted but you’ve gone in there and the minute you step over that door, it’s hello pickle, how you doing? Do you not see that? I didn’t see it. I never knew, and that was the best thing he ever said. I actually felt that observation I think saved our arses. Because I really didn’t see that. I just saw me as I saw her. I mean I would go downstairs and I would be cross. I didn’t think I was looking after her properly. I mean I knew she was having the right feeds and she was being changed but I didn’t think she was getting any kind of niceness from me or any kind of love from me. But in talking to everybody else, everyone was like you are. But I didn’t feel it or see it myself. So although I did it, I didn’t feel it. It was very strange, it was like someone else.

I: Right. A bit like on auto pilot.

P: Yeh, yeh, although according to mum, the …. are very genuine auto pilot because they didn’t see it and they really thought that I did feel that way.

I: Do you think it’s there now? Do you think you’ve managed to

P: Yeh, yeh

I: You’re okay now?

P: We’re getting there. I think the last month probably. The last three or four weeks we’ve started to click in. What they’ve said it’s nothing to do with the way she’s sleeping or she’s eating, it was something else.

I: Do you think it was the experience of the birth.

P: That’s slowing down. And it’s direct. That’s starting to disappear, everything else. And people say oh it’s because she does more, but no I don’t think it is. I think it’s a lot to do with the more I can let go of what happened and move on, the more she and I are doing. I go out with the pram and push it and it was like it belonged to somebody else. And it’s weird enough having someone else there anyway. It’s weird enough to suddenly think oh God you know you’re a mother. All those kind of things come in as well so you’re playing with that at the same time as you know starting from a minus. Which is what it felt like for me. That’s what it felt like for me. But interestingly no-one else, no-one else felt it, no-one else saw it. The only person it affected seemed to be me. (And you don’t care really do you?)

I: Do you think the experience affected how you felt about [stepson’s name]?

P: I don’t know whether the childbirth has but my feelings towards [stepson’s name] have changed significantly.

I: Right.

P: It’s something I’m having to especially keep in check. There was always, I mean I’ve known [stepson’s name] since he was born and so he’s always been a part of our lives, before we even got together when we were just friends. And we got on very
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... but sort of the year before [baby’s name] came along he was very daddified and he and I went through seven rounds of hell as to who was gonna have his attention and I used to go to work and work shifts at the weekend just to get away from having to be in the situation. When I was pregnant [stepson’s name] used to push me up the walls. He was only little but he used to go down crying and push me sideways. [partner’s name] would say on no no he’s only 4 he doesn’t know what he’s doing. I’d say I think he does know. No he doesn’t. And it was just very awkward. I mean his mum and I worked together on it and it actually improved and you know, you’ll have a little sister and all that kind of thing and he got quite excited about it. But yeh, I mean my tolerance for him disappears in the sense that it’s not my child and his child, it is but it isn’t. I find that when he’s over I can just lose myself somehow quite happily. And now I don’t care whether he doesn’t want to talk to me and he doesn’t want my breakfast, whereas I used to get really hurt and upset that he wouldn’t take breakfast from me, he’d rather starve sometimes. You know, there are times when he, he’s a stubborn little so and so, he’s a sweetheart as well but he just, he’s at a funny age and you know he’s starting to realise that there’s two boot camps now, not one. Luckily we get on well with his mum so she and I work together on that. It’s just I have to say when he does come round, he’s very fond of her, he’ll put the heavy snow globe on her head cos she like’s it. All that kind of in the middle of the night there’s a scream and I went in there and there’s 7 blankets on her, she was cold. Mental note, have a bigger baby gate. But I do find now, yeh, I do. I’m having to make a conscious effort with him whereas before it was never like that, and at times he even felt like my own. When he was younger especially. When he was younger. When he got a little bit older I felt less and less like that. When he comes round at weekends, I struggle. I now take the two of them out so that I’ve got time with him otherwise I could easily not do it. I used to be quite keen on having us all going together but now it’s like oh, it’s his son, if he wants to swear and stick his fingers up, and that, that’s the newest thing I have to say. That’s definitely changed since she was born. But he’s very fond of us.

I: Do you think the experience has changed any other sort of important relationships? Do you think anything else has changed? I mean, you mentioned your mum’s had sort of quite a lot to say about how you are with [baby’s name]. Do you think the difficult birth has affected that relationship at all?

P: My mum seems to think it’s changed her view on me. I mean I don’t think it’s changed, I mean a lot has changed with [baby’s name] being born but it’s not to do with that. Most of my family were quite unhappy that I was pregnant, except for my mum, but the rest of the family wasn’t. The minute she was born they all suddenly become grandparents and aunts and great grandparents, people who hadn’t spoken to me in a year now can’t get enough. It’s nothing to do with the birth, it’s just because she’s here, but with my mum, she, she seems to think that. She used to say, she said to me that I coped with a lot, I dealt with a lot, and that she was very surprised that I
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dealt with what I dealt with. She wasn’t saying that I, you know usually I handle most things, and I’ve been in some shitty situations where she’d say you know even down to the number, I mean I have bruises from all the canulars and all those things and I’m terrified of needles, and I was just stick them in and do what you’ve got to do. And she said she couldn’t, she would never have guessed or never have imagined the things that I would have done, cos I was saying I didn’t do this and I didn’t do that, but she said do you realise what you did do though? She said it surprised me. If someone said to me, because she wasn’t completely aware of how unwell I was because I didn’t want her to panic. Cos she’s a bit of a panicker. In hindsight maybe, maybe she sort of sees she’s more worried now because she didn’t know what was going on, but no, she was very surprised and she says she does see my strengths in a different light which is quite nice.

I: It’s been quite a positive thing really.

P: Yeh, yeh it is quite nice. I don’t see it that way. I don’t see it that way but obviously she does.

I: You can rely on your mum to see the positive.

P: Oh yes, yes.

I: Do you think there was anything that helped, I mean it sounds as though you are kind of getting back on track now, do you think, what’s been important in getting .... work through.

P: Other people. If I had sat, because we moved up here and I didn’t know anybody, I knew nobody in the area whereas in [Other town name] I had quite a support network. If I hadn’t met one lady sitting in a church hall that I happened to chance upon, cos I went to go and have coffee with elderly people cos I couldn’t think of anything else to do.

I: Oh.

P: They were lovely, I love the elderly. They don’t talk about nappies and stuff, they talk about great stuff. And this lady turned up also looking for the toddler group that didn’t exist and if I hadn’t talked to her about her induction, things that happened, problems she’d had with hospital, other things like that, I think it, that’s when everything started to start changing. And also, I mean talking to friends and stuff had helped but I’m the only one of my friends who has children so at the moment I’m a bit of a novelty, I’m their fact finding mission. And I keep saying you don’t want to be asking me. Do not ask me. Don’t ask me that question. You want children, don’t ask. I think that’s what, that was the bit that helped the most. I don’t think the Health Visitor really appreciated how bad I felt, I think a lot of people said well you know childbirth is never going to be pretty, you know. And it was sort of really brushed away as if you’re just self indulgent. That was the attitude I got from a couple of places. But sitting down and talking to her and realising the different situations that could be, the things that could have happened, then that started to help.

I: Do you see her, you said it was a chance meeting.
P: No, that was sort of where our similarities ended.
I: Oh right.
P: Which was a shame but no, I'd much rather go and do something. The Health Visitor keeps shoving me down there and I keep going down there but there's only so many times you can rehash it.
I: At the end, I can tell you it now, I don't know if you're connected to the Internet at all but through doing this research I've discovered this website called Mumsnet.com. They've put an advert on to get people to be involved, but actually it's really good. If you don't actually want to go and spend hours chatting with other mums it's really good just to be able to log on and see what other people's concerns are.
P: That's quite good. I have to say that's where I did look for help afterwards. I did start having a look around because I was a member of like the ivillage pregnancy thing and I'm still getting emails saying waiting for your pending birth? And you're like no I've had it, give me the next stage. Don't want a newsletter saying do you fancy this. I did look around and there's not, there's a lot of stuff on post natal depression but there's not very much on this kind of thing and it was only when I was at [friend's name]’s doing [friend’s name]’s little insect thing, which was rather hilarious, and she just sort of said you know, cos I hadn't even considered it as even a traumatic experience. And that was the irony. I went home and thought actually it's quite right, maybe I am within my rights. And that’s one of the things that I think’s the hardest. Because everyone says childbirth is painful, you know what you're letting yourself in for, you don’t want to do it, don’t do it and this kind of thing and you don’t, you kind of feel like you shouldn’t sit down and say actually it didn’t work the way it should do and actually it was pretty traumatic. And that's helping to think well fair enough this woman has a bad time, I'd expect them to feel pretty gross.
I: So it kind of puts it into perspective.
P: Yeh.
I: What do you think you’d like to see to stop this happening to other people?
P: The thing that I was told about or something the Health Visitor suggested, is apparently there’s a maternity listening service at the hospital. You can ring up and they can book an appointment and they can get your notes out and go through. Great idea, I’ve had the number for 4 weeks and for some reason I just can’t do it. Now if somebody had approached me within the first couple of days and given that kind of time had told me about it then, I think it would have been invaluable. Especially if you could go back to the midwife that you had. Because I wasn’t in this area I didn’t know any of the midwives or anybody and the one saving grace that day was the midwife. She was superb. And that’s one of the reasons I was determined to have it in her shift. She started when they gave me the first bit and I thought, you're gonna be here, I'm gonna try and get it done with you because I like you. The one that was here an hour ago I wasn’t so keen on, but she was fantastic and afterwards she was the only person who came out with any great positive comments. Those comments stuck and
they helped and I think without those comments I think it would have been a lot worse. So I think if someone had actually twigged that it may not have been the ideal situation, and I think it should be offered to everybody cos what I perceive as traumatic, someone might just find the normal way traumatic.

I: You’re right, it’s completely subjective.

P: I think having someone come up and offer to sit down and go through it with you in hindsight afterwards I think would be very good, because the Health Visitors don’t have time to do it. And this is another thing, special, special care. Because your baby’s in special care you don’t tend to see anybody. I didn’t see a midwife for any checks. Nobody checked me. The remit was if I wanted to be checked by a midwife all I had to do was turn up on the ward and ask for them to do it. If I’d gone home with [baby’s name], by law someone would have turned up and seen me. And then someone might have spoken to me. I avoided people. I didn’t see anybody. I think I had my first check after a week when I found what looked like a blood clot on my leg and I thought I’d better go and see somebody. I think especially in special care, you do get lost.

I: Very well planned.

P: I think that’s definitely where it needs to be. I think it should be offered to everybody. I mean I know it takes time but in the long run I think it would, I think it would save a lot. I think it really would. I think if I had someone else who would have been prepared to look after [baby’s name] at the time, I probably would have relinquished everything. But because I was the only one there, I had no choice. I managed to sort of do it. But I think you could, could find a lot of people losing out on a lot just for the sake of someone asking if they want to go through it, you know. Yeh, I think it would help.

I: Okay. I think we’ve come to the end of my questions actually. That’s brilliant. Thank you.
Log Book of Research Activity

September 2001 to July 2004

All three years
<table>
<thead>
<tr>
<th>Research Skill/ Experience</th>
<th>Description of how research skill/ experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
</table>
| Conduct a literature search              | 1. Conducted computerised literature search on the topics “supported employment in learning disability and mental health services”. Used Medline and Psyclit on the internet. Used key words “mental health” “learning disabilities” “supported employment” “supported work” “day centre” “day services”. Printed out 22 relevant abstracts. Learnt to combine key words to narrow search.  
2. Conducted literature search on the topics “activities and people with learning disabilities”. Used key words such as “occupation”, “quality of life”.  
3. Conducted a literature search on the topics, “anxiety reduction in medical procedures”. Used key words such as “anxiety”, “melanoma”, “surgery” and “stress management”  
4. Conducted a literature search on “transvestism and gender”. Used words such as “transvestite” and “gender”.  
5. Conducted a literature search on “PTSD and childbirth”. Used words such as “PTSD”, “childbirth”.                                                                                                                                                                                                                   | 26/10/01 (year 1)                                                                          |
| Critically review the literature         | 1. Reviewed literature for Service Related Research project  
2. Reviewed literature for Major Research Project  
3. Reviewed literature for Qualitative Research Project  
4. Reviewed literature for MRP-2                                                                                                                                                                                                                                                                                      | 09/02 (year 2) and 10/02 (year 2)                                                          |
| Formulate a specific research question   | 1. After discussions with placement supervisor decided to audit service users opinions of current supported workshop schemes they attend. Two services are due to merge. “A consumer audit of two sheltered workshops: gaining service users’ opinions”.  
2. Re-wrote research proposal “An audit of a group home for people with learning disabilities, using momentary time sampling techniques”.  
3. Discussed ideas with field and research supervisors. Devised title of research “Evaluating the effectiveness of different mediums in reducing anxiety for                                                                                                                                                     | 09/11/01 (year 1) and 04/02 (year 1) and 09/02 (year 2)                                    |
**patients attending for surgery for melanoma**

4. Revised research project, discussed with field and research supervisor “PTSD after childbirth, a qualitative account of the impact on relationships”

<table>
<thead>
<tr>
<th><strong>Write a brief research proposal</strong></th>
<th>1. Wrote brief research proposal regarding suitting service users views of current services. Discussed with research and placement supervisor.</th>
<th>12/01 (year 1)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Revised proposal after discussions with head of department</td>
<td>01/02 (year 1)</td>
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<tr>
<td></td>
<td>3. Wrote a brief proposal for major research project</td>
<td>10/02 (year 2)</td>
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</tbody>
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<table>
<thead>
<tr>
<th><strong>Write a detailed proposal/protocol</strong></th>
<th>1. Wrote a detailed proposal for attachment to ethics form</th>
<th>01/03 (year 2)</th>
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<tbody>
<tr>
<td></td>
<td>2. Wrote a second detailed proposal to attach to ethics form for MRP-2</td>
<td>08/03 (year 2)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Obtain appropriate supervision/collaboration for research</strong></th>
<th>1. Discussed ideas for research and obtained agreement from placement supervisor to supervise research.</th>
<th>10/01 (year 1)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>2. Discussed ideas with field supervisor and with supervisor at college, both agreed to supervise the project.</td>
<td>09/02 (year 2)</td>
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<td></td>
<td>3. Discussed progress of research with supervisors and decided insufficient support from medical staff so abandoned first research proposal.</td>
<td>05/03 (year 2)</td>
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<td></td>
<td>4. Discussed new ideas with supervisors and agreed to continue supervising</td>
<td>05/03 (year 2)</td>
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<table>
<thead>
<tr>
<th><strong>Write a participant information sheet and consent form</strong></th>
<th>1. Wrote participant information sheet and consent form for MRP.</th>
<th>02/03 (year 2)</th>
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<tbody>
<tr>
<td></td>
<td>2. Wrote participant information sheet for qualitative project.</td>
<td>03/03 (year 2)</td>
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<td></td>
<td>3. Wrote participant information sheet and consent form for MRP-2</td>
<td>06/03 (year 2)</td>
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<td></td>
<td>4. Wrote participant information sheet and consent form for MREC approval of MRP-2</td>
<td>12/03 (year 3)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Judge ethical issues in research and amend plans accordingly</strong></th>
<th>1. Wrote ethics application form and assessed plans for ethical issues for St George’s LREC</th>
<th>02/03 (year 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Wrote ethics application form for University ethics</td>
<td>08/03 (year 2)</td>
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<tr>
<td></td>
<td>3. Wrote ethics application for Multi-centre Research Ethics Committee</td>
<td>12/03 (year 3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Obtain approval from a research ethics committee</strong></th>
<th>1. Ethics application needed to be amended before approval could be given</th>
<th>04/03 (year 2)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>2. University ethics committee suggested MREC approval be sought</td>
<td>12/03 (year 3)</td>
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<tr>
<td></td>
<td>3. Attended MREC committee meeting, approval given, subject to amendments</td>
<td>01/04 (year 3)</td>
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<td></td>
<td>4. Amendments approved by MREC</td>
<td>02/04 (year 3)</td>
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<tr>
<td>Stage</td>
<td>Action</td>
<td>Details</td>
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<tr>
<td><strong>Negotiate ‘gate keepers’ to participants</strong></td>
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<tr>
<td>1.</td>
<td>Discussed research with co-ordinator of ‘birth crisis network’. Happy to be involved, had already been in touch with my supervisor – to contact again once ethical approval received.</td>
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<tr>
<td>11/03 (year 3)</td>
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<td>2.</td>
<td>Ethical approval obtained, discussed research again with co-ordinator, sent revised information sheet. Can no longer go ahead with research, considers it unethical to contact GPs.</td>
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<td>01/04 (year 3)</td>
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<td>3.</td>
<td>Discussed alternative recruitment options with supervisor, contact co-ordinator for birth.trauma.org and she is very positive.</td>
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<tr>
<td>01/04 (year 3)</td>
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<tr>
<td><strong>Collect data from research participants</strong></td>
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<tr>
<td>1.</td>
<td>Conducted observations of participants – over two week period. Including inter-rater reliability sessions.</td>
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<tr>
<td>04/02 (year 1)</td>
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<td>2.</td>
<td>Interviewed participant for qualitative research project</td>
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<tr>
<td>03/03 (year 2)</td>
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<tr>
<td>3.</td>
<td>Interviewed participants for MRP</td>
<td></td>
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<td>03-04-04 (year 3)</td>
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<tr>
<td><strong>Set up a data file</strong></td>
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<tr>
<td>1.</td>
<td>File set up for analysing data from SRRP</td>
<td></td>
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<tr>
<td>05/02 (year 1)</td>
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<tr>
<td><strong>Analyse quantitative data</strong></td>
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<tr>
<td>2.</td>
<td>Data analysed for SRRP</td>
<td></td>
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<tr>
<td>05/02 (year 1)</td>
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<tr>
<td><strong>Analyse qualitative data</strong></td>
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<tr>
<td>1.</td>
<td>Met with other members of research group to analyse data for qualitative research project</td>
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<tr>
<td>05/03 (year 2)</td>
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<tr>
<td>2.</td>
<td>Analysed transcripts for MRP &amp; discussed with supervisors</td>
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<tr>
<td>04-06/03 (year 3)</td>
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<tr>
<td>3.</td>
<td>Met with qualitative group to discuss themes for MRP</td>
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<td>05-06/03 (year 3)</td>
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<tr>
<td><strong>Summarise results in figures/ graphs</strong></td>
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<tr>
<td>1.</td>
<td>Summarised results from observations into graphs and tables - SRRP.</td>
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<tr>
<td>04/02 (year 1)</td>
<td></td>
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<tr>
<td>2.</td>
<td>Summarised demographic data into tables - MRP</td>
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<tr>
<td>05/02 (year 3)</td>
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<tr>
<td><strong>Interpret results from data analysis</strong></td>
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<tr>
<td>1.</td>
<td>Interpreted results from qualitative project</td>
<td></td>
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<tr>
<td>05/03 (year 2)</td>
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<tr>
<td>2.</td>
<td>Interpreted results from MRP</td>
<td></td>
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<td>05-06-03 (year 3)</td>
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<tr>
<td><strong>Present research findings / plans to an audience</strong></td>
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<tr>
<td>1.</td>
<td>Presented findings of SRRP to staff team in group home.</td>
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<tr>
<td>06/09/02 (year 1)</td>
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<tr>
<td>2.</td>
<td>Presented plans for MRP to year 2 trainees</td>
<td></td>
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<tr>
<td>10/03 (year 3)</td>
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<tr>
<td><strong>Produce a written report on a research project</strong></td>
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<tr>
<td>1.</td>
<td>Written report on Service Related Research Project</td>
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<tr>
<td>06/02 (year 1)</td>
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<tr>
<td>2.</td>
<td>Written report on Qualitative Research Project</td>
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<tr>
<td>05/03 (year 2)</td>
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<tr>
<td><strong>Defend research project at oral examination</strong></td>
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<td>Defended research report at viva exam</td>
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<td>09/04 (year 3)</td>
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</table>
Found in reference to older people essay (Year 2)  
Specialist placement, primary care (Year 3) |