The Personal Experience of Living with Chronic Pain following an Accident: An Interpretative Phenomenological Analysis

by

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Volume One of Portfolio

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Academic Section

This section contains four essays, one relating to each of the core client groups.
A case formulation within a cognitive-behavioural model is a desirable though not essential part of the therapeutic process and planning of the intervention. Critically discuss this statement.

January 2004

Year 1
Introduction

In reviewing the literature regarding cognitive case formulation (CF) and the usefulness of this approach to therapy, two things become clear. The first is that there is a distinct lack of studies looking at the reliability, validity or utility of cognitive CF. The second is, that despite this lack of evidence, many commentators consider CF as an essential or 'crucial' (Beck 1995) component of therapy and treatment planning.

The idea that developing a good formulation is central to therapy is one that is endorsed by the British Psychological Society’s Division of Clinical Psychology, who describe formulation as one of the core skills of the clinical psychologist. They provide a jargon free description of case formulation within clinical psychology, as the ‘summation’ and ‘integration’ of knowledge gained during assessment that “draws on psychological theory and data to provide a framework for describing a problem, how it developed and how it is maintained”. A formulation may then involve a number of hypotheses that become the basis of an intervention plan (if appropriate) as they are tested out and subsequently modified.

Historically, Crellin (2002) has described a desire for clinical psychology to be seen to base therapeutic interventions on ‘science’, and that this desire helped the development of the concept of formulation. She also points to a clear political agenda in explaining current and past emphasis on these skills of formulation, as they have helped to provide the professions distinctiveness and autonomy within the NHS and facilitated the profession’s transition to providing treatment.

Proponents of the CF approach put forward many potential benefits of using this approach, and these are usually based on clinical observations, illustrated case studies or personal experience. Some writers allude to the evidence that has accrued for the underlying theory (i.e. cognitive theory) as support for their CF approach (Beck 1995). However, others have pointed out that little evidence for the reliability, validity or utility of CF exists (see review by Bieling & Kuyken 2003). This lack of research is surprising (especially to the author who is a first year trainee) given the prominence given to CF on clinical training programmes and in defining the role of the clinical
psychologist. The need for empirical support in this area is highlighted by Tarrier & Callam (2002) who state:

"The factor that has distinguished the broad school of cognitive-behavioural therapies from other schools of psychotherapy has been a commitment to empirical validation both in terms of its theoretical premises and treatment outcomes. The issues surrounding case formulation should be no different and should be resolved by reference to empirical findings and not speculation" (p312).

This essay intends to describe cognitive CF and to discuss the proposed benefits of using this approach, and whether cognitive CF offers any advantage to using a simple diagnosis or manual based treatment. The potential disadvantages of CF will also be discussed, especially the inevitable involvement of human judgement (Wilson 1996) and the lack of empirical support for this approach. However, a lack of a particular type of evidence, does not mean that the CF approach should not be used, or is undesirable. A balance needs to be found between the need for research-based empirical evidence and the observations and reported benefits from practitioners. Using different sources of information should help to reach more complete decisions regarding the desirability or necessity of the CF approach (Neibling, Moss & Partridge 2002).

**What is a cognitive case formulation?**

Generally, case formulations aim to describe a person's difficulties, in terms that link theory to practice. Bieling and Kuyken (2003) summarise the shared 'key features' among case formulation schemes as including: a general description of a patients problems, relevant developmental information, causal factors, maintaining factors, coping strengths/weaknesses, a guide for intervention, and a set of hypotheses about underlying mechanisms.

More specifically, they define cognitive CF as a set of explanatory inferences (derived from cognitive theory) about the factors that are causing and maintaining a person's problems. A cognitive CF will include a description of a person's difficulties (usually in terms of affect, behaviour and cognition), relevant developmental history, the
individual’s strengths and resources, hypotheses about cognitive mechanisms, and the implications for intervention (based on tests of these hypotheses).

A number of formalised cognitive CF systems exist (e.g. Persons 1989, Beck 1995). Briefly, Person’s (1989) CF approach conceptualises psychological difficulties as occurring as 2 levels: overt difficulties (i.e. the problems the patient is facing in terms of mood, behaviour and cognition) and the underlying psychological mechanisms (i.e. the psychological deficits that are thought to underlie and cause the overt difficulties).

“The underlying mechanisms can often be expressed in terms of one (or a few) irrational beliefs about the self” (p.1).

These beliefs are then hypothesised to cause the persons difficulties. The therapist engages in a hypothesis testing approach that is continuously assessed and modified accordingly. Interestingly, one study looking at the content of written case formulations found that CF was more commonly used by clinicians to describe their client’s difficulties (95%), rather then to explore or infer any underlying mechanisms or causes – 43% (Ells, Kendjelic & Lucas, 1998). Person’s (1989) approach has been criticised as being somewhat narrow, as underlying mechanisms almost always turn out to be one irrational or dysfunctional belief: CF, according to Bruch (1998) is rarely reliant on one singular belief and tends to be much more complex.

Another formalised system is described by Judith Beck (1995). This has been of particular interest to the author as the system that has recently been part of both clinical training and experience on placement. Generally, the therapist gathers relevant developmental information and hypothesises as to how these experiences may have led to the individual’s core beliefs and assumptions. Information is collected on typical situations when the patient has become upset and patient and therapist together look for the automatic thoughts that were present, and their meaning to the client. The formulation is checked out with the client at strategic points to seek collaboration and accuracy.
There is however little, if any research looking into how these formalised systems may differ in terms of content and method, from actual cognitive CF carried out in the ‘real world’ (Beiling & Kuyken 2003). In the author’s limited experience, the approach described by Beck (1995) provided a fairly clear framework and treatment plan in working with a client with relatively straightforward panic attacks. The formulation led to the hypothesis that avoidance of certain social situations was helping to maintain the clients’ difficulties. This then helped provide an initial target for intervention.

**Proposed benefits of CF**

Proponents of the cognitive CF approach (e.g., Beck, 1995; Persons, 1993) put forward many proposed benefits of using this approach. They suggest that cognitive CF leads to a systematic framework for developing theoretically based hypotheses about a person’s problems and that this leads to more individualised cognitive interventions with more focussed treatment strategies. Sharing formulations with clients at strategic points can enhance description and understanding of the problem (by client and therapist), and can enhance the therapeutic alliance by developing a sense of collaboration (Beck 1995). Using a CF approach is also believed to help with the therapeutic process in terms of helping to predict any potential difficulties or obstacles that may arise in therapy like client resistance (Bruch 1998). These proposed benefits are often described with clinical observations and anecdotal evidence but no studies have yet to investigate these positive claims (Beiling & Kuyken 2003).

Aubuchan & Maletesta (1998) postulate (albeit from a behavioural perspective) that cognitive-behavioural CF has utility in managing the therapeutic relationship. They present 2 difficult and complex cases as ‘evidence’ where special attention was paid to the ‘therapist style’. Simply put, their methodology consisted of adapting the therapist’s style according to the case formulation. They define some ‘therapist styles’ as ‘constant’ and necessary (i.e. respect) while others may be ‘systematically varied’ according to the interpersonal style of the patient. Their two case studies used experimentation to test and validate their hypotheses about the patient’s interpersonal style and improvements were noticed when the only intervention applied, was the modification of therapist style. This study is obviously limited to a case study design,
but it does suggest CF may be useful in anticipating and reducing therapeutic non-compliance by strengthening the therapeutic relationship.

Regardless of levels of empirical support it is reported by some, that psychotherapists share a consensus as to the usefulness of CF (Ells et al 1998). Chadwick, Williams & MacKenzie (2003) have carried out a rare investigation of the impact of a cognitive CF on perceptions of the therapeutic alliance and on symptoms of anxiety and depression. 13 patients, referred for CBT for psychosis, took part and had two sessions (following two baseline assessment sessions where no interventions were offered) devoted to developing an individualised CF. Patients took their CF home and were encouraged to make any changes they liked. 11 patients were interviewed as to their experience of formulation. 9 of 11 patients found that this helped by enhancing their understanding of their own problems and 6 of the 11 also reported having positive emotions associated with this. However, 6 of the 11 also reported a negative emotional response to the CF which included a realisation that their difficulties had been around for a long time and were numerous, and a helplessness associated with not being able to stop these. However, 4 of these 6 respondents (who made negative comments) also made positive responses suggesting mixed emotions or ambivalence regarding formulation.

The therapists in this study were generally very positive toward cognitive CF. They found the CF approach powerful and validating in having the client endorse the formulation and felt it had increased the alliance and collaboration. They also felt it helped them to adhere to the CBT model. This study is limited to patients with more severe and enduring difficulties and psychosis, and to a very small sample but it does have interesting implications in terms of CF being more useful to therapists than to clients, and that we need to be aware that our clients may experience a shared formulation in a negative manner.

Beck (1995) suggests that formulations should be shared at strategic points over a number of sessions. Chadwick et al's study involved two CF sessions at the start. This highlights an important methodological issue regarding research into CF. It is obviously harder to study the impact of CFs if spread over a number of sessions.
However, the negative responses found in the above study may in part be due to how they were presented (i.e. over two intense sessions) and future studies should be aware of this. A common analogy used to explain CF is that of creating a ‘map’ of a person’s problem. If a driver is shown the whole map at the beginning of a route they may become confused. The question of when and how to share formulations to maximise their effectiveness requires further research.

More useful than a diagnosis?

It is argued that a treatment plan based on a CF will inevitably be more useful than one based on a diagnosis (e.g. Persons 1989, Beck 1995) because the emphasis is on hypothesis testing. This is believed to make CF more useful in terms of generating treatment ideas. Persons (1993) suggests that this is favourable to bombarding the individual with all potentially helpful strategies as determined by a diagnosis – which might be time consuming and discourage the patient. It is often argued that the same diagnosis may have different causes and a diagnosis sheds no light on this. However, there is a considerable debate regarding which approach is more effective – one based on diagnosis, or one based on CF (Tarrier & Callam 2002).

Schulte, Kunzel, Pepping & Schulte-Bahrenberg (1992) randomly assigned 120 individuals with a DSM III diagnosis of any phobia (and who did not meet criteria for any other disorder) into 3 groups: A standardised treatment group, an experimental group with an individual treatment planned by the therapist, and a yoked control group. The most improvement was found for the standardised treatment group and the authors hypothesis that standardised treatments might be better by preventing flexibility and tailoring. Therapists in the individualised group had a greater subjective impression of being able to make adaptations – but this was of no additional benefit. Decisions based solely on the clinical diagnosis were sufficient and “it was of no advantage to take additional aspects into consideration” (p.88).

It would be interesting to see if Schulte et al’s findings with patients with simple phobia, would be replicated with individuals with more severe and enduring difficulties. Proponents of the cognitive CF approach suggest that their approach is especially suitable for more complex cases (Beck, 1995) so we might expect the
standardised approach to do less well as the complexity of the problem increased. Conversely, it might also be argued that ‘flexibility’ and ‘tailoring’ were hypothesised to reduce the effectiveness of a treatment for simple phobia, and might therefore have much more of a negative influence in cases with more complex and enduring difficulties.

**Clinical Judgements**

CFs are always made from a particular perspective. This perspective might depend on such factors as the age, sex, background, and personal experience of the therapist which might be quite different from characteristics of the client. The author could find no studies looking at how differences between patient and therapist might play a part in reducing the reliability or utility of the cognitive CF approach.

Different cognitive therapists, with different backgrounds, may not agree on a formulation. Persons, Mooney & Pedasky (1995) have investigated the interrater reliability of clinicians using the Person’s (1989) CF approach. They asked therapists to listen to a tape of part of a session and then to identify the client’s overt difficulties and underlying cognitive mechanisms. Only moderate agreement was found (regardless of cognitive training) in relation to identifying adequate problem lists and the authors report surprise and disappointment at these results. They speculate that the therapist’s may focus on identifying underlying mechanisms (which produced higher interrater agreement), at the expense of the clients’ overt problems.

The finding that therapists do not initially agree on a patient’s difficulties may not be as problematic as it seems. For example, a therapist may soon become aware of the inadequacies of her initial formulation by the process of hypothesis testing. In addition, different therapists may focus on different aspects of a patient’s problem and both may be useful to the client in different ways. A lack of agreement may not therefore mean a lack of utility in clinical practice. However, it is important to establish under which conditions CFs are agreed upon and the extent to which information processing biases are influencing the formulation (Biejling & Kuyken 2003).
Wilson (1996) argues that CF is an undesirable process and he advocates manual based treatments on the basis that clinicians (and indeed all human beings) regardless of levels of experience, are open to all kinds of cognitive bias and perceptual error. He suggests that therapists are guided by personal experience and several well-researched cognitive biases can undermine the validity of this (including confirmatory bias, the availability, and representative heuristic). Contrary to Beck’s assertion that cognitive CF is especially useful with more complex cases, Wilson cites evidence to suggest that clinical judgement is further impaired when the information being processed is more complex. The essence of Wilson’s (1996) argument may be captured in the following comment regarding how he feels therapists ignore the empirical evidence before them:

“The availability heuristic helps explain why clinicians typically assign so much importance to individuals case studies despite their shortcomings. People in general tend to ignore or pay too little attention to valid information presented as a summary of well-controlled studies, whereas they will base their judgements on less valid information which is more vivid, such as a fascinating case history with personal details” (p299).

Manual Based Treatments
To determine whether CFs are a desirable or useful part of the therapeutic process, some studies have attempted to compare standardised or manual-based treatments with those based on individualised or a CF approach. Results from these comparisons have so far been largely equivocal (Tarrier and Calam, 2002). For example, Emmelkamp, Bouman & Blaauw (1994) compared a standardised exposure-based treatment with a tailored CBT approach, with 22 patients with OCD. They found no significant differences between these groups and both were found to improve.

Such comparisons might be complicated by Schulte’s interesting observation that ‘adaptation’ of the treatment manual to individual cases was found in all of their treatment groups – even in the manual based group. This occurred even when clinicians were asked specifically to adhere to the manual based approach. Hickling & Blanchard (2001) comment that most manuals tend to have a degree of flexibility. In
reflecting on how it felt to adhere to their own treatment manual of MVA related PTSD, these authors reported feeling constrained by their manual and they believe that deviating from it would have strengthened the treatment, not weakened it as Wilson (1996) has suggested. They argue that clinical judgement is important and that treatment manuals should provide the starting point for treatment, and not the ending point.

An interesting (and frequently cited) study is Jacobson’s (1989) comparison of a research based marital therapy with an individually tailored flexible version of the same therapy. (While this study is not a test of cognitive CF per se, the implications of their findings are of interest here). Importantly, the flexible version consisted of the same research based modules as in the standardised treatment but they could be presented in varying length or order - as determined by the individual case. No differences were noted post-treatment. However, 6 months post-treatment, couples who had received the standardised treatment were significantly more likely to have deteriorated. The authors suggest that their study may be a conservative test of the tailored approach to treatment, as the two treatments were very similar in many ways. However, it could be argued that the choice of intervention strategies available in the individualised package were based on the same evidence as the manual-based treatment. This study therefore limited clinical judgement to a choice of well-established techniques. This suggests clinical judgement might be useful in selecting the most appropriate empirically-based strategy.

**Manual-Based Treatments and a CF Approach**

Commentators such as Wilson (1996, 1997) argue strongly for the use of manual-based treatments and for limiting the scope of clinical judgement. At an extreme, this argument might assume that clinicians are tempted to pick any theory they like - in a manner completely free of clinical research and theory. However, a good cognitive CF would ideally be continuously consulting theory and is essentially experimental - testing hypotheses and modifying them accordingly (Beck 1995). It is possible for a therapist to use a CF approach to help choose the most appropriate manual-based treatment strategy.
Inevitably, some of the time, clinicians will not be able to follow a manual and no manual can cover every eventuality. Therefore, in using clinical judgements an individual may consult his/her understanding of a range of relevant theories and literature. Using a cognitive CF doesn’t mean that he/she can pull any theory from the air. Instead, a CF is purported to allow a degree of flexibility that will inevitably be needed when dealing with the complexities of human behaviour. However, as Wilson (1996) points out, clinicians need to be aware of the pitfalls associated with clinical judgements. Ideally, a formulation should be easily described to others, and this could provide an initial test of the appropriateness and objectivity of the judgements used to arrive at it.

Schulte et al’s study suggests a certain amount of tailoring is inevitable and a balance needs to found between the demands of evidence-based practise, and those of a clinical setting. As Wilson points out:

"On the one hand, the value of treatment guidelines reside in their grounding in the best research and in being implemented consistent with the underlying science. On the other hand, studies suggest that if practitioners are not allowed to modify empirically derived guidelines to meet local conditions, the guidelines are less likely to be followed" (p.209).

Flexibility on the front line (i.e. in clinical practice) may therefore be held to be important to the therapist who might feel constrained by a manual. However, selecting the most appropriate intervention with the strongest theoretical basis and evidence is also important. Some might argue that a cognitive CF approach can find a happy medium between these two positions (Tarrier & Calam, 2002).

Bond (1998) suggests that a CF should guide the therapeutic process, and that strategies that are consistent with the CF can be imported from treatment manuals. Manuals may offer or help implement techniques that the therapist is unaware or unsure of. For Bond (1998), the clinician can use a CF to monitor the client’s progress and therefore to establish whether any manual based techniques are bringing about the desired change.
Evidence-based practice

Wilson (1996, 1997) feels that there is no strong empirical foundation in support of cognitive CF and that clinical experience and anecdotal evidence are of little value in forming decisions about whether CF is desirable or essential. Some commentators argue that where there is a lack of evidence for a particular treatment, then it is important to acknowledge this and not to use the method uncritically, or at least not without clear statements as to its experimental nature (Whitaker 2002).

As desirable as strong empirical evidence might be for proponents of the CF approach, gaining such evidence is not easy. One example already mentioned in relation to Chadwick et al’s (2003) study, described how CFs are ordinarily developed and modified over a number of sessions. Measuring the impact that CF has in isolation is therefore problematic. Another obvious problem is that of sample sizes. Tarrier and Calam (2002) point out that many of the studies comparing standardised and formulation-based treatments (e.g. Schulte et al 1992) have been significantly under powered and they calculate estimates of the sample sizes that would have been needed in two previous studies (these were much higher than the numbers sample sizes actually used). The point they make is that the practicalities of carrying out such comparisons, and especially obtaining funding for this, is limited.

There is some debate as to what actually constitutes the evidence in evidence-based practice. Writers, like Craig Newnes (2001), argue for the acceptance and use of much broader categories of evidence – including such sources as our senses, our personal experiences, or the books (fact and fiction) we read. While the wider debate on this is beyond the scope of this essay, it seems relevant to question the basis by which we might reject or accept the use of cognitive formulations.

On this subject, Neibor, Moss and Partridge (2000) have commented the following:

“Should evidence-based practice mean only practice based on scientifically derived, mean-based, statistical knowledge? The logic behind this particular version would eventually lead us to providing standardized packages of care...
and ultimately to privileging psychological technologies over psychological thought. Here the tail seems to wag the dog and evidence is master” (p.18).

These authors remark that the dominant discourse of current clinical psychology training programmes continues to be “positivist empiricist construction of the scientist practitioner” (p.17). From this perspective, we (the scientist-practitioners) observe from a distance to collect ‘evidence’ which culminates in mean-based statistics. Currently, it is this version of evidence that is privileged in the NHS today and in forming the basis of decisions regarding resource allocation (Neibor et al., 2000).

For Neibor et al (2000) the context will determine the evidence questions posed (i.e. is this practice helpful to patients?) and there will be many types of available ‘evidence-making processes and evidence-products’. The few they list include feedback, testimonies, gut feelings, thoughts and facts. The ‘feedback’ received by Chadwick et al is a form of evidence and this indicated that therapists found CF a useful approach. Furthermore, 9 of 11 patients had something positive to say about the experience. There are many clinicians arguing for the desirability and utility of cognitive CF for effective CBT and many of these use experiences and observations to back this up (e.g. Persons, 1989; AuBuchon & Maletesta, 1998; Davison & Gann, 1998).

Conclusion

While it is frequently accepted that cognitive CF is a crucial part of the therapeutic process (and is strongly emphasised in clinical psychology training), little research has been carried out on it. Cognitive theory, partly due to its concurrence with the scientist practitioner model, has received many empirical tests of its hypotheses and assumptions. Unfortunately these have not extended to cognitive CF (Tarrier & Callam 2002).

In the absence of empirical support, many proponents of the cognitive CF approach have illustrated the proposed benefits of CF on the basis of cognitive theory, logic, speculation, clinical experience, illustrated case studies, or a few small scale studies. Firm conclusions regarding the utility, desirability or necessity of CF cannot be made on this basis. Further research is therefore required to test the utility and proposed
benefits of using a cognitive CF approach and many questions remain unanswered. Do cognitive case formulations actually relate to a person's difficulties in the real world (i.e. construct validity) and can they predict obstacles to treatment as suggested by AuBuchon & Malatesta (1998) and therefore smooth out the planning of interventions (i.e. predictive validity).

However, CFs could be found to have little general reliability and/or validity and still be useful (and the opposite might also be true). Studies of treatment outcome are needed to test whether a good cognitive CF is more effective at achieving better results than if one were not used. Chadwick et al.'s (2003) study has been discussed as one of the few studies (if not the only one) to ask for feedback from patients (and therapists) on how they experienced the CF approach.

It is commonly argued that there is a lack of evidence regarding CF and that more evidence is needed (Wilson 1996). It might be useful to look at what we mean by 'evidence' and to be aware of what types of evidence are privileged in our discourse. The absence of mean-based statistics, does not necessarily mean the complete absence of evidence and such sources as feedback, thoughts, or narratives (i.e. Newnes 2001) may all provide different sources of evidence in helping to form decisions regarding how desirable or necessary cognitive case formulations are.
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Critically discuss the argument that it is not possible to use CBT with people with a learning disability.

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Year 1
Introduction

Individuals with learning disabilities may have an increased likelihood of displaying cognitive deficits in a number of areas including language and memory, problem solving, speed of processing, and abstract thinking and it is therefore likely that these will complicate the process of CBT (Jones, Miller, Williams & Goldthorp, 1997). Indeed one argument for not developing CBT for people with learning disabilities is that the cognitive and linguistic demands of this approach are too great for this population. However, research in this area is notably absent and has little to offer in the way of firm conclusions.

Hatton, Hastings & Vetere (1999) report only 5 (3%) of 163 papers in the British Journal of Clinical Psychology between 1991 and 1995 were related to learning disabilities, compared with 21 (13%) articles relating to psychosis (a disorder that concerns far fewer people). These authors suggest a number of reasons for this paucity of research including: a lack of status around working with people with learning disabilities both in academia (with difficulties publishing in mainstream journals, and in attracting funding) and in clinical practise; that people have been until more recently segregated in hospitals and have remained largely invisible; and that it is difficult to use established research procedures with people with learning disabilities. Yet some research suggests people with learning disabilities are more likely to be at risk of developing mental health problems due to life experiences and known risk factors (Arthur 2003). Specifying prevalence rates is difficult however, due to a number of issues related to detection and diagnosis (i.e. diagnostic overshadowing) (Prosser, 1999).

In exploring the potential for CBT with people with learning disabilities, this essay will at first consider what CBT is, and who 'people with learning disabilities' are. In considering these definitions, it becomes clear how unclear research is in specifying which cognitive techniques work particularly well with which groups of people. Many obstacles are believed to stand in the way of successful CBT for people with learning disabilities and some of the main assumptions made will be discussed. These will focus on the challenges facing CBT, but may well generalise to the utility of any therapeutic approach.
It is argued that many assumptions regarding the impracticality of CBT for this group are unfounded. Indeed, CBT may potentially be useful to many people with learning disabilities though there would appear to be a consensus that a minimum level of abilities is required. While a substantial evidence base is notably lacking, practice-based evidence is emerging that will be discussed in order to highlight the potential for adapting cognitive strategies for use with people with learning disabilities. The current state of evidence in this area would seem to suggest that with some thought and attention, cognitive techniques may be adapted and modified to be made more accessible and useful to people with learning disabilities. Ways in which this has been attempted are discussed.

**Definitions**

To think of people with learning disabilities as a homogenous group hides many differences that might be important mediators of how successful particular cognitive strategies are, and with whom. Similarly, Stallard (2002) reports that researchers applying cognitive principles to working with children have typically lost valuable information on developmental variations by viewing children as one solid group. Within my experience, the clients I have worked with have been very different to each other and to me as would be expected of different people, though contributing to this diversity is a very wide range of abilities.

There appears to be much more optimism in terms of adapting CBT for people with mild learning disabilities as opposed to more severe disabilities. Furthermore, differences have been noted in the expressions of emotional disorders between people with mild and more severe degrees of impairment (Reed, 1997). An interesting possible explanation is put forward by Glick & Zigler (1995) based on a view that the expression of emotional disturbance has a developmental progression, with more immediate and direct responses associated with early stages of development while more indirect and verbal responses develop at later stages. Thus individuals with severe learning disabilities may express emotional disturbance via actions rather than through cognitions, arguably making a cognitive approach less suitable here.
The term cognitive behaviour therapy (CBT) hides many different strategies (Kroese, 1997). Indeed, there is no single definition of what constitutes CBT (Williams 1992) though in most forms of cognitive therapy, the basic principle is that emotions and behaviour may be mediated by a person’s thoughts or belief systems (Beck 1995). The absence of any clear framework for using CBT for people with learning disabilities means different strategies or combinations have developed under the umbrella of CBT. It is therefore sometimes difficult to define or identify, core elements of programmes of therapy.

Kroese (1997) has distinguished two main approaches to CBT with learning disabilities: those that focus on cognitive processing and those looking more at cognitive content. The former approach focuses on teaching skills or self management to address deficits, while the later focussing more on the content of thoughts and assumptions. Dagnan and Chadwick (1997) list a number of similar distinctions noted by other authors (e.g. rote learning and meta-cognition; simple and elegant therapy, passive and active). Kroese (1997) points out that there is generally more research associated with the cognitive process approach because cognitive deficits are more observable, and therefore easier to identify, analyse and measure in comparison with cognitive content, which relies more on communicating abstract concepts and obtaining self reports.

Suitability for CBT

One of the main causes for concern in terms of using cognitive strategies with people with learning disabilities is that a minimum level of cognitive and linguistic skills are required. For example, Whitaker has reviewed CBT programmes for anger control and breaks down the cognitive demands involved in these: clients will need to recall instructions (requiring memory and language); know when and where to use the skills they have learnt; assess a situation and problem solve the most appropriate way of responding (requiring verbal reasoning and memory); and do this at a time of high arousal.

For Safran, Segal, Vallis, et al. (1993) three main areas should be assessed when thinking about a client’s suitability for CBT. The client needs to be able to access
automatic thoughts (using scenarios may help with this) and have a compatibility with
the cognitive model (i.e. understand links between thoughts and feelings, and identify
short term goals). They also require an awareness and differentiation of emotions.

These elements are incorporated in the approach by Dagnan & Chadwick (1997) who
use Ellis' (1977) well known ABC framework to assess what a person needs to have
understood, to be said to have a grasp of the cognitive model. An essential part of this
is being able to differentiate the three components of the ABC model which are: the
activating event (A: the situation), its meaning (B: the belief, thought) and the
behavioural consequences (C: the associated emotion). The ability to recognise
emotions is therefore very important. The person needs to acknowledge that an
activating event can lead to an emotional response (the A-C link) and that this
response may be mediated by cognition (the B-C link). It is essential that the person
realises that the consequence is most closely linked to the belief, and not the
antecedent.

Using the above framework, Dagnan, Chadwick & Proudlove (2000) assessed the
abilities of 40 people with learning disabilities to link beliefs, emotions and behaviour
in line with the idea of cognitive mediation: 75% of this sample linked situations to
emotions appropriately. However, performance on cognitive mediational tasks (i.e.
picking the appropriate emotion given a belief and a situation; picking the appropriate
belief given an emotion and a situation) was well below that for simply linking
situations to emotions. Linking all three components may be a more complex task than
just linking situations to reactions. They conclude that people with learning disabilities
may well have some skills enabling them to use cognitive therapy but that training
might be needed to facilitate the development of skills, if absent, to help grasp the
concept of cognitive mediation.

**Emotional awareness**

In order for a person to report on how they are feeling, they need to be able to
recognise and be aware of different emotions and people with learning disabilities
may have problems recognising and expressing even basic emotions (Reed, 1997).
There is some evidence that people with learning disabilities may have specific
emotional awareness deficits that are not associated with intellectual impairment (Reed & Clements 1989). It may therefore be useful to assess for emotional awareness in helping decide if self-report measures are appropriate, and whether interventions aimed at increasing emotional awareness would be useful.

**Stable cognitions**

There has also been a previous assumption that people with learning disabilities do not have stable and potent cognitions (Lindsay et al, 1997). It would therefore be impossible to know why changes are occurring and to ensure they are as a result of clinical manipulations. However, this view has been contested by Lindsay, Michie, Baty, Smith, & Miller (1994) who assessed the convergent validity of a number of various self-report measures of anxiety and depression with people with mild/moderate learning disabilities. The measures were revised to make them simpler to understand. They found a high degree of consistency in the responses obtained. They conclude that the self perception of a person with learning disabilities is as reliable as those of people from non-disabled populations, and that this provides evidence of a stable and reliable cognitive system related to emotion in people with learning disabilities.

**Self report and abstract concepts**

One of the perceived obstacles to using CBT has been that self-report information is required from the client (Kroese 1997). Generally, self-report measures are susceptible to a range of threats to their validity and reliability (Kline 1993) and those obtained from people with learning disabilities are often thought to be more susceptible to some of these (including acquiescence, memory problems, incomprehension & social desirability). A client with limited language and cognitive capacity may have difficulty reporting on abstract concepts and beliefs, thoughts and emotional experiences (Kroese 1997). Based on this assumption, clinicians have tended to rely on information from others thought it is easy to see how information from carers/relatives may be biased, or may miss the meaning of an event to an individual (Lindsay 1999). However, the process of CBT may be complicated by difficulties in describing cognitions in reliable and valid ways.
Kroese (1997) suggests that many of the perceived problems in obtaining accurate self-report can be overcome with small modifications. The examples he offers include: using pictorial materials to make abstract ideas more concrete where possible; using open-ended questions which may help avoid acquiescence; and inserting a ‘probe’ question after each item to check for understanding. Lindsay (1999) describes clients using empty/full containers, or the distance between their hands to help express the strength of an emotion. However, modifications may alter the psychometric properties of a measure and would ideally be tested (Kline 1993), though time constraints and clinical needs will obviously hinder this.

Other obstacles
Regardless of whether a person has the ‘ability’ to make use of CBT or not, it is important to assess the appropriateness of starting a programme of CBT (or any other treatment). If the systems surrounding the individual are lacking in support, or creating the ‘problem’ in the first place, then treatment may be doomed to failure from the start, and feeding in to a pattern of repeated failure obviously needs to be avoided. Engaging in therapy when contextual issues are more important may serve to further blame or alienate the client.

The motivation of the client may also be significant in all treatments and the circumstances around a person’s referral may be important. For example, are they attending to please a carer or someone else? Is the carer the person who actually has the ‘problem’ and who will actually benefit from treatment? The person’s ‘problem’ may, for example be functional and some benefit may be being derived from it.

A complex issue here is the importance and difficulty in obtaining informed consent. It is essential that a person understands what they are taking part in and ideally this would be checked and not assumed, at every stage of an intervention and when any changes occur. Clients should be encouraged to take an active role in treatment and empowered to ask questions about what is going on. Understanding may be enhanced by providing information that is broken down with simple direct language. The person may be unaware for example, of the role of a psychologist, and what the assessment or
intervention is for. They may simply be complying or have an indirect incentive (i.e. a day out).

Indeed, little attention is paid to ideas of power in the CBT literature. Proctor (2003) compellingly points out that while CBT speaks of the virtues of ‘collaboration’, its methods suggest seeking ‘compliance’. For example, its measurement of success is based on how much of the model is bought; beliefs are challenged if they are deemed ‘inappropriate’ by the therapist; and therapist is viewed as the holder of knowledge, of scientific ‘truth’. These arguments make more noise when thought about in the context of vulnerable people.

The repeated experience of failure, and subsequent social rejections, may leave people with learning disabilities more resistant to therapeutic change (Jones et al, 1997). For example, a person with learning disabilities may experience repeated failures throughout life and subsequently develop a learned helplessness and a low level of personal empowerment. A life long reinforced belief that one can do little to change anything may adversely affect therapy. Jones et al (1997) go as far as to suggest that it might be important to focus on improvements in a person’s self esteem, before any in-depth cognitive interventions can occur.

Becoming aware of these obstacles is crucial to developing means of increasing readiness for CBT. For example, people may need initial interventions aimed at increasing motivation (i.e. motivational interviewing techniques), or self-esteem and self-efficacy (i.e. could highlight early gains in therapy); or aimed at building up ability levels and understanding of the ABC model.

Practise-based evidence
In terms of providing evidence based practise, a strong evidence base is lacking and firm conclusions remain tentative. Few randomised controlled studies have been carried out on cognitive interventions with people with learning disabilities. The majority of studies that do exist are write-ups of routine practise and case studies, or reviews of the literature. While practise based evidence is accruing, studies are so far largely limited to just a few problem areas, including mainly anxiety, depression,
anger and offending behaviour (Lindsay 1999). However, some studies have ventured to applying CBT to other areas, like developing a minimally aversive cognitive behaviour intervention for inappropriate masturbation (Withers 1998).

It is not known to what extent models of CBT developed for non-disabled populations may be simply extended to people with learning disabilities. An assumption that they will simply apply may halt research attempts to clarify what works with whom. Simply applying models developed with non-disabled populations takes no account of the impact of different levels of ability, and goes against emerging evidence that some disorders may have different symptom patterns in people with learning disabilities (Reed, 1997). For example, it is possible that intellectual disability means cognitions function in different ways, compared with non-disabled populations, and may have a different developmental pathway (Lindsay 1999). People with learning disabilities may not express the typical symptoms of a disorder or may have a more limited range of symptoms than the general population (Moss, Prosser, & Goldberg, 1996). This had obvious implications for missed diagnosis, especially where criteria developed on non-disabled populations are used. In relation to anxiety, Lindsay et al (1997) conclude that assuming that anxiety works in the same way for people with, and without learning disabilities is unjustified.

Lindsay et al (1997) and Lindsay (1999) have illustrated how the main principles of CBT can be maintained, while simplified and revised for use with people with learning disabilities. Both report significant gains obtained on self report anxiety and depression measures. This was in addition to improvements in weekly self-report records of anxious thoughts, and feelings of embarrassment using a simplified analogous scale. They report that treatments lasted an average of 23 sessions (ranging from 15 to 47).

The procedures adhered to in both of the above studies included the following: setting an agenda; establishing a relationship between thoughts, anxiety and behaviour; monitoring automatic thoughts; identifying underlying beliefs; testing the accuracy of these and generating alternative positive ways of thinking; and setting homework
tasks. Lindsay (1999) reassures the reader that while these procedures might sound complicated, previous case examples demonstrate that they can be simplified.

A similar set of procedures was followed by Lindsay, Howells, and Pitcaithly (1993) who report on adapting CBT for depression in 2 case studies of people with mild learning disabilities. Improvements were noted in both cases, on an adapted Zung Depression Scale (Zung 1965) and on a daily monitoring of depressive feelings. In all of the above studies, only people with mild learning disabilities were participants and exclusion criteria included a lack of sufficient language ability.

Dagnan & Chadwick (1997) present a case of a 58 yr old woman with mild disabilities. Suitability for CBT was assessed using the ABC framework to establish that the client could a) distinguish an incident, its meaning and associated emotion/behaviour, b) recognise the consequence is more closely linked to the belief than antecedent and c) recognise the belief is open to testing. The therapist focussed on specific prior upsetting incidents to identify negative thoughts and beliefs. These beliefs were then challenged and counterevidence was looked for - but limited detail is offered as to how this was specifically carried out. Improvements were noted by staff recording behavioural signs of depression (i.e. incidents of crying).

In looking for more stringent research designs, only one randomised controlled trial (RCT) was found (Willner, Jones, Tams & Green, 2002). This explored the efficacy of CBT for anger management with 14 clients with mild learning disabilities. Clients were randomly assigned to a waiting list control group and a treatment group consisting of nine 2-hour group sessions using a variety of techniques (role-play, relaxation exercises, brainstorming discussions). Outcome measures were two similar rating scales that asked participants to rate anger on a number of hypothetical scenarios, using 4 cartoon faces depicting 'not angry' to 'very angry'.

Results indicated that improvements were obtained on both anger rating scales following treatment, and at 3 month follow up. In addition, the authors observed that while clients developed a good grasp of the more behavioural coping strategies, they showed more difficulty grasping ideas of cognitive restructuring. Only one client was
thought to have sufficiently grasped the idea of ‘thinking differently’. They conclude the cognitive elements of their intervention were less effective than the behavioural and educational components.

However, it should be noted that no psychometric data was available on their outcome measures and no direct assessment of skills was carried out - just responses to hypothetical situations. As treatment was presented as a package, firm conclusions about the relative effectiveness of individual components cannot really be made. Conclusions of component success were based entirely on therapist observations during treatment and were therefore subjective. In addition, a failure to pick up any cognitive changes may have been due to a lack of psychometrically sound outcome measures. Nevertheless, this study represents the first RCT of anger treatment in clients with learning disabilities, and is perhaps the first RCT comparing treated and untreated groups of any cognitive behavioural intervention in learning disabilities.

A good illustration of the methodological limitations of research in this area is offered by Whitaker’s review of 16 studies using a cognitive based approach for anger control in people with learning disabilities. All but two studies used a single case or a small series of case studies. Overall, positive benefits were reported at completion of training and at follow up (with wide ranging follow up periods, from 2 weeks to 12 months). However, most of the studies did not give reports of the validity and reliability of the outcome measures they used. In addition, a number of core components were identified (relaxation, self monitoring, education about anger, self-instruction & problem solving) though because treatments were presented as packages, it remains unclear as to which of the various components were effective.

Evidence of direct testing was found for only relaxation, and self-monitoring for challenging behaviour. Thus of the individual components, clear evidence was found for only the non-cognitive procedures of relaxation and self monitoring. Whitaker adds that one study found using distracter statements and positive self talk difficult and sometimes confusing for clients to apply while another reported the best strategies were behavioural and educational in nature.
However, that clearer evidence was found for non-cognitive components could simply be due to their more observable nature, being easier to identify, assess and measure (Kroese, 1997). A lack of observable evidence does not necessarily indicate that cognitive techniques are ineffective. It cannot be ruled out that observable difficulties understanding cognitive techniques may be due, in part, to how these are presented (i.e. if presented at too high a level, too quickly, or along with too much other information). The subjective nature of these observations makes them prone to the biases of the therapist who may lack confidence or conviction in these strategies. As components were presented as packages, it remains impossible to say which strategies were ineffective and this highlights the need for more stringent research efforts.

**Modifications**

Adapting cognitive strategies to meet the needs of client groups other than the general population is quite common (Jones, et al 1997) and many of the suggestions used for other client groups may be usefully adopted for people with learning disabilities. For example, Stallard (2002) has reviewed modifications made for the use of CBT with young children and these involve many similar challenges like developing materials that have a greater visual emphasis, or making abstract concepts more concrete. For young children, his review encourages the development of thought bubbles, cartoons, imagery and metaphors based upon the child’s everyday life. These sound similar to those made by psychologists adapting CBT for people with learning disabilities. Further exploration of the modifications of cognitive techniques for use with young children may therefore prove helpful.

From experience in an adult mental health setting, I am aware that even well established manual-based cognitive strategies are not without potential difficulties (i.e. establishing trusting relationship, non-compliance with homework, maintaining focus on agenda items, identifying ‘hot’ versus not so relevant cognitions, ‘selling’ the model). Given the added complexity of cognitive impairment, these techniques may at first appear too difficult for a client, and for the therapist who must present them. However, an assumption that a technique will be too difficult or cannot be adapted may deprive someone of a potentially useful strategy. In addition, reports of tried and
tested modifications are becoming available and these should illuminate how cognitive techniques may be more successfully applied.

For example, visual representations wherever possible may help make abstract concepts more concrete. Rossiter, Hunnisett & Pulsford (1998) describe using a traffic light metaphor with a group of 6 participants for anger management training, with each light representing a different stage in managing anger: relaxation, self-instruction and problem solving. The importance of using materials that clients are familiar with is illustrated by Howells, Rogers & Wilcock (2000) who found their clients could not relate to the above traffic light metaphor, as they had no experience of what traffic lights actually do.

To help with monitoring thoughts and emotions, cartoon representations of emotions or pictures and diagrams have been found useful (Lindsay 1999). I have found using pictures and simple books (with pictures) very helpful in stimulating discussions around anger with a teenager with mild learning disabilities. Characters in the book provided a good basis to discuss how their thoughts and feelings were linked, and what the consequences might be if that character had different thoughts. Using colourful modern pictures also helped with engagement and maintaining a more 'light-hearted' feeling to our sessions.

Role play has also been found to be useful in eliciting automatic thoughts, by re-enacting previously stressful events. Reversing roles of therapist and client may also be useful where the client acts as the therapist and will hopefully ask some leading questions (Lindsay 1997). Role play may also be useful in reinforcing positive beliefs and problem solving skills (Howells et al 2000). In relation to generating alternative cognitions, the simplest cognitions should be focussed on and where possible the direct converse of this can be used (Lindsay 1993).

The potential for client and therapist to take a humorous perspective on the client's unhelpful thoughts is touched on by Lindsay (1997) in terms of helping to 'lightly' challenge the accuracy of cognitions. However, caution on the use of humour is
expressed by Kroese (1997) in terms of being clear as to the clients understanding to avoid 'abusive humour'.

Howells et al (2000) found that their participants were able to understand and engage with complex elements of an anger management course if it was presented in a simple manner, and repeatedly practised. Other suggestions have centred on being flexible and generally breaking complex information down into small simple steps, and using simple language wherever possible. It would seem logical to suggest shorter sessions too.

Whitaker (2001) suggests tailoring a programmes to specific situations. For example, if a person has a problem dealing with a particular situation, they could be taught specific cognitive behavioural skills to deal with that situation – reducing the amount of information needed and tailoring the approach to meeting a persons specific cognitive deficits. However, Whitaker concludes fairly pessimistically that many people will not have the prerequisite cognitive and linguistic skills to benefit from cognitively based anger treatment, despite modifications being made.

Conclusions
Of course CBT is not the only therapeutic approach that could be made more useful and accessible to people with learning disabilities. For example, a growing interest in ways of applying psychoanalytic approaches has been apparent, illustrated particularly by the opening of a specialist learning disabilities service in 1995 at the Tavistock Clinic (Hernandez-Halton, Hodges, Miller & Simpson 2000). Providing an equal choice of treatment strategies as those available to the non-disabled population would seem an ideal.

The success with which CBT has been applied to many areas in the non-disabled population suggests a potentially unethical stance in holding back the development of techniques that could prove as useful for people with learning disabilities as they are for people without. Given that there is strong evidence that individuals with learning disabilities experience a range of emotional problems and are potentially more at risk due to increased life stressors and negative experiences (Arthur, 2003), it is notably
that so little has been done. Bender (1993) refers to a persistent ignoring of our moral obligation as psychologists and mental health workers to provide services that are equal to those provided for non-disabled people.

Many efforts have been made more recently to build on emerging practise-based evidence that cognitive techniques can be useful for people with learning disabilities. Numerous small scale studies, usually based on routine clinical practise and case presentations have been reported. Modifications to existing cognitive strategies have been tried to varying success and it would seem unjust to conclude that CBT has absolutely no use for people with learning disabilities.

Given the lack of a substantial evidence-base and of any detailed protocols, the confidence of therapists to adapt cognitive-behavioural strategies for their clients may well be low. It might therefore prove useful to look at ways of addressing this. For example, peer supervision and group training could prove valuable in encouraging peer support and reflective practice. The dissemination of knowledge and resources might be useful, encouraged perhaps by pooling together and making available any relevant texts and materials. This could also be facilitated by obtaining feedback from attendees at appropriate conferences. Shared interest groups could be a useful way of developing guidelines and encouraging a consistency in approach, based on the best available practise based evidence. The publication of clinical experiences might be a useful source of information, encouraged through trust-wide or psychology department newsletters. Another way of facilitating communication and problem solving could be to set up a related e-mail discussion board or website. In addition, service-user perspectives could be encouraged through links with local charities.

Hatton et al (1999) highlight a number of potential incentives for theorists who wish to test their theories under 'what may be described as extreme conditions' (p.233), the mark of a good psychological theory arguably being that it can be applied to all groups in society. The need for more research is made by most of the authors working in this area yet it's absence persists. Generally, the studies that have emerged recently suggest interesting possibilities for CBT with people with mild learning disabilities.
Hopefully, this will reinforce to others the contribution cognitive strategies can make to the lives of people with learning disabilities, and draw the attention of more theorists and clinicians to this fascinating area.
References


“Divorce is bad for children”. Discuss with reference to the literature on the psychological effects on children of divorce and parental conflict.
Introduction

"The worst thing by far about my parents divorce is that it's still going on. I mean, my parents don't talk. If they have to talk it's like screaming. I thought that once the divorce was over, my Mom and Dad could just get on with their lives, but it hasn't worked out that way. I think the fighting will never stop".

‘Tracy’, aged 16.

"As for getting married someday myself, yes, I'd like to get married, and sure, I'd like it to last and have a golden wedding anniversary after fifty years, but life isn't perfect, and at least if it doesn't work out I can always say, "Well, divorce isn't that bad as long as you handle it in a way that doesn't hurt the children!"".

‘Corinne’, aged 16.

The above quotes are taken from a collection of narratives provided by nineteen different children, aged 7 to 16 (Krementz, 1985). The quotes above seemed particularly salient to me in terms of the issues I want to raise within this essay, but many could have been used from this collection. Each child's story illustrates a different way in which the divorce of their parents impacted upon them. In thinking about the impact divorce can have, it would seem ideal that children's voices be heard (the impact of divorce being made much clearer and more 'real' to the reader than viewing research trends, hypothesised links and general findings). Yet, from my brief encounter with the available literature on divorce there appears to be much less available from children themselves.

Defining 'divorce'

The term 'divorce' refers to a single legal action. However, a marital separation may begin much earlier, while a couple are still together, and end a long time after the actual divorce. In this essay, divorce will be referred to as meaning this process, and not a discrete event. Thinking of divorce as a process can be useful in expanding our views of the effects divorce can have over time (Amato 2000). For example, an adult may become increasingly dissatisfied with their marriage, and respond in ways (i.e. overt/covert conflict) that impact on a child long before a separation takes place, and long after.
Aims
The plan of this essay is to present and discuss the arguments that divorce is uniformly ‘bad’ for children, with reference to research that supports and refutes this view. Initially, I will briefly discuss the narratives written by the children in Jill Krementz’s (1985) compilation of divorce stories. I have put this first in order to facilitate subsequent comparisons between what children say about their own experiences of divorce related events, and what the more influential voices of research say about children’s experiences. The few narratives (or edited quotes) from children that I did come across, appear to more readily present positive outcomes or resiliency than do some of the research findings.

In particular, the work of Judith Wallerstein will be presented, as one of the most influential researchers to argue that divorce has profoundly negative and long-lasting implications for children. The controversy surrounding her claims will be discussed as counter-perspectives are presented. The work of another influential author in this field, Hetherington, will be discussed as highlighting a more optimistic outlook on the impact of the divorce process. Possible reasons for the discrepancies between their findings will be explored.

Much of the literature reviewed suggests that divorce itself may not necessarily be detrimental to a child, and much seems to depend on the presence or absence of various risk/vulnerability factors and protective factors, in conjunction with the stage or transition the family are in. Hetherington, Bridges & Insabella’s (1998) transactional model will be briefly reviewed as this draws together many different perspectives that have been taken in exploring adjustment post-divorce.

A number of risk factors and protective factors will be highlighted before focussing on two of these factors in particular: marital conflict, and disruptions to family relationships. I have chosen these two for a number of reasons. In discussing marital conflict, it is possible to clearly see how a risk factor associated with divorce can be viewed as more detrimental to a child’s well-being than the divorce itself. And it is by looking at marital conflict that the argument for divorce being a ‘good’ thing may be
clearly made – in freeing a child (and parent) from the effects of conflict. In addition, marital conflict can severely impact on the child-parent relationship (Riggio, 2004), another postulated key factor in predicting adjustment post-divorce.

Family relationships are of central importance in the transactional model presented by Hetherington et al (1998). It is postulated that the divorce process, with or without high conflict, can have an impact on child-parent relationships and indeed that most factors have their influence via their impact on family relationships. Good child-parent relationships are consistently reported to be a significant buffer for the effects of the divorce process on a child’s well-being. In addition, discussions based on this will facilitate discussion of the child’s relationship with the non-custodial parent – most often the father.

Children’s Stories
The children’s stories in Krementz’s compilation report a wide range of experiences and their responses vary greatly, with each child telling a very different story. All express a certain amount of sadness at the time their parents formally separated or at the time when they first found out, and all refer to these events as negative in some way. Some children reported feeling very angry at witnessing or being drawn into arguments between their parents. On the other hand, others report feeling that divorce was the right thing to do, and that they noticed big changes in their parents (for the better) since the divorce. Especially notable is that in some of the narratives there appears evidence of a positive outlook or resiliency, and an attitude that the separation was painful back then, but now it’s OK. In one or two cases, the situation is reportedly better than before.

On reading some of these narratives, one might conclude that parental divorce had many negative consequences for the child. However, this may be ignoring the positive elements (one child wrote of feeling more independent now; that if he wants to escape from one parent for a while he can go and stay with the other; and that he believes it was nobody’s fault that his parents separated). In addition, painful recollections also say little about current well-being and adjustment.
As each person and family is unique, the impact of divorce will inevitably be different for any given child, and much will depend on their particular situation. Zimiles (2004) states that researchers have called for attention to be placed on the ‘uniqueness’ of the divorce experience and how:

“...the outcome of divorce is played out by an almost infinite number of individually defined traits, perceptions and circumstances that impose limits on the lawfulness and level of generality that may be expected” (p.245).

However, these positive outcomes, or resiliencies are not always picked up on in the research literature and controversy continues over how severe the potential effects of divorce are to a child’s well-being.

Controversy
Judith Wallerstein’s research has been very influential in how researchers, practitioners and policy makers have understood the impact or ‘legacy’ of divorce (Brayer & Cookson, 2003) yet her work has been at the centre of controversy for many years. In recent years, a number of longitudinal studies have been published with very different implications regarding the long term impact of divorce. Where some researchers highlight evidence of the resiliency of children, others (like Wallerstein) emphasis the pessimistic nature of the evidence they found. This controversy becomes especially salient in relation to informing policy makers, as courts and legislatures look to research in order to update policy and instigate reforms (Brayer & Cookson, 2003).

In a report on their 25 year longitudinal study, ‘the unexpected legacy of divorce’ Wallerstein and Lewis (2004) strongly argue that divorce is an extremely undermining experience, affecting a child well into adulthood in terms of anxiety, depression, and their ability to reach their full potential. Divorce is said to be of detriment to a young adult’s ability to form lasting committed relationships:

“At young adulthood, when love, sexual intimacy, commitment and marriage take centre stage, children of divorce are haunted by the ghosts of their parents’
divorce and are frightened that the same fate awaits them. These fears, which reach a crescendo at young adulthood, impede their developmental progress into full adulthood... They have a great deal to learn about the give and take of living with another person, about how to deal with differences, and about how to resolve conflict” (p363).

These authors continue in this fashion and paint a very bleak picture of divorce. Their conclusions are based on clinical interviews conducted by experienced clinicians, individually guided and analysed within a psychodynamic framework. They suggest their study stands alone in it’s qualitative study of each child within his or her family over several decades.

While this approach may be deemed useful by some in facilitating an exploration of experiences as complex as divorce-related events and their subjective meaning to the individual, it will inevitably be hard for those who value adherence to scientific principles to accept. It may be that this exploratory approach was more useful when the study was first initiated 25 years ago, when less was known about the impact of divorce.

On reading their conclusions, it is difficult to ascertain how these are more than highly subjective interpretations or sweeping generalisations that are focussed from the start on the negative and the pathological. As Brayer & Cookson (2003) point out:

“If the clinician is searching or ‘pulling’ for pathology, she or he is far more likely to ‘find’ it, than is another clinician working with the same client who assumes that the respondent or family is highly functional and healthy” (p. 315).

This subjectivity is fuelled by a lack of objective data and statistical analysis and the absence of any standardized measures of current psychological functioning. In addition, the data is reported in merged interpretations or themes making it difficult to assess the accuracy of these, or how they were arrived at.
These authors have also been criticised for using a relatively small sample, disproportionately consisting of upper-middle class families, as well as troubled and dysfunctional families (Kelly & Emery, 2003). The families in this study were originally recruited via local family courts and were experiencing relationship problems. The exclusion criteria for children included failing to achieve academic and developmental norms, and having been referred to counselling, and Wallerstein and Lewis concluded that this constitutes a ‘psychologically sturdy group’ from the outset. However, this conclusion seems a little premature given the absence of any standardised measures, and the problems being experienced at home.

Hetherington, Bridges & Insabella (1998) represent another viewpoint. They argue that the vast majority of children from divorced families do not have these problems in the long term, and eventually will develop into functioning individuals within the normal range of adjustment. While acknowledging that children often report divorce as the most painful experiences in their lives, these authors point to the research evidence that supports the ability of most children to cope with parental divorce and remarriage and that “counters the position that children are permanently blighted by their parents marital transitions” (p.170).

Hetherington’s Virginia study (1993) was initially set up as a comparison of a group of over 70 ‘divorced’ families with an equal sized group of ‘non-divorced’ families with 4 year old children. These were followed up a number of times post divorce: at 2, 6, 12, and 20 years. However, the complexities of longitudinal research are highlighted by the changing nature of Hetherington’s groups at each follow up. By their last assessment over two thirds of the divorced mothers had remarried and nearly half of the non-divorced families had since divorced. These are important family transitions resulting in some people changing group, or new groups emerging (‘remarried’), highlighting the artificial nature of these groupings.

The findings of this study were that at 2-years post divorce, children showed declining academic performance, social and emotional adjustment problems in school, higher levels of anxiety and depression, and more anger and angry outbursts than their counterparts in the non-divorced group. However, at 6-years post divorce, these
behaviours or reactions were no longer evident in over 70% of the children, while the remaining children continued to show difficulties years later.

Consistent with the finding that the impact of divorce may be less than previously thought are the results of a meta-analysis of 92 studies that compared children from divorced, and intact, families (Amato & Keith, 1991). The basic conclusion of this study was that children from divorced families scored lower on a number of outcome measures (i.e. academic attainment, conduct, self-concept, psychological adjustment and social competence). However, the effect sizes (and therefore the differences between groups) were small. Interestingly, studies carried out in the 1980s had smaller effect sizes than in earlier years which the authors suggest may reflect the more socially acceptable nature of divorce over time.

Painful memories and current adjustment

A way of reconciling some of the variability in the above studies is to distinguish between the memories of painful events, and current levels of adjustment. Kelly & Emery (2003) suggest that while painful memories may be a ‘lingering and lasting residue of the divorce process’, an individual can still continue to function without current psychological symptoms or pathology. In other words, good psychological adjustment and painful memories can co-exist. Thus, research designs that explore an individual’s memories of painful experiences, should not portray these as indicative of poor psychological adjustment.

In support of this, Laumann-Billings & Emery (2000) found that ‘well-functioning’ college students also reported continued pain and distress about their parents divorce, reporting more painful childhood feelings (of loss mainly) and increased worry. They did not however differ on standardised measures of depression and anxiety from a comparison group of students in still-married families, nor did they blame themselves for the divorce with 80% feeling that it was the right thing for the parents to have done.

However, it may also be argued that adjustment does not equate to being untouched by the experiences of the divorce process. Being able to work, or attend university for
example, and scoring in the ‘well-adjusted’ range of scores on a psychological measure may not necessarily indicate that young adults are not, as Wallerstein & Lewis (2004) put it: “haunted by the ghosts of their parents divorce” (p.363).

Theoretical perspectives
A useful summary of the many views that have been used to explain the adjustment of children following divorce is made by Hetherington et al (1998), who distinguish between five main perspectives. The first perspective relates to individual vulnerability and risk, where characteristics of the children may make them more vulnerable or protected from the risks associated with divorce. The second perspective questions family composition and parental absence with increased risk being associated with a deviation from a family structure with two married parents who are biologically linked with their children. The third perspective explains increased risk in terms of the stresses experienced by the divorcing family (including socio-economic hardship). A forth perspective of adjustment to divorce in children is the parental distress perspective, which advocates parental response to the stresses of divorce as the most important factor, via diminished parenting capabilities. The last perspective relates to disrupted family process and proposes that divorce brings with it many changes in family roles and functioning. The impact of the above risk factors (i.e. parental distress, stress, individual attributes) is mediated by disruption to family relationships. In other words, without a disruption to family functioning, the risk factors mentioned are less likely to have an impact on the child’s well-being.

In weighing up the evidence for each perspective, Hetherington et al (1998) conclude that all of these are important contributors to a child’s adjustment though the relative contribution of each perspective (of individual characteristics, parental distress, etc) remains unclear and attempts to address this have led to conflicting results. They suggest this may be because the variance explained by each study differs by the sample used, the methods employed, and because different risk or vulnerability factors come into play at different points in the process of divorce/remarriage. In turn these risk factors will be magnified or buffered by varying and shifting protective factors. These principles form the basis of the ‘transactional model’ they present.
Mediating and Moderating Factors
A number of factors have been reported to be important in the mediating effects they have on the relationship between divorce-related events and adjustment. Some may be usefully thought of as important in terms of predisposing factors or factors that are important at early stages of the divorce process: age, attachment difficulties, parental conflict, diminished parenting abilities and parental mental health, socio-economic factors; while other factors may be thought of as especially important in maintaining lower adjustment levels post-separation: passive coping style, negative cognitions about divorce, guilt, fear of losing non-custodial parent, continuing conflict, permissive parenting, loss of peers and extended family, diminished social network, high levels of family stress, moving home (see Amato, 2000 for review). The list could go on.

The impact that such risk factors have, may vary depending on various protective factors (Hetherington et al, 1998). These could include: being older, female, having positive 'illusions' or attributional bias, co-operative parents, secure attachment with both parents or one parent, understanding of divorce as a shared family problem, regular contact with non-custodial parent, good social support and the ability to reconstruct social networks (see Leon, 2003). Again the list of possible protective factors could go on.

It would be difficult to do justice to all of these factors given the limits of this essay and any discussion of the relative contributions of each is likely to be difficult, given their interactive and transient natures (Hetherington et al 998). Instead, two areas have received particular attention in the literature and these shall be discussed: Marital Conflict, and Family Relationships.

Marital conflict
Marital conflict has been consistently reported to be a strong predictor of adjustment in children (Ayoub, Deutsch, & Maraganore, 1999; Kelly 2000), and this has been shown to be the case regardless of marital status (Amato & Keith, 1991).
Amato & Keith (1991) report evidence that children in intact families with high-conflict are no better off than high-conflict families who divorce, suggesting that marital conflict is more strongly associated with adjustment in children than divorce. In support of this is the finding that when marital conflict stops after separation, children from divorced parents have been shown to be as well-adjusted in the years following divorce as children from intact families (Ayoub et al, 1999).

Different aspects of marital conflict have been identified as important (i.e. frequency and intensity of conflict, parental conflict style) and there is some debate over which factors have more significance (Kelly 2000). For example, Buehler, Krishnakumar & Stone (1998) report an association between openly hostile conflict styles between parents, and negative behaviour in children, both externalised and internalised, more so than for covert conflict style (i.e. passive-aggressive, resentment), and frequency of conflict. Witnessing domestic violence and continuing hostility post-separation between parents is consistently reported to be a predictor of poorer outcome among children (Amato, 2000).

Oppawsky (2000) uses quotes and art work from children aged 3 to 18 years, with the aim of ‘explaining’ their reactions to their parents ‘bickering and screaming’. This study therefore represents an effort to present the views of children. The reactions reported by them included increased crying, sadness, shame of ‘the family situation’, anger towards the parents, becoming absent-minded, falling behind at school, and fear (of losing contact with non-custodial parent, and having no control over situation). Oppawsky concludes:

"From the view of these German children, reducing parental strife was the most significant thing parents could do to reduce and/or ameliorate their trauma from the divorce crisis. When this was achieved by the parents, severe reactions were reduced and the children regained much of their equilibrium" (p.146).

In order to abstract the main themes, Oppawsky groups quotes from the various stories she obtained into a number of themes, and these are therefore open to her subjective
interpretation. In addition, no attempt to describe the children involved in this study is undertaken.

Kelly (2000) distinguishes between the direct and indirect impact of marital conflict on well-being in children. Children may directly model parental behaviour, or may fail to learn more appropriate ways of dealing with social situations. The conflict resolution-style of the parents may therefore be important. Indirectly, marital conflict may undermine the quality and amount of parent-child interactions. For Kelly & Emery (2003), parenting styles may be affected by high conflict marriages with mothers becoming less warm, more rejecting and depressed, while fathers become more withdrawn and exhibit more intrusive style interactions with their children.

Riggio (2004) reports on a questionnaire study of 566 young adults from divorced, and intact families. Divorce and conflict were found to have significant independent effects on outcomes. Conflict had a negative effect on the quality of parent-child relationships and on perceived social support and anxiety. However, divorce was only negatively associated with poorer father-child relationships. Interestingly, divorce was associated with positive outcomes for mother-child relationships, social support and independence being facilitated by both parents. These were regardless of gender, or parental remarriage. This adds further weight to the argument that divorce, per se, is not necessarily detrimental to children, or to the mother-child relationship, but that marital conflict can have negative effects on a child’s relationship with both parents.

**Disruptions to family relationships**

Moxnes (2003) reports on interviews conducted with 114 adults and 96 children from a wider study conducted in Norway. Children were asked to tell their divorce story and asked to elaborate on a number of topics in terms of how they experienced them: decline in household income, change of residence, lack of daily contact with one parent, acquiring stepparents. It is unclear what adults were asked yet comparisons between adult and child responses continue throughout the results and discussion. 52 of these children were selected on the basis of having experienced the most change and the general themes to emerge are described in the study. From the responses given by the children it is stated that overall, even though the divorce process is stressful and
causes a loss of capital for most, the crucial determinant of a child’s well being is whether they retain a close relationship with family members and keep their family.

Moxnes study found that the majority of children talked about an improved relationship with the residential parent post-divorce. They had got to know their mothers more, and mutual respect had increased. The reports were not all good however, and a minority of children reported that their residential parent had not coped well and that they felt abandoned, that they knew the support they need would not be there. One child reported having to ‘mother’ her own mother.

Indeed the deterioration of the child-parent relationship may be further impacted by the poor adjustment of the parent post-separation. A custodial parent may no longer have the buffering support of a partner, at a time when a child is adjusting and may require extra time and resources. They may themselves be depressed, anxious or experiencing other mental health problems and may be preoccupied with their own emotional responses to the separation. The task of providing appropriate parenting at this time sounds far from easy:

“When custodial parents provide appropriate emotional support, adequately monitor children’s activities, discipline authoritatively, and maintain age-appropriate expectations, children and adolescents are better adjusted compared with divorced children with less appropriate parenting” (Kelly 2000, p.969).

An interesting study looking at the longer term impact on child-family relations was carried out by Amato & Sobolewski (2001). They report the findings of a 17-year longitudinal study that tested a number of pathways between martial separation and discord in childhood, and subsequent well-being in adulthood. Their results indicate that for fathers, divorce was associated with more negative father-child relations in adulthood, regardless of pre-divorce marital discord and pre-divorce father-child relations; whereas for mothers, the effects of divorce on mother-child relations were mainly accounted for by pre-divorce marital discord only. This echoes findings to suggest that divorce per se may not have a huge impact on a child’s relationship with
their mother (generally the custodial parent) while the opposite is true for father-child relations.

Amato & Sobolewski (2001) highlight the long term implications of marital discord on parent-child relations. Using structural equation modelling, they tested a number of causal models, with the results suggesting that marital problems in childhood are related to weakened parent-child relations in adulthood, and these weak relations in turn, place the young adult at risk of distress and low self esteem. This continuation of weak bonds between parents and their children into adulthood, is taken by these authors as helping to explain why psychological difficulties associated with divorce and marital discord do not go away in some people. This would also suggest that the life of a parent and a child are linked throughout the life course. These children may lack the support of parents (and extended family) as they go through important stages of life.

The above study suggests that the father-child relationship may be especially vulnerable to the impact of divorce. Many fathers are reported to spend less time with their children post-separation and a variety of reasons have been put forward for this: that there are ambiguities as to the visiting parents role; that the child chooses not to see his/her father; legal constraints; that visiting every other weekend is too emotionally distressing; and mothers’ remarriage may present an obstacle (Kelly & Emery, 2003).

Ahrons & Tanner (2003) interviewed 173 adults 20 years post-divorce, about their relationships with their fathers. Sixty-three (of which the majority were girls) reported that their relationship had got much worse post-separation suggesting the father-daughter relationship is especially vulnerable. Father’s remarriage was often cited as the reason for the deterioration. However, the majority of children in this study (62%) described relationships with fathers as having stayed the same or got better. This was largely attributed to either the divorce process (i.e. saw more of their fathers due to custodial arranged times) or because of maturation (i.e. developing new ways of relating to each other). Early post-divorce involvement was the best predictor of the relationship between child and father continuing to get better over time. However, this
study was based on a sample of middle class white American families, and may not therefore represent other populations.

**Conclusion**

To conclude, while some researchers have claimed divorce to be uniformly 'bad' for children, there is insufficient evidence to back up this claim. In fact, one need not look too far to find children who are exceptions to this and function (at least externally) very well. If one is asked to dwell and elaborate on a negative area of life, while a listener expects to hear the negative and focuses in on it, it is not difficult to see how a bleak picture may emerge that does not necessarily reflect the reality for that person. Indeed, it may well be that the memories of a painful time are there, but the individual has managed this in the past, and gets on with life, adjusting well.

Some argue that the divorce process may actually be a ‘good’ or positive thing, bringing relief from the stresses or conflicts involved in a marriage, and a second chance for happiness. However, there appears little evidence for this too. Most researchers acknowledge that divorce brings with it many potential risks and vulnerability factors that a child and his/her family may not otherwise have to deal with.

Children who experience a parental divorce may report a variety of responses, 'good' and 'bad', neither or both. As Amato (2000) states:

> "Divorce benefits some individuals, leads others to experience temporary decrements in well-being that improve over time, and forces others on a downward cycle from which they might never fully recover" (p.1282).

It is clear from the research literature that some risk factors are particularly salient (i.e. parental conflict) as consistent predictors of negative outcome in children. It is also clear that of particular importance is the threat the divorce process, and conflict, place on the child’s relationship with family members.
With a process as complicated as divorce is, the potential to generalise particular risk factors to everyone is understandably impeded and an emphasis on the individual and their particular situation, and resources, is required. In reading stories written by children of their actual experiences of the divorce process, all are different, yet many relate sadness, confusion, and a lack of control over numerous unwelcome changes. In relating their stories they also raise many positive aspects of these sad events and it is to this resiliency that more attention would be useful.
References


What psychological models, theories and practices are helpful to clinical psychologists when working with instances of suspected and/or actual abuse of older people?

August 2005

Year 2
Introduction

Marriot (1997) points out that psychological issues are of relevance to almost all aspects of elder abuse and even the most situational aspects of abuse are potentially mediated by psychological factors. It is possible to look towards many psychological ideas in thinking about what is useful in working with people in general, and evaluate how useful these are in instances of abuse (suspected or actual). The choice of what to discuss in this essay is made slightly simpler by a lack empirically supported research that is specifically aimed at elder abuse. However, several specific models and theories have been put forward and some of these will be explored within this essay. The term ‘elder abuse’ is used most predominately in the literature to indicate abuse of older people and shall be used here.

Pillemer and Finkelhor (1988) found most cases of elder abuse appear to occur within a family context. Their survey of a community sample found 58% of abusers were reported to be spouses, 24% were adult children, and 18% formed a category of ‘other’. It is a little unfortunate that the ‘other’ category merged other family members (i.e. grandchildren, siblings) with non-family members (i.e. boarders) as this blurs the total proportion of abusers that are family relations. Regardless, the study showed that over 82% of cases were within a family context. The most commonly reported perpetrator – victim relationship involved wives as the abusers of their husbands (36%) followed by husbands as the abusers of their wives (22%), although women were reported to suffer the more serious abuse. As a second year trainee, I have recently been working with a client on my current placement (i.e. working with older adults) where a suspicion of an ‘abusive relationship’ was raised by a team member. Because of this, I have been somewhat biased in reading around this essay towards issues relating to abuse in a family context.

Bradley (1996) describes a sequence of identification, assessment, and action that is usually followed by staff working with instances of elder abuse. This essay will involve starting with a discussion of various models and theories that are pre-dominate in the literature on elder abuse. It will then focus on issues that might be salient at different stages of working with instances of elder abuse, beginning with identifying abuse. An emphasis on working within a multi-disciplinary team setting will be made,
followed by an exploration of the psychological issues relevant during assessment. How various models and theories may be effectively integrated and applied will be reflected on in relation to formulating. The focus of the essay will then turn to psychological ideas and practices that are potentially useful in terms of providing interventions.

Unfortunately, the focus of this essay will be at the expense of other areas and one omission is a focus on institutional abuse. One reason is my experience on placement which has been within a family context. Another reason is that very little research has been conducted looking at abuse in institutions (Tonks & Bennet, 1999). In addition, institutional abuse is likely to have very different dynamics and causes compared to abuse in other settings (Lachs & Pillemer, 2004).

In terms of prevalence, there is general call in the literature for further refined methods of gauging the frequency of elder abuse. For the purposes of this essay it is sufficient to say that “elder abuse is common enough to be encountered regularly in daily clinical practice” (Lachs & Pillemer, 2004, p.1264). Psychological theories will inevitably be useful in thinking about certain methodological problems in research attempts to establish prevalence (i.e. people’s willingness to disclose, consent issues) but this is beyond the scope of this essay.

**Definitions and perceptions of abuse**

There is no standard definition of elder abuse in the UK. Defining abuse is made difficult by the fact that the phenomenon of abuse is multi-faceted and may encompass very different behaviours. In addition, people may interpret definitions in various ways and have different perceptions of what constitutes ‘abuse’. The Department of Health’s document on protecting ‘vulnerable adults’, No Secrets (2000), offers the following definition of abuse:

“Abuse may consist of a single or repeated acts. It may be physical, verbal or psychological, it may be an act of neglect or an omission to act, or it may occur when a vulnerable person is persuaded to enter into a financial or sexual transaction to which he or she has not consented, or cannot consent. Abuse can occur in any
relationship and may result in significant harm to, or exploitation of, the person subjected to it” (p.10).

Lachs and Pillemer (2004) report that within the general framework of elder abuse, there is now some agreement on the type of actions that are covered by the term and they list five types of abuse: physical abuse, psychological abuse, sexual assault, material exploitation and neglect. However, given the wide variety of situations where abuse may occur, some authors have questioned the feasibility of achieving a single category or definition of what might be several different problems (Ogg & Munn-Giddings, 1993).

The usefulness of a definition may depend on its interpretation by the parties involved and psychological ideas may aid an understanding of individual differences here. Even where clear definitions are available people may still make their own interpretations based on their prior experiences, perceptions and beliefs, especially when the situation is less clear cut (Marriot, 1997). Perceptions and definitions of abuse may therefore differ between professionals and service-users, and also within these groups.

This is especially highlighted when working with people with different cultural backgrounds. For example, Moon & Williams (1993) found significant differences between 3 groups of American elderly women with different cultural backgrounds, on their responses to 13 scenarios of elder abuse. The three groups differed in their perceptions of whether a situation was abusive or not, and also in their intended use of formal and informal sources of help.

While this study used only a relatively small sample (all women) it does illustrate the influence cultural context can play in perceptions of abuse, and help seeking behaviour. Indeed, concepts of what constitutes ‘old age’ generally will vary between cultures. Definitions may be constructed according to various factors, such as chronological age, ability to work, or social performance (Dein & Huline-Dickens, 1997).

Models of elder abuse
Several models have developed in attempts to understanding and explain elder abuse and all contain some discussion of psychological factors (Marriot, 1997). Elder abuse has been conceptualised as a response to the overwhelming stress of care giving: the 'situational model' (Philips, 1986). It is not difficult to imagine how adult children of older adults, who might be faced with their own issues of ageing at the same time, may become overwhelmed by having to care for a dependent older family member. It is possible that their situation might be made worse by conflicting roles, if the carer feels the needs of their spouse or children are being subordinated to those of the older family member. This model fits with ideas from the child abuse literature (Wilber & McNeilly, 2001).

One problem with this model is the issue of dependency in light of evidence to suggest that dependency may potentially work the other way: that an abuser may be dependent on the person they abuse in some way (Pillemer & Finkelhor, 1989). Ogg & Munn-Giddings (1993) conclude that it is perhaps best to think of an imbalance of power in either direction as a potential risk factor. Generally, empirical evidence has not supported the idea that increased levels of caregiver stress are associated with abuse directly (Wilber & McNeilly, 2001). This might well be because psychological factors have been overlooked, that mediate the relationship between increasing carer duties, and the stress experienced by the carer. What the increase in caring tasks actually means to the individual carer might therefore be more important.

A client I have been working with has witnessed a rapid deterioration in her husbands cognitive functioning and this has been associated with high levels of stress and anger on her part. Following a particular discussion with her, it was hypothesised that the meaning of this deterioration to her was partly that she felt that she now has to face a future alone without the support of her husband. In addition, the wife had played a significant caring role in the past for a family member and accepting the current deterioration of her husband meant accepting the role of carer once again. This is a more complex picture than that portrayed by the situational stress model alone. Another approach has been to emphasis the psychopathology of the abuser. Several studies have suggested that mental health difficulties or alcohol and substance misuse are related to abuse (Homer & Gillear, 1990). It is unclear whether alcohol leads to
abuse through decreasing inhibitions, or whether it is a strategy for coping with the burden of carer responsibilities. Research has appeared to consider this model too simplistic (Giordano & Giordano, 1984). However, it appears that abuse has been linked more to the characteristics of the abuser, than to characteristics of the abused. For example, in developing a screening tool for elder abuse, Reis & Nahmiash (1998) isolated 29 abuse indicators from a checklist of 60 items relating to caregiver and care-receiver. The 29 indictors, differentiating abusive from non-abusive relationships were divided into three groups: intra-individual caregiver problems (e.g. mental health, alcohol or substance misuse), caregiver interpersonal problems (e.g. poor relationship with care receiver) and care receiver social support shortages and previous abuse. The pathology of the abuser was found to be the most significant risk factor in this study.

Marriot (1997) adds that research that has attempted to implicate the characteristics of victims of abuse, has produced inconsistent results partly because there are “few elder characteristics which are intrinsically determinants of abuse in themselves” (p. 130). Instead, she suggests that various psychological factors related to the way that the abuser perceives, understands and responds to the victim’s characteristics are important.

In the example of the client I have been working with, a suspicion of abuse was raised by the team member who had carried out the initial assessment, and framed entirely within a ‘caregiver stress’ framework, or the ‘situational model’. However, as more detail came to light during the subsequent assessment it was reported that others had noticed a ‘personality change’ in her husband. Several researchers have highlighted a potentially important association between caregiver aggression and care-receiver aggression: sometimes termed a ‘double directional’ model (Wolf & Pillemer, 1989). Theories that emphasis intra-individual dynamics direct attention at the individual level, taking responsibility away from the system and from potentially important social issues relating to access to resources. Ogg & Munn-Giddings (1993) suggest that models of elder abuse have generally emphasised characteristics of individuals and families at the expense of wider sociological factors that are essential to a fuller understanding of elder abuse such as race, class, gender, poverty, and ageism.
Another theory that has been put forward to help explain elder abuse is social exchange theory. This theory is based on the idea that people in a relationship expect the things or rewards they provide to others to be reciprocated in some form. In non-family contexts, if reciprocity is no longer obtained the relationship is likely to end but families provide instances of exchange where it is not feasible to end a relationship (Suitor & Pillemer, 1988). Abuse may occur as a result and other forces (i.e. ageism, poverty, etc) make it difficult for a person to obtain exchange resources, or create alternative relationships. Evidence in relation to dependency however suggests that social exchange theory may be reversed in some research findings. For example, Wolf & Pillemer (1989) found that financial dependency of the abuser on the person is a risk factor for abuse. An interpretation of this by Wilber & McNeilly (2001) is that a feeling of powerlessness might be compensated for by abusive behaviour.

Another model that has been postulated to be important in understanding elder abuse is the trans-generational violence model which is based on principles of social learning theory. Briefly, this model suggests that abusers learn violent behaviour within the family, where violence is seen as an acceptable means of responding to stress. Abusers may grow up to re-enact the parent child cycle of violence, or become caregivers that seek some form of revenge or retribution for the way they were treated (Philips, 1986).

This theory is reported to have gained popularity because of the evidence that has acquired for it within the family violence literature (Wilber & McNeilly, 2001). However, in a review by Kingston & Reay (1996) of six studies that made use of a control group, no support was found for this theory. An alternative is put forward by Homer & Gillear’d’s (1990) study, where a long history of abuse was found to be a significant risk factor for elder abuse, often predating any disabilities or dementia. These authors conclude much of the reason for abusiveness, whether it is the spouse or the adult child who is the abuser, lies in the relationship rather than in the external circumstances or dependency of the abused person. They therefore conceptualise abuse as involving the “elderly graduates of domestic violence” where difficulties are exacerbated by changes associated with ageing (Homer & Gillear’d, 1990, p.1361).
No single theory appears to have received a great deal of support in the literature. The diversity in types and situations of abuse suggests that no one theory will be able to explain elder abuse adequately anyway. Instead each model provides a different perspective, or highlights the importance of a different aspect of the abuse, and may be helpful in generating hypotheses that are relevant to the individual case. Taken together they may usefully provide ways to better understand the behaviours of the perpetrator, the various risk factors affecting the victim, and the dynamics of the relationship between the perpetrator and the older adult victim.

Psychological issues around identifying abuse

**Team Work**

Suspicions of abuse may already have been raised by the time a person is referred to a psychologist. This was the case for the lady I am currently working with, where the staff member who had completed the initial assessment fed back her concerns to the multi-disciplinary team within which we work. In this case, the staff member felt confident enough to raise her suspicion and ask for opinions from her team. The team provided a source of different opinions and perspectives and a consensus was reached as to how to move forward with the client above. As part of this, it was decided that a psychological assessment might be useful. The findings from the psychology assessment were subsequently fed back into the team for further, albeit brief, discussion and the team provided a place for a shared discussion of this.

However, in some cases the influence of a team or group may not necessarily be positive and Marriot (1997) looks to social psychological models as a way of understanding the potential for groups to have a negative influence on the identification of elder abuse. She points specifically to social impact theory (Latané, 1973). This postulates that people make less effort if they are in a group than if working independently. In relation to working with elder abuse, being part of a team may mean that individual professionals feel that risk and responsibility is shared by the team which leads to less effort being made by each member. Other psychological aspects of group behaviour, such as conformity or compliance, (Tesser, 1995) may influence whether a professional raises particular concerns about abuse within the team and these may be related to issues of power (i.e. perceptions of status, duration
of team membership). An understanding of group processes might therefore be important if one is to minimise the influence of the group on the individual and prevent failures in identifying or openly discussing abuse.

Staff Cognitions

Taylor & Dodd (2003) interviewed 150 professionals from a variety of backgrounds (i.e. health and social services, police, nurses) and found substantial gaps in professionals' knowledge of abuse. Also, the majority of staff reported a lack of confidence in identifying abuse, with 75% of staff saying they would only report abuse if they had concrete evidence for it (i.e. bruising or an injury). The organisation ‘Action on Elder Abuse’ argues that all health professionals need to be able to feel confident to detect and manage suspected abuse, where the factors involved are complex and may require an early detection of warning signals.

Attributional processes may also interfere with the identification of abuse and theories like the ‘Just world theory’ (Lerner & Miller, 1978) may be helpful for psychologists to understand how abuse may be missed in some cases. According to this theory, people have a strong desire or need to believe that the world is a predictable and just place where people get what they deserve. This helps individuals to assume predictable consequences from their actions. However, when we encounter evidence suggesting that the world is not just, as might be especially the case of an adult child abusing their parent, we quickly act in ways to restore our view, perhaps by persuading ourselves that nothing unjust has occurred (Andre & Velasquez, 1990). This process may therefore serve to bias a person’s view of whether or not abuse has occurred.

Making a decision about whether an incident constitutes abuse can be difficult, and may involve both moral and ethical aspects. Brown & Keating (1998) explain that a person needs to make a moral judgment about what is right or wrong and needs to define the incident or circumstances as abusive. Ethical considerations are required around how we, as professionals, make appropriate well-informed evidence based decisions that maintain and inform professional standards.
Assessment issues

Kingston & Reay (1996) point out that working with instances of abuse requires a full comprehensive assessment of the person’s situation and they provide a list of areas that need to be covered in an assessment. These include obtaining an account of the abuse, the survivor’s behavioural and cognitive coping strategies, the intent of the abuser, and the reasons or meaning that is attributed to the abuse. An account of the psychological problems and history of both the abuser and the victim needs to be considered. As abuse most frequently occurs within a family context (Pillemer & Finkelhor, 1988), an assessment of the quality of relationships within the family and especially between the abuser and the victim, is desirable. Social exchange theory would suggest that an assessment of the power balances within the family would be important.

Kingston & Reay (1996) suggest that assessments in instances of elder abuse may take longer than in other instances. Survivors of abuse may take longer to engage as there might be a reluctance to talk about the problem. In addition, people who have suffered a long history of abuse may never have talked about their situation or the thoughts and feelings they have about this. Marriot (1997) advocates the use of behavioural analysis as a means of helping to structure an assessment, where obtaining information about the abuse has become difficult. This is based on the premise that a simple behavioural analysis will not ask in any depth about the person’s thoughts and feelings about the event, but will focus more on obtaining an objective account of the antecedents, the behaviour, and its consequences. This might be of use when the person is finding it emotionally difficult to talk about certain issues and it may help as a starting point for a more detailed conversation.

Brown & Keating (1998) describe that a key component of the Care Programme Approach is the systematic assessment of health and social care needs and that integral to this approach is a full risk assessment, covering risk to the client him/herself, and risk to others. This will include assessing the possibility of other victims or risks to others, and whether the person is still at risk of abuse. Assessing the seriousness of abuse is essential and will involve exploring the extent of the person’s
vulnerability (i.e. how isolated they are), the extent of the abuse, and the impact of the abuse on the individual’s well being.

Another consideration in assessment is going to be the capacity of the person involved. Questions around the person’s ability to make their own decisions, and make use of relevant information to weigh up the pros and cons of a decision will be important. If deemed incapable of decisions, questions around who will act in their best interests will need to be considered and this will be informed by the outcome of the team’s assessments. An awareness is needed that it might not be cognitive deterioration, for example, that is affecting a person’s decision making abilities, but the fact that they have been abused.

**Formulating**

The Division of Clinical Psychology’s (2001) Core Purpose and Philosophy of the Profession states that formulating is a central part of the practice of clinical psychologists. Formulating involves drawing on a number of different explanatory models so that a formulation may comprise of several provisional hypotheses. However, an uncritical use of formulating may be unhelpful in working with instances of abuse. For example, as a person’s narrative or story unfolds in therapy, a formulation of a client’s situation needs to be constantly adapted. Crellin (1998) suggests that in psychotherapy for example, formulation may only be possible at the end of a long therapy. She adds that because of the power that is held by a position of ‘expert’, an early (and incomplete) formulation by a therapist may become ‘fixed’ and have the appearance of being ‘right’. From this point of view, Crellin reminds us that formulation is a dynamic process that is continuously revised but she warns that “an intuitive piece of informed guesswork may be all that we can claim to have” (p. 26).

The complexity of working with cases of suspected or actual elder abuse may benefit from a flexibility in approach to formulation which would facilitate the integration of relevant psychological ideas and theories. From a social constructionist perspective, Harper & Moss (2003) suggest that formulations be seen as ‘stories for therapists’ and as ‘perspectives’ that are constructed for particular purposes in a particular context.
They state that:

“good theories are, after all, often very good stories – it is about emphasizing that those theories are servants of a larger engagement in collaborative ‘sense making’ rather than masters of a scientific eye whose gaze assumes a questionable objectivity over a person’s experience” (p. 8).

Particular ways then, of thinking about formulating may facilitate the use of the above psychological ideas and their integration and application when working with instances of elder abuse.

**Issues around intervention**

Writing just 15 years ago, Homer & Gilleard (1990) described the general pattern then, of interventions in cases of elder abuse:

“As there is no legal requirement in Britain to notify cases of abuse the usual response is to offer respite care on an inpatient or day care basis, increase the input from formal services, and monitor the situation. If this fails, then the old person is often removed from his or her home (even when it is thought that the carer should be the one to leave)” (p. 1362).

Their study goes on to question the use of increasing the input of formal services as few carers in their study expressed the desire for increased support. They reported that it was not the physical or personal aspects of caring that caused distress, but the socially disruptive and abusive behaviour they experienced. Homer & Gilleard conclude that a clinical psychologist can play an important part in efforts to change either the behaviour of the patient, or improve the coping skills of the carer.

A client attending for therapy may find it extremely difficult to talk about the abuse for a variety of reasons and the sessions with a psychologist may represent the first time the client has been heard individually. As always, establishing a good therapeutic relationship will be important (Roth & Fonagy, 1996). This may be made especially salient in working with an individual who has suffered potentially years of abuse and disempowerment. It might therefore be useful for psychologists working with
instances of abuse to remind themselves of the skills and attitudes that can facilitate a strong therapeutic relationship. A Rogerian client-centred approach to therapy aims to maintain the focus of therapy on the client's phenomenal world (Rogers, 1966). This kind of approach alone may be of benefit to clients who have had years of abuse and disempowerment.

Each of the psychological models and theories of elder abuse discussed earlier may help to inform the intervention that is provided. For example, the situational model would recommend an intervention aimed at reducing the source of stress, providing respite, and giving support to the carer. This might include psycho-education and stress management techniques. The 'trans-generational model' or 'double-directional violence model' have implications for working with the family. As elder abuse often occurs within a family context, the usefulness of applying systemic principles and a family therapy approach have been discussed as potentially important (e.g. Kingston & Reay, 1996; Homer & Gillear, 1990).

The type of intervention selected will also depend to a large extent on the type of abuse. In addition, any intervention that is chosen needs to avoid stereotyping the older person and should be based on information gathered via a comprehensive assessment procedure (Kingston & Reay, 1996). In any intervention, consideration of the person's cultural context will be essential. An awareness of how the abuse is defined, perceived and understood, and the client's ideas about how best to deal with the situation, will be crucial in tailoring an effective intervention that is acceptable to the individual in their family and social context (Dein & Hulne-Dickens, 1997).

One of the few studies to attempt to gauge the perspectives of older adults who have experienced abuse is provided by Pritchard (2003) who describes work with 3 support groups over a two year period. Individuals attending these groups reported that they were happy to talk about their experiences in the group, but that they had chosen to deal with their experiences of abuse at different times in their lives. In instances of abuse, the timing of interventions may therefore be particularly important and stresses the need to adapt any interventions or support to the needs of the individual at that particular time.
Personal & Ethical Considerations

Certain aspects of clinical practice stand out as potentially very important in considering work with instances of elder abuse (suspected or known). One of these would be the need to look after ourselves. Working with older adults generally has the potential to be stressful and raise personal issues for the professional, especially around issues of loss, bereavement or death (Woods, 2002). This is likely to increase when working with instances of abuse. Working with and making use of a team approach can be potentially very useful in this context for sharing ideas, concerns and knowledge with others. It is also essential that all professionals receive support and engage in adequate supervision (Kingston & Reay, 1996).

Issues of power are also important in working with older adults in general and especially where the individual is frail, has dementia, or is devalued or disempowered in some way (Britton & Woods, 2002). In instances of abuse, the survivor of abuse may have a history of feeling disempowered and helpless and this may leave psychologists in powerful positions. The professional needs to be aware of this and the ease for example with which a decision may be made in the clients perceived ‘best interests’. One example of the issue of power offered by Britton & Woods (2002) involves the impact of cognitive testing. Testing may lead to a diagnosis that is used to help ‘explain’ a carer’s abusive behaviour as relating to their being overwhelmed by the ‘significant cognitive deterioration’ of the person; as opposed for example to labelling the abusive behaviour as ‘abusive’ or even ‘criminal’.

Conclusion

Many of the papers that arose from the literature search for this essay were review articles or chapters that initially gave the impression that more work had been done in this area than actually has been. Very little research has been carried out in this field, especially when compared with the child abuse literature and this has been compounded by a lack of clear definitions which would benefit policy makers, clinicians and researchers. A significant gap in the literature is research that has explored elder abuse amongst ethnic minorities (Lachs & Pillemer, 2004). Another
unfortunate gap in the literature appears to be the voices of older people themselves and these require further attention.

Psychologists have a number of professional responsibilities when working with cases of abuse, including reporting any concerns of abuse they may have to social services, contributing to investigations, providing evidence of capacity, and/or providing treatment and following-up people who have been abused. Many theories and models from psychology are useful in helping us to fulfil these roles and a number of models specifically designed to aid our understanding of elder abuse, have been explored in this essay.

It is clear that psychological ideas apply to most aspects of working with instances of elder abuse. Indeed, many theories and practices that are used in our everyday approach to working as psychologists may take on an extra significance when working with instances of abuse. These might include basic listening skills, ‘flexible’ formulating, or emphasising a client-centred approach to therapy. Another example might be the importance of supervision. These are aspects of routine practise that become especially important in working with abuse or in raising suspicions of abuse.
References


Clinical Section

This section contains summaries of the clinical experience gained on each placement, and summaries of the five case reports written (one relating to each core placement, and one specialist placement).

Actual case reports may be found in Volume 2 of this portfolio, with placement contracts, supervisor evaluation forms, and log books of clinical activity.
Summary of Clinical Experience
Adult Mental Health Placement

Placement Details

Supervisor: Jo Gathard
NHS Trust: Surrey Oaklands NHS Trust
Base: Dorking CMHT
Settings: CMHT outpatient, day unit, home visits

Clients

- Individual work with 10 clients (2 male, 8 female) ranging in age from 21 to 61.

Presenting Problems / Issues

- Agoraphobia and Panic Disorder
- Social Anxiety
- Depression and Self esteem
- Self Harm
- Anger
- Sexual Abuse
- Relationship Difficulties
- Memory Loss
- Bipolar
- Chronic Fatigue
- OCD
- Borderline Personality Disorder

Assessments

- Assessment Interviews.
- Questionnaires: BDI-II, BAI, Beck Hopelessness Scale, Impact of Events Scale, Thought Diaries, Panic Rating Scale/Diaries, Social Avoidance and Distress Scale, Maudsley Obsessive Compulsive Scale.
Neuropsychological assessment: WAIS-III-R, WMS-III.

Interventions
- CBT
- Psychodynamic
- Anger management
- Psychoeducational

Other Experiences
- Served CPA care coordinator role
- Observed CPA reviews in CMHT and inpatient ward
- Discussed work of team members and observed CPN and SW on home visits
- Observed supervisor in assessments/interventions with clients
- Attended regular departmental and locality meetings
- Visits to local day centres, a rehabilitation unit, and sheltered accommodation.
- Attended 'CBT for Depression' workshop
People with Learning Disabilities Placement Summary

Placement Details

Supervisor: Rowena Rossiter, Zilla Webb.
NHS Trust: Surrey Oaklands NHS Trust
Base: Kingsfield Centre, Redhill.
Settings: Community outpatient, inpatient unit, group homes, home visits,

Clients

- Individual work with 7 clients (5 male, 2 female) ranging in age from 7 to 41.
- Group work with 4 male clients, aged 14/15.

Presenting Problems / Issues

- Challenging behaviour
- Autistic Spectrum Disorder
- Assessment of cognitive functioning to inform placement suitability
- Family difficulties
- Anger
- Emotional and physical abuse
- Road Safety
- Severe and Enduring Mental Illness
- Interpersonal difficulties
- Inappropriate sexual behaviour

Assessments

- Assessment interviews with clients/staff/relatives/carers
- Functional analysis (diaries, observations, charts)
- Emotion Cards
- Questionnaires: HADS, PAS-ADD, Brief Symptom Scale.
Neuropsychological assessments (WISC-III, WAIS-III, Leichter, British Ability Scales, Neale Analysis of Reading).

Daily living skills assessment using HALO.

Interventions

- Behavioural
- Systemic
- Anger Management / expressing emotion
- Cognitive Behavioural
- Staff support sessions

Other Experiences:

- Visits to various services for people with learning disabilities including day centres, group homes, and schools.
- Presented formulation of a client with challenging behaviour to staff at an assessment and treatment unit (n=6) for feedback, and evaluation.
- Observed nurse assessment. Met with team members to discuss their roles (clinical nurse specialist, speech therapist, social worker).
- Developed organisational and systemic formulations of a specific problem relating to the use of a particular tool (the HALO) for assessing domestic skills.
- Involved in updating data as part an audit of respite needs and provision for children with LD and challenging behaviour.
- Observed supervisor assess and work with 4 clients, family members and teachers/staff. Joint home visits to a family.
- Presentation on Care Management within CLDTs
- Attended workshop on CBT for People with LD (Surrey Oaklands PLD Special interest group).
- Observation skills training by supervisor (over two sessions) using video of an autistic boy in class/nursery environment.
- Consulted a group of staff on 2 occasions to help develop formulation of challenging behaviour presented by a male client and subsequently evaluate.
Children, Adolescents & Family Placement Summary

Placement Details

*Dates:* October 2004 to March 2005

*Supervisor:* Lucy Thomas, Sarah Johnstone.

*NHS Trust:* Surrey Oaklands NHS Trust.

*Base:* Mole Valley CAMHS (Leatherhead)

*Settings:* Community based outpatients, Home visits

*Clients:* Individual work with 11 clients (4 male, 7 female) ranging in age from 3 to 17.

Presenting Problems / Issues

- School refusal
- Query ASD
- ADHD
- Learning difficulties
- Selective Mutism
- Depression, Self harm
- Self Esteem. Relationship difficulties with peers.
- Trichotomania
- Anxiety, Low mood

Assessments

- Assessment interviews (child, families, couples) for individual and family therapy.
- Functional analysis
- Questionnaires: Children’s Anxiety Scale, Children’s Depression Scale, Parenting Stress index.
- Neuropsychological Assessments: WRAT, WORD, WOND.

Interventions
o Systemic
o Cognitive-behavioural
o Behavioural
o Psychoeducational

Other Experiences
o Presentation to psychology department.

o Direct observation of supervisor: 3 triage assessments, 2 assessments, 2 intervention/ending sessions.

o Involvement in family therapy assessment sessions - part of reflecting team.

o Day visit to adolescent service: participated in creative writing group, attended group therapy sessions.

o Attended regular meetings and presentations (Psychology Dept., Child Psychology Dept., CAMHS case allocations meetings).

o Attended case review meeting at school: presented assessment.

o Nursery visit. Observation of teachers, children, levels of work.

o Attended a child protection conference

o Joint work with family therapist.
Older People Placement Summary

Placement Details


Supervisor: Clare Crellin

NHS Trust: Mid Sussex NHS Trust

Base: Linwood Community Mental Health Centre

Settings: Community outpatient, Day unit, Home visits

Clients: Individual work with 7 clients (3 male, 4 female) ranging in age from 66 to 83.

Presenting Problems / Issues:

- Memory difficulties / cognitive impairment
- Severe Depression
- Carer Stress, Anger toward spouse
- PTSD
- Panic Attacks, Obsessions. Severe and enduring difficulties.
- Anxiety
- Bereavement
- Fear of falling
- Adjustment to spouse’s cognitive impairment

Assessments

- Assessment Interviews (Client, Couple, Family)
- Structured clinical assessment interview
- Questionnaires included: BDI, BAI, BHS, HADS
- Neuropsychological assessments: WAIS-III, WMS-III, NART, FAS, Category naming, Rivermead Behavioural Memory Scale, Mini-mental state examination.

Interventions
o Psychoanalytic
o Cognitive-behavioural
o Psychoeducational
o Life-review

Other Experiences
o Carried out psychoanalytic observation in nursing home
o Day visit to hospital in-patient unit and day service for older adults.
o Attended regular Older Adult CMHT meetings
o Spoke with staff on team and in day service as to their roles and service provision
o Attended PSIGE conferences (Diversity in neuropsychological testing; Pre-diagnostic counselling issues in memory screening clinic)
o Joint supervision
Traumatic Stress Specialist Placement Summary

Placement Details

Dates: October 2003 – March 2004
Supervisor: Ian Robbins, Shariff El-Leithy
NHS Trust: St Georges NHS Trust
Base: Traumatic Stress Service, St Georges Hospital
Settings: Hospital outpatient

Client s: Individual work with 12 clients (9 male, 3 female) ranging in age from 26 to 44.

Presenting Problems / Issues

- PTSD following torture; war exposure; assault; RTA; surgery;
- Secondary:
  - Panic Attacks
  - Depression
  - Anger
  - Bereavement/traumatic grief
  - Relationship Difficulties.

Assessments

- Assessment Interviews (client, couple, with interpreters).
- Questionnaires: BDI-II, BAI, Posttraumatic Diagnostic Scale. Impact of Events Scale.
- Panic Diaries

Interventions

- Cognitive-behavioural
- Narrative
**Other Experiences**

- Case presentations to team
- Joint screening assessments
- Routinely audio/video taped sessions, and discussed in supervision.
- Attended weekly team meetings (business issues, new referrals, case discussions)
- Observed supervisor intervention sessions, training tapes.
- **Weekly in-house education sessions** (trauma-related issues, PTSD assessment/intervention, models of PTSD, medication, delivery of CBT)
- Joint supervision with trainee.
- Attended team away day; discussions around efficiency of new screening process.
Primary Care: Specialist Placement Summary

Placement Details

Supervisor: Katrina Wynne, Susan Rodgers
NHS Trust: St Georges NHS Trust
Base: Adult Psychology & Counselling Service, Acre Road Clinic.
Settings: Outpatient clinic, GP Surgery.

Clients: Individual work with 15 clients (5 male, 10 female) ranging in age from 22 to 60.

Presenting Problems / Issues

- Anxiety, Panic Attacks, Stress, Claustrophobia.
- Social anxiety, Adult ADHD.
- Depression.
- Alcohol misuse.
- Obesity, Self-esteem.
- Anger, Irritability.
- Bereavement.
- Interpersonal Difficulties.
- Gambling/relationship difficulties.

Assessments

- Assessment Interviews (client, couple).
- Questionnaires: GHQ, GAF, BDI-II, BAI.
- Panic Diaries

Interventions

- Brief psychodynamic
- Cognitive-behavioural
Other Experiences

- Attended weekly team meetings (business issues, new referrals, case discussions)
- Supported running of stress management group
- Visit to psychotherapy department.
- Regular in-house CPD sessions (discussions of articles/cases relevant to various psychodynamic/CBT therapeutic issues)
- Observed GP with patients.
- Lead role in development of survey of service-user experiences of service.
Clinical Case Report Summaries
Summary of Adult Mental Health Case Report

Cognitive behavioural therapy with a 26 year old female with panic attacks and social anxiety

Year 1

March 2004
Referral
Gemma was a 26 year old woman referred to her local CMHT by her GP for help with anxiety and a fear of flying.

Presenting problem
Gemma described feeling anxious in social situations and experiencing frequent panic attacks. She was concerned that she would be sick in front of other people during a panic attack, and she feared embarrassment. As a result she avoided a number of situations, and would monitor her sensations during anxiety-provoking events. She worried in anticipation of social events, and would analyse her behaviour following the event. She described being fearful of eating in public, as she felt that eating made the likelihood of her being sick greater. She clarified she did not have a fear of flying (as suggested in her referral) but of having a panic attack on the plane where there would be no escape or avoidance of people seeing her panic.

Assessment
This consisted of interviews with Gemma to obtain information on the nature and history of her difficulties and to obtain background information (i.e. family & psychiatric history). Gemma was asked to complete the Beck Depression Inventory II (BDI-II) and the Beck Anxiety Inventory (BAI) to obtain measures of anxiety and depression, and a baseline for monitoring progress. Her scores indicating moderate levels of depression and anxiety. She was also asked to maintain a panic diary and a Panic Rating Scale to assist in obtaining information as to the frequency and nature of her panic attacks. The aim of this was to facilitate monitoring of the effectiveness of treatment on key maintenance factors.

Formulation
Gemma’s difficulties were formulated within a cognitive-behavioural framework, with particular reference to Clark’s model of panic, and Clark & Wells’ cognitive model of social anxiety. Gemma’s panic attacks were conceptualised as vicious circles of increasing anxiety when in certain social situations. These appeared to be
triggered by catastrophically interpreting her anxiety symptoms as signs that she was going to be sick. Her avoidance of situations and monitoring of sensations were conceptualised as safety behaviours that were contributing to the maintenance of her difficulties (i.e. by preventing her finding out that she can cope, or that won't be sick). In addition, Gemma's pre-event and post-event worrying was hypothesised to be contributing to the maintenance of her negative beliefs about herself (by directing attention towards evidence of failure, and subsequently processing information based on this basis).

**Intervention**

An intervention was planned with the aim of exploring and challenging some of Gemma's unhelpful cognitions around the likelihood and consequences of her feared outcome (having a panic attack and being sick) and her cognitions around social situations. A cognitive formulation of her difficulties was shared with Gemma, and collaboratively developed further. In particular, a number of panic cycles were drawn up with recent examples from her life. Socratic questioning was used to address the meaning of her symptoms to her, and to challenge her negative beliefs about herself, generating more helpful cognitions. The utility of particular safety behaviours was discussed and behavioural experiments were designed to test beliefs around dropping these. Questioning of panic-related beliefs aided the identification of a number of negative beliefs about Gemma's perception of herself in social situations. These were addressed using Socratic questioning and homework tasks were set to gather evidence for alternatives. Gemma and I met for a total of 15 sessions.

**Outcome**

Gemma's BDI-II score reduced to 7, and her BAI score was 6. Her panic diaries showed no more panic attacks on a weekly basis. The Panic Rating Scale revealed a reduction in the strength of a range of negative beliefs. All of the safety behaviours on the scale showed a reduction in their frequency. By the end our sessions, Gemma had decided to keep a 'diary of evidence' to reinforce her evidence-gathering and to hinder her discounting positive evidence in the absence of attending for treatment.
Summary of People with Learning Disabilities Case Report

An extended assessment of a twelve year old girl with severe learning disabilities and challenging behaviour

Year 1

September 2004
Reason for referral
Jane was a 12 year old girl who was referred to her local Community Team for People with Learning Disabilities by the Deputy Head Teacher at her school. Her school were considering requesting a transfer to a school they believed could more effectively meet Jane’s needs, and they were therefore requesting an assessment of her abilities.

Presenting Problem
Jane’s school staff described Jane as verbally abusive and physically aggressive towards staff and pupils around the school. They described her as difficult to manage and she had been excluded from school for the day on three occasions.

Assessment
Following initial information gathering from a number of sources (staff at Jane’s school, medical notes, SENCO report, a social service report, observations of Jane in class and in response to being assessed by a Clinical Psychologist on one occasion) it was hypothesised that Jane was a girl with intellectual impairments who lacked the range of communication and social skills necessary to meet the demands of her environment. Her behaviour was viewed as an interaction of intellectual impairments, early life experiences, and current situational demands. Further assessments were carried out to test the initial formulation and aid indecision making around school placement. The following tests were used: the Weschler Intelligence Scale for Children - 3rd Edition, the British Abilities Scale, and the Neale Analysis of Reading.

Formulation
Analysis of the data obtain from assessments partially supported the initial formulation, but suggested a more severe picture of cognitive impairment, than had been previously acknowledged. Her pattern of scores suggested someone with a general and severe intellectual impairment. Her presentation on the other hand (as lively and talkative) was considered to give her the impression of being more able than she was. The tendency to conceptualise Jane’s behaviour in terms of aggression...
was considered to be at the expense of a clearer understanding of the impact of her intellectual impairments.

**Outcome & Recommendations**

Based on the extended assessment of Jane's abilities, a number of recommendations were made and a report was sent to the deputy head teacher at Jane's school. Suggestions were made as to how to more usefully present information to Jane, and how to understand/respond to her behaviour.
Summary of children, adolescents, & families case report

Systemic therapy with a 12 year old girl
presenting with low mood and school refusal

March 2005

Year 2
Reason for referral
Karen Smith was a 12 year old girl, referred for assessment by her health visitor for difficulties relating to school refusal and low mood.

History of presenting problem
Karen’s parents reported she had been unhappy since leaving primary school at the end of year 6. She completed year 7 at a secondary school but was frequently absent through illness, or injury, which led to her initial referral by the EWO. Karen then transferred to another secondary school for year 8 but was unable to settle, rarely managing to complete a week. She had stopped attending completely by our first meeting. Reports from her previous school described her as having some difficulties with reading. Karen’s parents described her as becoming hysterical on attempts to go to school. They described her as depressed, and difficult to manage. Karen described feeling sick before school and feeling unhappy there. She described herself as ‘horrible’ and always sad.

Assessment
The assessment procedure included interviews with the family together, and interviews with Karen alone. In addition, the Wechsler Intelligence Scale for Children – Third Edition (WISC-III) was administered. The aim of this was to gather information regarding the factors that might be contributing and maintaining the family’s difficulties. The results of psychometric testing suggested that Karen had more severe learning difficulties than had previously been acknowledged.

Formulation
A contextual approach, as presented by Carr, was used to facilitate organising potentially useful hypotheses. The formulation focussed on learning difficulties making the transition from primary school to secondary school difficult. The increased demands of secondary school, and the potential difficulty in recognising and expressing her own emotions/needs, were considered important in contributed to her anxieties about attending school. It was considered that a mixture of Karen’s
difficulty in expressing her needs, and her family’s lack of resources to meet them, may have resulted in Karen generally not feeling heard with her needs remaining unmet.

**Intervention**
The results of the assessment were fed back to Karen and her parents and psychoeducational support was provided to facilitate their understanding of the level of Karen’s intellectual functioning and how best to support her. On the basis of the formulation, anxiety-management strategies (i.e. Ollendick, King & Yule, 1994) the nature of anxiety and its management were discussed and simple relaxation skills were practised with Karen. Karen’s prior enjoyment of art was used to engage her in some form of activity during the week. Art was used as a means by which Karen’s thoughts and feelings could be brought to sessions, and explored. Through her drawings we were able to hold somewhat more specific conversations school.

**Outcome**
Our impression of Karen’s situation was shared at a meeting of professionals held by the EWO at Karen’s school and there was an agreement with the reports of other professionals. Together, these contributed to the EWO’s decision that Karen would be best suited to attended a local special needs school and the process of applying for this was initiated. Karen was referred to a Community Psychiatric Nurse on a Children with Learning Disabilities Team who was in a potential position to provide ongoing support and advice to this family. A gradual change in Karen’s mood and presentation became evident in our sessions (i.e. smiling more frequently, initiating conversation more). However, Karen often still reported that it felt like her sisters would take attention away from her and that when they were present, nobody seemed to notice her.
Summary of Older People Case Report

Psychometric testing with a 71 year old woman presenting with memory difficulties

October 2005

Year 2
The referral
Mrs Penfold was a 71 year old woman who was referred to her local CMHT for Older Persons by her GP, because of increasing difficulties with memory. She was subsequently screened by a member of the team, and referred to psychology.

Presenting problem
Mrs Penfold reported experiencing increasing difficulties with her memory. She would often forget appointments or the things she had done in the day. She described waking up each day and not knowing what day it was. Her daughter reported concern about her mother, and that her mother was not fully aware of how severe her memory difficulties were. Mrs Penfold reported first noticing these difficulties about 18 months prior to referral. This had been at the same time as a move to a new house, which had been followed by a brief period of depression.

Assessment
Interviews were conducted with Mrs Penfold and her daughter to obtain information regarding her difficulties and background history. Based on initial assessment, it was hypothesised that Mrs Penfold's memory difficulties might have been related to dementia, depression, or both, or related to normal ageing. It was decided that further psychometric testing of a range of cognitive abilities, not just memory skills, would be useful in exploring the above hypotheses and contributing to informing about differential diagnoses. Mrs Penfold and her daughter were met prior to testing to discuss the possibility and consequences of testing, to obtain consent and address any concerns, and to ask how feedback would be liked.

The Rivermead Behavioural Memory Test (RBMT) was used to assess everyday aspects of memory, and as it contains tasks of prospective memory, a skill that was central to Mrs Penfold's complaints. Wechsler Adult Test of Reading (WTAR): Wechsler (2001) was used as a means of estimating pre-morbid ability. The Wechsler Adult Intelligence Scale – 3rd edition (WAIS-III) was used to assess to current intellectual functioning. The Verbal Associative Fluency Test (F-A-S test) was
also given as a potentially useful indicator of dementia and frontal lesions; the Trail Making Test (TMT) as an indicator of problems of attention, concentration and executive functioning. In addition, the Hospital Anxiety & Depression Scale (HADS) was also given to help gauge anxiety and depression.

**Formulation**

Test results suggested Mrs Penfold had experienced a decline in functioning that was consistent with a diagnosis of Dementia of the Alzheimer’s type (AD). Her decline was beyond those expected with normal ageing, and involved multiple cognitive deficits. Memory impairments were central and language difficulties were apparent, especially word retrieval. There was subtle evidence for problems in executive functioning. Evidence to support a differential diagnosis of AD included the gradual onset of difficulties, that memory difficulties were predominant (and more so than impairment of executive functioning) and that there were clear difficulties with word retrieval. Mrs Penfold’s pattern of scores did not appear to fit with other neuropsychological profiles associated with cognitive deficits.

**Outcome & Recommendations**

The results of the assessment were fed back to Mrs Penfold and her daughter. A summary was also sent to Mrs Penfold of the feedback. A set of potentially useful memory strategies was drawn up. These were then discussed with Mrs Penfold, revised accordingly, and sent to her. The possibility of a further medical assessment was discussed and arranged. Based on the findings of our assessment, a number of recommendations were made in relation to interventions with Mrs Penfold. The results of the assessment were fed back to the team and there was a consensus that a fuller assessment of daily living skills by the Occupational Therapist (OT) would be useful as well as a medical assessment, which might include a CT scan and medication review. This would help rule out possible causes of Mrs Penfold’s cognitive symptoms (i.e. a brain tumour) and may indicate suitability for particular medication. I therefore made an inter-team referral to the Psychiatrist and OT on the team.
Specialist Placement Case Report

Cognitive behavioural therapy for a 47 year old Portuguese woman presenting with Posttraumatic Stress Disorder following a road traffic accident.

April 2006

Year 3
Referral
Mrs. Martins was a 47 year old Portuguese woman referred by her local CMHT for an assessment relating to possible Posttraumatic Stress Disorder, following a road traffic accident.

Presenting Difficulties
Mrs. Martins described difficulty in overcoming a road traffic accident (RTA) she experienced two years previous. She described intrusive thoughts and images that were accompanied by anxiety. She described recurrent dreams and nightmares relating to her RTA. She reported being fearful when outside of another accident occurring and was hyper-vigilant to signs of this. She reported a desire to avoid traffic and travel by car or public transport. She related having trouble concentrating on tasks for long and described frequent headaches. She had been unable to support herself financially since the accident, and was sleeping in the lounge of her daughter’s flat, sharing this with her daughter and her two grandchildren.

Assessment
The initial assessment consisted of interviews with a Portuguese interpreter. Information was gathered regarding the event and its aftermath, her current situation, her personal, social, occupational and family history. The Posttraumatic Diagnostic Scale (PDS) was used to help assess for the presence of DSM-IV criteria for PTSD. Her score was 38, which is within the ‘severe’ range of PTSD symptoms.

Formulation
Mrs. Martins’ difficulties were formulated within a cognitive-behavioural framework, with particular reference to Ehlers & Clark’s (2000) model of PTSD. Her difficulties were conceptualised as related to negative appraisals of her RTA, and its aftermath, and that these were contributing to a sense of current threat. To cope, Mrs. Martins avoided a number situations that reminded her of her accident, but this avoidance was hypothesised to then limit her opportunities to gather evidence that contradict her predictions. In addition, her appraisals of her reactions since her accident were also
hypothesised to be contributing to her distress by feeding into a perception of having permanently changed. Mrs Martins’ intrusive thoughts and memories were conceptualised within this model as a failure to sufficiently process trauma-related information.

**Intervention**

Based on our formulation of Mrs Martins’ difficulties, and the central role played by avoidance in maintaining her fears/difficulties, a graded programme of exposure was planned with the aim of exploring and challenging some of her unhelpful cognitions around going out, getting on the bus, and the likelihood of another accident. Anxiety management strategies were taught in relation to facilitating this exposure work. Our hypotheses around Mrs Martins’ intrusive thoughts/memories (as related to a failure in processing) implied a process of ‘reliving’ might be useful, identifying moments in the trauma memory that were particularly distressing. Mrs Martins identified she was particularly distressed that she had ‘frozen’ at a point when she had needed to move, and took this to mean that she was, and would again be, unable to cope with the stress. This was challenged through a Socratic dialogue.

**Outcome**

Mrs Martins score on the PDS had reduced to 16, which is within the ‘mild’ to ‘moderate’ range of PTSD. By the end our sessions, she was attending our sessions alone, by bus, and reported feeling more comfortable going out alone and less distressed by reminders of the her RTA. Her avoidance of situations had decreased significantly. Mrs Martins reported feeling more comfortable talking about the accident and that she felt more engaged with her family. She reported no longer experiencing nightmares relating to the accident.
Research Section

This section contains the Research Logbook Checklist, Service Related Research Project conducted in year 1, and the Major Research Project carried out in years 2 and 3.
Research Logbook Checklist
<p>| | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>1</td>
<td>Formulating and testing hypotheses and research questions</td>
</tr>
<tr>
<td>2</td>
<td>Carrying out a structured literature search using information technology and literature</td>
</tr>
<tr>
<td></td>
<td>search tools</td>
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<tr>
<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
</tr>
<tr>
<td>4</td>
<td>Formulating specific research questions</td>
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<td>5</td>
<td>Writing brief research proposals</td>
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<td>6</td>
<td>Writing detailed research proposals/protocols</td>
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<tr>
<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of diversity,</td>
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<tr>
<td></td>
<td>and structuring plans accordingly</td>
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<tr>
<td>8</td>
<td>Obtaining approval from a research ethics committee</td>
</tr>
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<td>15</td>
<td>Negotiating access to study participants in applied NHS settings</td>
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<td>Setting up a data file</td>
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<td>Conducting statistical data analysis using SPSS</td>
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<td>21</td>
<td>Summarising results in figures and tables</td>
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<td>22</td>
<td>Conducting semi-structured interviews</td>
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<td>23</td>
<td>Transcribing and analysing interview data using qualitative methods</td>
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<td>24</td>
<td>Choosing appropriate qualitative analyses</td>
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<td>Interpreting results from quantitative and qualitative data analysis</td>
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<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
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<td>27</td>
<td>Producing a written report on a research project</td>
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<td>28</td>
<td>Defending own research decisions and analyses</td>
</tr>
<tr>
<td>29</td>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
</tr>
<tr>
<td>30</td>
<td>Applying research findings to clinical practice</td>
</tr>
</tbody>
</table>
Service Related Research Project

A brief audit of the respite care needs of children with learning disabilities and challenging behaviour and their families, in a local borough.

July 2004

Year 1
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: .................
Date: 12/7/04
Abstract

Title: A brief audit of the respite care needs of children with learning disabilities and challenging behaviour and their families in the local government borough.

Objective: To assess current need for respite care, and whether this need is being met in children with learning disabilities and challenging behaviour in the local area.

Method: A cross-sectional review of current respite provision and unmet need in 33 children with learning disabilities and challenging behaviour. This provides up-to-date information on data collected two years ago from service providers, a range of community professionals and parents.

Participants: Five community professionals with knowledge of the respite usage of children involved in a previous data collection responded to an invitation to participate in updating this information.

Results: Updated information was obtained on 33, of the original 43 children identified in the previous study. Overall, the results were encouraging with 61% of children having no reported unmet needs in 2004, compared with only 24% in 2002. However, 6 of the 33 children were reported to still be without any form of respite care in 2004 and current unmet needs were identified in 9 (27%) of the 33 families.

Conclusions: A range of respite services are currently being provided in the local area, and the data obtained seem to suggest an improvement in meeting the respite needs of the families identified in 2002. A potential bias in reports by community professionals and the importance of obtaining service user representation in assessing any unmet respite need is discussed.
Introduction
Respite care incorporates a diverse range of services and although traditionally aimed at providing a break for carers, it is now widely acknowledged that it can also offer a positive experience for service users (Gerrard, 1990). For carers, simply knowing that a break is not too far away, may make a significant difference in reducing stress levels and burnout, increasing their ability to cope with everyday issues. For service users, appropriate respite care might facilitate new experiences and provide important developmental opportunities, encouraging independence, social interactions and the development of wider social networks. Enhancing the availability of appropriate respite can also help services in providing local support, rather than resorting to external (out-of-county) agencies.

Policy
A government study of service provision for people with learning disabilities, ‘Facing the Facts’ (1990) identified huge variation in service provision across 24 local authority areas in England. In one particular authority, 60% of people living with their carer reported no regular respite care, even though this was rated of ‘major importance’ by both users and carers.

A range of legislation (i.e. Children Act 1989, Carers Recognition and Services Act 1995, Carers and Disabled Children Act 2000) has placed a duty on Local Authorities to ensure support services to ‘children in need’ and their families/carers. The recent ‘Valuing People’ White Paper (March 2001) makes as a priority, the provision of adequate support services to families and carers, and emphasises that assessed needs of children and carers must be adequately met and reviewed. Of the specific objectives set out, appropriate respite could particularly help:

- ‘enable people to lead full and purposeful lives within their communities, developing a range of friendships, activities and relationships’ (p.9) and,
- ‘increase help and support for carers so they can fulfil their family and caring roles effectively’ (p.9).
The document is based on the 4 key principles of Rights, Choice, Independence and Social Inclusion, and good respite care can go some way to promoting these.

**Accessing Services**

Despite the potential benefits of respite care, there appears an inconsistent uptake of such services:

"It seems that availability and uptake of formal support is limited due to the impersonal, slow, cumbersome and insensitive nature of services, and to a lack of information" (Treneman et al 1997, p548).

Treneman, et al. (1997) sum up the organisation of respite services as taking place largely ‘without informed planning’ and that little is known about the respite needs of parents, how these needs are being met, and how they may subsequently be developed.

**Aims of present study**

In the previous study, children with learning disabilities and challenging behaviour were identified via liaison with a range of service providers and community professionals working across different settings, and some parents. Information on their respite usage and need was initially sought from social workers (as professionals with knowledge of respite funding and applications) and then cross referenced with interviews/liaison with other professionals (see appendix I for full list of sources). The range of information obtained was a mix of objective (i.e. amount of respite received) and more subjective data (i.e. ratings of severity of challenging behaviour).

The following information was gathered for each child via interview (in person or by phone): nature of learning disability and challenging behaviour, respite/leisure services received/refused (or on waiting list for) and views on unmet needs. This information was especially pertinent at a time when planning and provision mechanisms were not clearly placed, due to huge organisational change in terms of Primary Care Trusts being introduced and Local Authorities services merging.
The current study was set up to update data obtained in July 2002 by collecting more recent information on the respite need of the children in the original sample, from community professionals in a position to comment on their current respite usage/unmet needs. The aim of the current study is to see what changes if any, have occurred over the 2 year period since data was initially collected. The main question to be addressed is therefore whether the amount or level of unmet need has increased or decreased over the past 2 years. This will help inform decisions and recommendations for the appropriate planning and prioritising of respite services in the local government borough. Consulting the families and children directly is beyond the scope of this current study, but is an aim for the future development of the data collected here.

Method

Participants
Five community professionals based at a local Community Team for People with Learning Disabilities, and a local Children with Disabilities Team, took part in this study. These were professionals with knowledge of the respite usage/need of the 43 children identified in the previous study.

Design
A cross-sectional survey of community professionals working with 43 children with learning disabilities and challenging behaviour (identified in a previous study) to assess current levels of respite usage and met/unmet need.

Measures
A questionnaire was constructed in order to elicit updated information on the respite usage of the 43 children. This contained a summary of the information previously collected for each child, and prompt questions (with space to respond) on current respite need: ‘What respite services are currently being received?’ , ‘Is there a need for respite services?’ and ‘What is preventing this need being fulfilled?’ (see appendix II for an example part of the questionnaire used - i.e. anonymised for 4 children).
Severity of Challenging Behaviour was assessed as part of the previous data collection and involved interviews with the participating community professionals to elicit the nature of the challenging behaviours, and the frequency and intensity of these behaviours. These were coded with an established classification system (Emerson 1998).

Procedure
The questionnaire was sent to community professionals with knowledge of the respite usage and unmet need of the 43 children identified in 2002. A covering letter was also sent stating the purpose of this update (see appendix III). These professionals were then followed up with phone calls or e-mail. Responses or completed forms could then be faxed back, or a visit arranged to collect this information in person. The information collected was then analysed with that obtained in the previous collection in 2002 to allow for comparisons between the 2 time points (July 2002 and July 2004).

Results
Five community professionals (3 social workers, a community nurse and a clinical psychologist) provided updated information on 33 of the 43 children. Unless stated otherwise, the following analyses are based on this sample of children (n=33) only, and for the two time points, July 2002 and July 2004.

Table 1 showing number of children across 4 age-bands.

<table>
<thead>
<tr>
<th>Age Range</th>
<th>N</th>
<th>Severe N (male:female)</th>
<th>Not Severe N (male:female)</th>
<th>Inconsistent Severity Rating N (male:female)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>5-9</td>
<td>10</td>
<td>4 (4:0)</td>
<td>3 (1:2)</td>
<td>3 (3:0)</td>
</tr>
<tr>
<td>10-15</td>
<td>19</td>
<td>6 (5:1)</td>
<td>11 (10:1)</td>
<td>2 (2:0)</td>
</tr>
<tr>
<td>16,17</td>
<td>4</td>
<td>1 (0:1)</td>
<td>2 (2:0)</td>
<td>1 (1:0)</td>
</tr>
<tr>
<td>Total:</td>
<td>33</td>
<td>11 (9:2)</td>
<td>16 (13:3)</td>
<td>6 (6:0)</td>
</tr>
</tbody>
</table>

N.B. Severity ratings were inconsistent in 6 children and have been included as a separate column. This inconsistency is unsurprising given the subjective nature of rating challenging behaviour, and the variability of behaviour across contexts.
Table 1 shows number of children across 4 age-bands. No children were identified in the under-5 age-band and only 4 children were identified in the 16 to 17 age-band. More male than female children is in line with expectations.

Table 2: A list of respite services provided to 33 children/families in current study.

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Number of families</th>
</tr>
</thead>
<tbody>
<tr>
<td>A day care &amp; 8-bed residential unit (children age 6 to 18 yrs):</td>
<td>23:</td>
</tr>
<tr>
<td>* Overnight</td>
<td>8</td>
</tr>
<tr>
<td>* Overnight &amp; day care</td>
<td>7</td>
</tr>
<tr>
<td>* Day care</td>
<td>5</td>
</tr>
<tr>
<td>* On waiting list</td>
<td>3</td>
</tr>
<tr>
<td>A community based home support and leisure service.</td>
<td>9</td>
</tr>
<tr>
<td>A family-based respite service (linking families for respite support).</td>
<td>5</td>
</tr>
<tr>
<td>Playschemes / Saturday Club.</td>
<td>2</td>
</tr>
<tr>
<td>Social Services / Support Worker.</td>
<td>2</td>
</tr>
<tr>
<td>A social services run 8-bed residential unit (out of local area)</td>
<td>2</td>
</tr>
<tr>
<td>A voluntary sector home-based support service (i.e. home visits, arranging outings).</td>
<td>1</td>
</tr>
<tr>
<td>A voluntary sector leisure &amp; respite service (i.e school holiday and weekend support service).</td>
<td>3</td>
</tr>
<tr>
<td>Voluntary sector day care and 5-bed residential unit.</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2 shows the range of respite services provided to the 33 children/families in this study.

No respite
Six children (compared with 7 in 2002) were reported to be without any form of respite services in 2004 and 3 of these had also reported no respite in 2002.

In 22 cases, reports of unmet need were obtained from 2 different professionals, who unsurprisingly sometimes differed in their reports of unmet need. Inconsistent reports were therefore found in 6 (27%) of 22 families for which more than one report was obtained.

Although there were only 6 inconsistent ratings, it was interesting to note that social workers appeared more likely (i.e. in all but one case) to report no unmet need, conflicting with reports from other professionals.
Unmet respite need

Table 3 shows a decrease from 58% of children having unmet needs in 2002, to 27% in 2004. Conversely, those reporting no unmet needs had risen from 24% to 61% in 2004.

Table 3 showing met/unmet respite need for 2002 and 2004 (n=33).

<table>
<thead>
<tr>
<th>More respite needed?</th>
<th>July 2002</th>
<th>July 2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>19 (58%)</td>
<td>9 (27%)</td>
</tr>
<tr>
<td>No</td>
<td>8 (24%)</td>
<td>18 (55%)</td>
</tr>
<tr>
<td>Clinical Disagreement</td>
<td>6 (18%)</td>
<td>6 (18%)</td>
</tr>
</tbody>
</table>

Of the 9 children with unmet need for respite services, 3 of these were receiving no respite at all and 7 had also reported unmet need in 2002. (A summary of the ‘degree of change’ in unmet need over the two year period can be found as appendix IV).

Reported obstacles to meeting respite need

Where there was unmet need for respite care, respondents were asked what the perceived obstacles were and these can be seen in table 4.

Table 4: Reported obstacles to receiving respite services in 9 children with learning disabilities and challenging behaviour and their families.

<table>
<thead>
<tr>
<th>Reported reasons for unmet need:</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Child will not stay overnight and mum anxious.</td>
</tr>
<tr>
<td>o Awaiting panel process to request an increase in respite amount - x2</td>
</tr>
<tr>
<td>o Parental disagreement</td>
</tr>
<tr>
<td>o On waiting list - x2</td>
</tr>
<tr>
<td>o Awaiting residential school (gap between respite and school).</td>
</tr>
<tr>
<td>o No appropriate respite – x2 (i.e. previous service unable to manage child’s challenging behaviour; child doesn’t like one of the other children at service).</td>
</tr>
<tr>
<td>o Funding unavailable</td>
</tr>
<tr>
<td>o Parents reluctant</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reported reasons for unmet need in only those families receiving no respite at both time points:</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Mother anxious at son staying away from home overnight</td>
</tr>
<tr>
<td>o Father against idea of respite and will reduce maintenance payments if respite used</td>
</tr>
<tr>
<td>o Respite attempted and ended, due to service not being able to manage child’s challenging behaviour appropriately</td>
</tr>
</tbody>
</table>
Reasons for no unmet need for respite

Eight children who had unmet needs for respite (and 4 with inconsistent reports of unmet need) in 2002, were reported to have no further need in 2004. Table 5 shows the reasons offered for these 12 children/families no longer needing respite care.

<table>
<thead>
<tr>
<th>Table 5 showing reported reasons for no longer needing respite care.</th>
<th>Frequency of mentions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requested respite obtained</td>
<td>4</td>
</tr>
<tr>
<td>An increase in respite service already received (became</td>
<td>3</td>
</tr>
<tr>
<td>more frequent, additional nights allocated)</td>
<td></td>
</tr>
<tr>
<td>Move to residential home</td>
<td>2</td>
</tr>
<tr>
<td>Not specified</td>
<td>2</td>
</tr>
<tr>
<td>Appropriate alternative respite found</td>
<td>1</td>
</tr>
</tbody>
</table>

Challenging Behaviour & Respite Needs

Table 6 shows reported respite need and severity of challenging behaviour.

<table>
<thead>
<tr>
<th>Table 6: Reported respite need and severity of challenging behaviour in 33 children with learning disabilities and challenging behaviour.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenging Behaviour (as assessed in 2002)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Severe (n=11)</td>
</tr>
<tr>
<td>Not severe (n=16)</td>
</tr>
<tr>
<td>Inconsistent Severity Ratings (n=6)</td>
</tr>
<tr>
<td>Total (n=33): ISH (58%) (24%) (18%)</td>
</tr>
</tbody>
</table>

It should be noted that challenging behaviour was only assessed in 2002, and may no longer be accurate in 2004. Nevertheless, the data in table 5 gives a general impression of change for the better, since challenging behaviour was assessed in 2002. Specifically, there have been decreases in reports of unmet needs, and increases in reports of met need, regardless of severity of challenging behaviour. The small sample size hinders any commentary on whether the degree of change is larger for the ‘not severely’ challenging group over time.
Discussion

There appears to be a range of respite and leisure services for children with learning disabilities and challenging behaviour available in the local Borough. However, overnight respite is mainly provided by one service which is receiving children of a wide range of ages (6 to 18 years) and needs. Providing a wide range of services is important in facilitating the choices people have, though ‘range’ does not necessarily indicate ‘choice’. Two children had attempted overnight respite at this residential unit but this had ended, reportedly due to the child’s challenging behaviour and no alternative respite was found.

Overall, the results of this study are positive. Approximately half of the children appear to be receiving good supportive respite care and have no current reported unmet need for respite. Ten children who had reports of unmet need in 2002 were reported to have no further need in 2004. The main reasons offered for this were that they had obtained the services they requested, or had current services extended.

However, around a quarter of the children had unmet need and 7 of had had reports of unmet need at both time points. Six children were currently reported to have no respite care at all. A number of perceived obstacles to obtaining respite care were raised.

One such obstacle was reported to be waiting for decisions to be made or waiting for services. One child was found to be receiving no respite care while between the failure of one placement (due to challenging behaviour) and the wait for a place at a residential school. Providing adequate support may require overcoming the usual hurdles (i.e. assessing family suitability, funding) and these may be deemed too laborious given the ‘short-term’ nature of the gap. This may leave people without support at important transitory periods (which may be especially pertinent if the placement they are awaiting falls through).

An inability to manage challenging behaviour was also reported to be an important obstacle. In one family, difficulty in obtaining further home-based respite was
reportedly due to a lack of adequately trained staff to manage the child’s challenging behaviour. A consistency of approach across service providers was also deemed to be important for this child but lacking. During discussions and liaison while collecting data, it appeared that there are some examples of good ‘team’ working across services for some children (e.g. consistency facilitated by a local Special Support and Development Team).

The most common reported obstacle to receiving respite care was that family members did not want it. This was the case in five families with unmet need and reasons included parental anxiety about the service itself, anxiety about the child staying away from home, competing views on respite within the family and a failure to acknowledge the need for respite. In some situations, it is possible that parental attitudes, styles (i.e. over-involved relationships) and anxieties may contribute to additional difficulties for the child. Legislation, such as The Children Act (1989) places the child’s welfare as paramount, and yet where the family do not request help, it may be tempting to not advocate for the child, especially given long waiting lists and limited funding.

The current study was based on information obtained from community professionals and a largely positive picture of increasingly met needs emerged. However, it is unknown how biased this source of information is. Some inconsistency was noted in ratings of need by professionals and it was interesting to note a tendency for social workers to appear more likely to report no further need, which conflicted with the community nurse or psychologist. A similar pattern was found in the previous study. Perhaps a deeper involvement by social workers with the pressures of funding, application processes and waiting lists, may influence their perceptions of what constitutes ‘need’.

Another possible bias may arise from not fully appreciating the benefits of ‘appropriate’ respite: where conclusions of no further need are drawn on inappropriate offers being turned down. Comparisons of community professionals’ reports of respite
need, with those of family members would be useful. This further highlights the need for the views of parents, children and other family members to be represented and is an aim for the future development of this work.

It remains unclear as to whether there is any overall monitoring of respite service provision, waiting lists and unmet need, as this would especially useful in redirecting newly identified children with needs who might otherwise be put onto a waiting list while other services may provide adequate support.

Recommendations
Based on the findings of this data collection, the following recommendations may be made.

- Families may refuse services for a variety of reasons and these will need to be assessed individually. The current findings suggest some parents may benefit from input relating to their own anxieties (e.g. about their child staying away from home) or from information about the potential benefits of respite care. In the face of families who refuse, services need to remain aware of duty of care to the child, as well as to the carer.

- Unmet need may be masked by possible biases in community professionals’ ratings, highlighting the need for child/family perspectives. Further planned data collection from parents will help illuminate this area.

- The importance of a consistent approach for some children with severely challenging behaviour was highlighted by one case. In such cases, benefits may be gained from a clear emphasis on consistency written into individual care plans. Shared understandings and implementations of relevant policy may also facilitate consistency across settings.
- Shared staff training schemes could also facilitate consistency of approach, while increasing the availability of staff trained to manage challenging behaviour.

- An awareness is needed that children on waiting lists, or in between placements, remain in need of respite care. Applying for appropriate respite should not therefore be avoided here, especially if it can provide a valuable continuity and support during difficult transitory periods.
References


Appendices

I: Full list of sources of information used in the earlier study (July 2002)

II: An example part of questionnaire used (i.e. anonymised for 4 children)

III: Cover letter sent to community professionals inviting participation.

IV: Summary of 'degree of change' in unmet need from 2002 to 2004.

V: Evidence of feedback to team
Appendix I: Full list of sources of information used in the earlier study (July 2002).

- A local Children with Disabilities Team (All social workers and managers)
- A local Community Learning Disabilities Team – Children (2 Clinical Psychologists, 2 community nurses)
- A paediatrician from a local community health team
- Special needs register and disability register
- Three head teachers
- Parents (small sample of 6 children)
- Special educational needs team
- Service providers (a day care and 8-bed residential unit; a voluntary sector day care and 5-bed residential unit).
- Local special support and development team.
Appendix II: An example part of the questionnaire used (i.e. anonymised for 4 children).

<table>
<thead>
<tr>
<th>ID</th>
<th>School</th>
<th>Diagnosis</th>
<th>DOB</th>
<th>Need More?</th>
<th>Replte Received now?</th>
<th>Why?</th>
<th>Needs preventing now?</th>
<th>Replte Received now?</th>
<th>Why?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Local School</td>
<td>Autism</td>
<td>xx.xx.90</td>
<td>No</td>
<td>Yes</td>
<td>Social Worker; Yes, not used at home.</td>
<td>Lack of appropriate services</td>
<td>Yes</td>
<td>Social Worker; Yes, needs residential care.</td>
</tr>
<tr>
<td>2</td>
<td>Local School</td>
<td>Autism Spectrum</td>
<td>xx.xx.94</td>
<td>No</td>
<td>Yes</td>
<td>Social Worker; Yes, needs residential care.</td>
<td>Lack of appropriate services</td>
<td>Yes</td>
<td>Social Worker; Yes, needs residential care.</td>
</tr>
<tr>
<td>3</td>
<td>Local School</td>
<td>M.D.</td>
<td>xx.xx.90</td>
<td>No</td>
<td>Yes</td>
<td>Social Worker; Yes, needs residential care.</td>
<td>Lack of appropriate services</td>
<td>Yes</td>
<td>Social Worker; Yes, needs residential care.</td>
</tr>
<tr>
<td>4</td>
<td>Local School</td>
<td>Autism Spectrum, P.A.D.S.</td>
<td>xx.xx.90</td>
<td>No</td>
<td>Yes</td>
<td>Social Worker; Yes, needs residential care.</td>
<td>Lack of appropriate services</td>
<td>Yes</td>
<td>Social Worker; Yes, needs residential care.</td>
</tr>
</tbody>
</table>
Appendix III: Covering letter sent to community professionals inviting participation.

Dear

Re: Children with Learning Disabilities and Challenging Behaviour

Respite Services – Needs & Provision.

I am writing to you regarding an opportunity to update the above piece of work. I am a trainee on the Surrey University Doctorate in Clinical Psychology and am on placement with in for the next 6 months. I have a particular interest in the role of respite as an important support for both children and their families and am keen to update the information we have. This also fulfils a course requirement for a service related research project.

I have spoken to in the first instance, as the social workers are the holders of the information on respite packages and she thought it would be possible to do the updating reasonably easily.

I have enclosed a table of some of the data collected previously along with 3 blank columns that need updating and have scribbled names on so that individuals can be identified by community professionals for the purpose of this update only – the database we have is anonymous and confidential and will of course remain so. This table can be filled in where appropriate and then faxed back to us on the above number, or sent by post. Alternatively, I am happy to arrange to meet with you to collect this information.

I will give you a call shortly to discuss how this update might progress. Thank you in anticipation of your help and if you have any queries at all please call on or . We would be very happy to arrange a meeting to discuss any of this with you further.

Yours sincerely
Appendix IV: Summary of ‘degree of change’ in unmet need from 2002 to 2004.

Need for respite (yes/no)

<table>
<thead>
<tr>
<th>2002</th>
<th>2004</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>8</td>
</tr>
<tr>
<td>?</td>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
<td>6</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>?</td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>Yes</td>
<td>1*</td>
</tr>
<tr>
<td>Yes</td>
<td>?</td>
<td>4</td>
</tr>
<tr>
<td>?</td>
<td>?</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>?</td>
<td>1</td>
</tr>
</tbody>
</table>

*Interestingly, only one family changed from no unmet need in 2002, to reportedly having a need in 2004. Unfortunately, the reason for this was unspecified but the child had been rated as ‘severely challenging’ in 2002.
Appendix V: Evidence of feedback to team

Dear Tarick,

Re: Service Related Project

Just a note to say thank you for presenting the results of your project.

Both the project and the presentation were very useful for the team and generated some interesting and useful debate.

Best Wishes,

Rowena Rossiter

Clinical Psychologist
The personal experience of living with chronic pain following an accident: an interpretative phenomenological analysis.

Year 3

July 2006
Abstract

Aim
Several quantitative studies suggest that chronic pain sufferers may experience increased disability and distress when pain-onset is related to an accident. The aim of this study was to explore the experience of living with chronic pain following an accident from the sufferer’s point of view.

Method
Eight people (three men, five women) on a waiting list to begin a programme of pain management took part in this study. Semi-structured interviews were conducted and the verbatim transcripts of these interviews formed the data.

Results
Transcripts were explored using Interpretative Phenomenological Analysis. A number of themes emerged from the analysis and were grouped under three broad headings: ‘Making sense of accident’, ‘Understanding injury and pain’ and ‘The impact of pain’. Participants described a struggle to understand and accept the chronic nature of their pain. In trying to make sense of their situations, participants made use of their expectations and conceptions of what their injuries should mean in terms of a recovery and treatment process. As a result, ongoing pain was viewed as related to damage and injury and/or a failure in treatment process. Participants described becoming involved in a stressful legal process that undermined their understandings of their pain and formally challenged the legitimacy of their suffering.

Conclusions
Themes are discussed in relation to existing research. Implications for clinical practice are considered and potential areas for further research are highlighted.
INTRODUCTION

Overview
The aim of this study is to explore the personal experience of living with chronic pain (CP) as the result of an accident.

Several studies have suggested that people’s experiences of living with CP may differ according to the type of onset the pain condition has (i.e. pain-onset related to an accident compared with pain that develops with no apparent reason; Turk, Okifuji, Starz & Sinclair, 1996; Geisser, Roth, Bachman, & Eckert, 1996; Waylonis & Perkins; 1994). These studies are few and their findings remain relatively unclear. Nevertheless, a number of speculations have arisen as to the factors that might be particularly salient in understanding the experiences of CP following an accident. These speculations have generally been theory driven, or derived at from the perspective of the researcher and studies adopting ‘an insider’s perspective’ are lacking. It is also often argued that the meaning of pain is of central importance in understanding people’s experiences (Kleinman, 1988). Yet few studies in psychology have explored meaning in relation to chronic pain directly (Osborn & Smith, 1998) and none have looked at this in relation to CP following an accident.

The aim of the present study is not to define what makes accident-related CP different from idiopathic pain (i.e. pain that occurs with no known cause), but to explore in-depth, the experiences of living with chronic pain as a result of having had an accident. A focus of this study will be on how people make sense of the circumstances surrounding the onset of their pain. In addition the study aims explore any ongoing influence the accident has on living with pain.

Chronic Pain

Prevalence
Accurate population estimates of the prevalence of CP are likely to be obscured by a number of factors, including the absence of any standard internationally accepted
definitions, differences in the experience, reporting and assessment of pain (Harstall & Ospina, 2003). Regardless, many commentators agree that CP is one of the most significant causes of suffering in the UK today and a major health problem placing increasing and insatiable demands on the health service (i.e. Osborn & Smith, 1998).

In a systematic review of studies exploring population prevalence rates of chronic pain in several countries between 1991 and 2002, Harstall & Ospina (2003) conclude that prevalence rates of ‘severe’ CP, however defined in the general population, is approximately 11% among adults. Similarly, the British Pain Society reports an estimated 13% of the UK population suffer with a disabling chronic pain condition.

**Definition**

While frequently used in research and in clinical practise, the term ‘chronic pain’ is not a formally established diagnosis (Sharp & Harvey, 2001). Generally, many texts appear to define CP as pain that persists past an expected time of tissue healing or recovery. Melzack & Wall (1996) describe CP as pain that persists after it can serve any useful function. By function, they refer to how acute pain serves to initiate behaviour useful to the recovery process (i.e. bed-rest, finding safety from a source of injury). They suggest that these behaviours appear to fail in CP and may even hinder recovery. Melzack & Wall (1996) add that adequate definitions of pain have been impossible to achieve due to the diversity of pain experiences and our limited understanding, so far, of the pain mechanisms involved.

Nevertheless, the experience of pain has become increasingly recognised as a subjective experience and a range of psychological, social and biological factors are now thought to be important in understanding the relationship between injury and pain (Turk, 1996). Osborn & Smith (2003) suggest that the challenge now upon us is “to understand the relationship between pain, distress and disability, which is neither linear nor causal, but dynamic and multidimensional” (p.66).

**Impact of CP and meaning**

It has been well documented that CP can have a pervasive impact on a person’s life, leading to significant difficulties in physical, emotional, social and occupational
functioning (Melzack & Wall, 1996) as well as impacting on a person’s sense of who they are (Eccleston, Williams & Rogers, 1997). Melzack & Wall (1996) summarise that CP patients become “beset with a sense of helplessness, hopelessness and meaningfulness” (p. 36).

The impact of chronic conditions may be mediated by the meaning that is attributed to experience and how people make sense of what is happening to them (Conrad, 1990). Osborn and Smith (1998) highlight that this has been somewhat overlooked in the psychological literature in that studies directly exploring the meaning of pain have been rare. Kleinman (1988) suggests that a failure to focus on meaning may result in obstacles to helping people with otherwise treatable aspects of their illness experience.

In a study aimed at exploring the personal meaning of pain to sufferers of chronic benign lower back pain, Osborn and Smith (1998) interviewed nine women attending an outpatient pain clinic. Interview transcripts were explored using interpretative phenomenological analysis (IPA) and four main themes emerged from these: searching for an explanation; comparing self with other selves; not being believed; and withdrawing from others. The study highlighted how participants shared a difficulty in finding an explanation for the presence of their pain and how they struggled to establish its legitimacy to others.

All of the participants in Osborn and Smith’s study experienced a gradual-onset of chronic pain, unrelated to a specified event, raising questions as to how this data might have looked in the context of accident-related pain? Would searching for an explanation for the chronic nature of their pain emerge as a dominate theme, given that the point of onset is known? Would issues around establishing the legitimacy of their pain maintain their salience? Several quantitative studies appear to suggest that individuals with accident-related and sudden-onset CP, may present quite differently from those whose pain-onset is gradual or not attributed to a specific event (e.g. Turk, Okifuji, Starz & Sinclair, 1996).

**Chronic pain following an accident**
Following an accident, people may experience a wide range of physical and psychological reactions that contribute to distress and dysfunction (Brewin, Andrews, Rose & Kirk, 1999). For a few people, these reactions may develop into more persistent difficulties with anxiety, phobia, or depression (Kuch, Evans, Watson & Bubela, 1991) or they may develop reactions that are consistent with DSM-IV criteria for Acute Stress Disorder or Posttraumatic Stress Disorder (PTSD) (Harvey & Bryant, 1998). However, research has shown considerable variability in the response of individuals to similar accidents and it has been suggested that the perceptions made about an accident may be more important than the severity of the injuries sustained (Blanchard, Hickling, Taylor, et al. 1996; Ehlers & Clark, 2000).

For a significant proportion of CP sufferers, an accident may represent the start or cause of their ongoing pain condition. For example, Turk et al. (1996) found that 30% of 152 consecutive referrals to a pain clinic in Pittsburgh, USA, attributed the onset of their Fibromyalgia Syndrome to an injury caused by an accident. Fibromyalgia Syndrome (FS) refers to a musculoskeletal syndrome that is characterised by widespread pain (Wall, 1999). Participants in this ‘traumatic-onset’ group reported that their pain symptoms began following a ‘work related-accident’ (41%), a ‘road-traffic accident’ (RTA, 39%) or ‘other accident’ (20%).

Other studies have also demonstrated that a high proportion of their CP samples have attributed an accident as the starting point to their pain. However, comparisons between studies are often complicated by the use of different categories. For example, 23% of Greenfield et al.’s (1992) sample of FS patients attributed their pain symptoms to ‘a sudden event’. While ‘accidents’ represented the majority of ‘sudden events’, other events were also included, like ‘brief medical illnesses’.

Thus, the few studies that have attempted to explore the influence of ‘type of pain-onset’ on ongoing pain have tended to use different categories, making it difficult to explicate the relative contributions of various factors (e.g. the influence of having experienced an accident per se, compared to the sudden development of CP).
Definitions as to what constitutes 'traumatic' may also influence reported rates. For example, Aaron, Bradley, Alcron, et al. (1997) found that some people with FS symptoms reported 'unaccustomed exercise' as the 'physically traumatic event' that precipitated their pain, although these people were 'non-patients' and not seeking treatment.

The focus of this study is on chronic pain that is experienced in relation to an accident, as the recognised point of onset.

**Group comparisons**

Turk et al. (1996) draw attention to a lack of research exploring whether the type of pain-onset has any specific effects on the way patients adjust to their chronic conditions. They suggest that this is surprising, given that a number of studies have pointed in the direction of their being some differences between people who develop pain as the result of an accident, or sudden event and those whose pain develops gradually or for no apparent reason (e.g. Toomey, 1983; Waylonis & Perkins, 1994).

In order to investigate this further, Turk et al. (1996) compared 46 individuals with 'accident-related CP' (from 152 consecutive referrals) to a sample of 46 individuals with 'idiopathic-onset CP', matched by age and gender. All participants were asked to complete a number of self-report inventories, including the Multidimensional Pain Inventory (Kerns, Turk & Rudy, 1985) as an assessment of various aspects of chronic pain, including 'pain severity', 'perceived interference' and 'affective distress'.

Patients with traumatic-onset pain were found to report significantly higher levels of pain severity, perceived disability, affective distress, life interference and to have lower levels of activity compared to patients with idiopathic onset. This was the case, despite the two groups reporting similar levels of physical abnormalities, suggesting that pain severity and disability were not being determined solely on a physical basis. In addition, compensation status was controlled for making it more difficult to explain these findings in terms of financial incentive.
Turk et al. conclude that accident-related pain and idiopathic pain present "quite different clinical pictures" (p. 429) and they recommend further explorations of the experiences of such subgroups of patients in order to facilitate the development of "more efficient clinical pathways and maximise the cost effectiveness of treatments" (p. 430).

Similarly, Geisser et al. (1996) observed that an 'accident-related CP' group reported higher levels of disability compared to a 'no accident' CP group, as assessed by the Pain Disability Index (Tait, Chibnall & Krause, 1990).

Additionally, these authors divided their 'accident-related' group into a 'Low-PTSD' and a 'High-PTSD' group. This was done in accordance with a median split on a modified Posttraumatic Chronic Pain Test (Muse & Frigola, 1986); a test designed to assess PTSD in CP sufferers. No data regarding the validity of this measure was given and the modified scale consisted of only six items. Nevertheless, three groups (No PTSD/No Accident, Accident/High PTSD and Accident/Low PTSD) were formed and compared on measures of self-reported pain, disability and affective distress. The findings indicated that patients in the 'high PTSD/accident' group reported greater 'affective distress' and higher 'levels of pain' than both of the other groups.

The above studies suggest that the experience of an accident as the starting point of an ongoing pain condition is potentially associated with more problematic experiences in living with CP and increased disability. Geisser et al. (1996) add the suggestion that individuals with more problematic psychological responses following an accident (i.e. higher PTSD scores) may report more intense pain and increased affective distress than those less disturbed by their accident.

Other studies have offered some support for the observed trend towards greater difficulties in patients with posttraumatic onset of pain, though findings remain tentative. Toomey et al. (1983) found that 'post-traumatic onset' was related to higher scores on a measure of general distress (the SCL-90-R) and on the McGill Pain Questionnaire - a frequently used measure of subjective pain experience, including sensory and affective components (Melzack, 1975). However, unlike Turk et al.'s
study, no differences emerged for functional impairment or coping. This difference may be partly accounted for by the different assessment tools used and different groupings (i.e. ‘accident-related’ and ‘posttraumatic-onset CP’).

Waylonis & Perkins (1994) compared individuals with ‘posttraumatic FS’ with people who developed pain for no apparent reason, on a range of measures. Onset of pain in the ‘posttraumatic FS’ group included road traffic accidents (RTA, 61%), injuries at work (13%), surgical procedures (7%), sports injuries (5%), physical abuse (2%), or ‘other trauma’ (12%). Group differences emerged on 14 of 32 possible FS-related symptoms. Specifically, patients with ‘post-traumatic FS’ were more symptomatic with regards to fatigue, sensations in hands and feet, rib cage pain, waking during the night, morning fatigue and stiffness and were less likely to report pelvic pain, problems getting to sleep, swollen glands and sexual dysfunction in comparison with the ‘idiopathic FS’ patients. However, Waylonis & Perkins are somewhat dismissive of these differences, suggesting that their groups showed largely similar histories and profiles and that differences were ‘slight’, potentially due to sampling differences. They comment that perhaps the most noteworthy finding in their study were reports by members of the ‘posttraumatic FS’ group that they had ‘simply learned to live’ with their condition.

PTSD and chronic pain

Given the significant proportion of individuals who develop ongoing pain as the result of trauma, it is perhaps not surprising that several studies have found a high prevalence of PTSD in chronic pain samples (e.g. Muse, 1986; Sherman, Turk & Okifuji, 2000). More recently, there has been an increase in interest around the interaction of CP and PTSD (Sharp & Harvey, 2001). The general picture that seems to be emerging is that PTSD symptoms are related to further disability and distress in CP sufferers (Sharp, 2000) and poorer pain treatment outcome (Kulich, Mencher, Bertrand & Maciewicz, 2000).

However, it should be noted that PTSD-like symptoms may be found in CP patients who have not had an accident. For example, Sherman, Turk & Okifuji (2000) found 56% of 93 consecutive FS referrals could be classified as having ‘clinically significant
levels of PTSD-like symptoms'. However, only half of the ‘PTSD’ group reported an injury to have precipitated their pain and this rate was not significantly different from the ‘No PTSD’ group. Thus ‘PTSD-like symptoms’ may have a high prevalence in CP patients, regardless of having had the experience of an accident.

Sharp and Harvey (2001) have put forward a number of ways that PTSD and Chronic pain may be seen to mutually maintain each other. Where relevant, these will be referred to in the next section.

Hypotheses as to the experience of CP following an accident
The above studies suggest that individuals who experience pain that is related to an accident may differ from those whose pain onset is idiopathic on a number of measures. These studies have used cross-sectional, between-groups designs, obtaining largely correlational data and have only therefore been able to speculate about causal relationships or underlying processes. Nevertheless, a number of interesting speculations have been put forward in terms of what might be particularly salient in understanding the experience of CP following an accident.

One possibility is that the experience of an accident feeds into a desire to avoid re-injury. Turk et al. (1996) suggest that fear of re-injury may be particularly important where a person perceives or labels him/herself as ‘injured’. A fear of re-injury then contributes to disability via decreased activity and further de-conditioning (Vlayean & Linton, 2000). No studies could be found that explored fear of re-injury/damage in relation to type of pain onset.

It has been demonstrated that following a traumatic event, individuals may try to avoid thoughts or reminders of the event, as these may be associated with high levels of distress (Ehlers & Clark, 2000). It is possible that pain may become a reminder of the distressing event associated with pain-onset and may increase a person’s desire to avoid activities that associated with pain, further contributing to muscle de-conditioning (Geisser et al. 1996; Sharp & Harvey, 2001).
Another suggestion put forward by Sharp & Harvey (2001) is that coming to terms with a traumatic event may place extra demands on a person's coping skills and attentional or cognitive capacity. This additional burden may then limit an individuals' capacity to employ adaptive strategies in the management of their pain.

An issue that may have significance in understanding the experiences of people with accident-related CP, is the impact of having a recognised 'cause' or point of onset. As mentioned above, research suggests that individuals who do not have a recognised 'cause' of their pain encounter difficulties in 'legitimising' their pain to others and other people may be perceived to be associated with a questioning of the individual's complaints (Osborn & Smith, 1998). From this point of view, we might expect people with pain that has a recognised point of onset to be better off in relation to justifying or legitimising their pain. Miles (2005) points out that while research has tended to focus on understanding what it is like to live with 'unexplained' pain, relatively little work has examined the difficulties facing those who know the cause of their pain.

Another factor that might be important is a person's perception of who is at fault for their injury or pain. DeGood & Kiernan (1994) present findings from a survey of 200 CP patients, completed prior to their initial visit to an outpatient university hospital pain centre. 38% of their sample reported holding somebody (i.e. an employer, or other) accountable for their CP. This perception of fault was related to self-report ratings of decreased mood and poorer response to treatment, compared with when nobody was felt to be responsible.

Similarly, patients who have experienced an accident where they hold someone accountable may experience heightened anger. Anger and angry rumination about an event have been shown to be correlated with ratings of pain severity and pain-related interference (Fernandez & Turk, 1995).

Blame and anger may also be related to engagement in a litigation process. Romano (1990) has commented that litigation issues can create stress which in turn may slow down a person's recovery process and exacerbate symptoms of FS. He suggests that the majority of patients continue to seek treatment after settling their compensation.
claims and that this counters 'the common perception' of malingering in patients who are seeking compensation. Romano highlights that the major obstacles then, for people with posttraumatic FS, are delay in the time it takes for them to receive a diagnosis, misperception of malingering and the stress involved in the litigation process.

Rationale for the current study
A number of ideas have been uncovered in a review of the literature, highlighting what the experience of chronic pain following an accident might be like for the individual sufferer. However, the studies reviewed above have predominately used quantitative research methods, usually focussing on differences between groups of CP sufferers with various circumstances of pain-onset. Most of the hypotheses generated from the above studies have been theory-driven, or generated from a researcher's perspective. Few studies have gained an 'insider's perspective' in relation to the experience of living with CP (Osborn & Smith, 1998) and none have explored the personal experience of living with CP following an accident. It would therefore seem useful to conduct an exploration of this area from the point of view of the individual sufferer. Highlighting the particular difficulties and issues faced by this group and how they make sense of their experiences may therefore help to optimise the efficacy of treatment for these people.

Adopting a qualitative approach was thought to be useful in attempting to gain an 'insider's perspective' on living with chronic pain following an accident. While 'qualitative research' refers to a diverse range of methods, all of these are generally concerned with eliciting meaning and gaining understanding, as opposed to a more 'quantitative' stance of predicting and controlling (Lyons, 1999). A qualitative approach would therefore enable questions to be asked about the personal context of CP following an accident, the meaning of CP to the individual and the lived experience of this (Lyons, 1999).

Crossley (2002) has advocated a shift towards using qualitative research methods in the study of chronic pain to enable an exploration of the 'meaning system' of individuals and to obtain information that is rich and detailed within its context. This
would then serve to complement other approaches to research in this area. Crossley adds that while mainstream health psychology approaches do not deny the importance of meaning, the need to maintain an 'objective' approach to gathering data, judged valid along the lines of biomedical data, means information that is harder to quantify may be neglected as variables are factored out or held constant. A qualitative approach may therefore usefully contribute to the emergence of new insights or may serve to complement existing theories.

**Aims and research question**

The overall research question being addressed in this study is: what is it like to live with a chronic pain condition that has developed as the result of an accident?

Specific aims are to:

1. Explore how people understand the onset of their pain and the circumstances that led to their pain,

2. Gain an understanding of how people understand the ongoing or chronic nature of their pain, and

3. Explore any influence of the accident on current living with CP.
METHOD

Rationale for methodology
The aim of this study was to explore the personal experience of what it is like to live with chronic pain following an accident. For this purpose, IPA was considered to be the most suitable approach, partly because it is specifically designed towards capturing an individual's subjective experience of the world, at a particular time, or within a particular context (Smith, 1995). As a 'phenomenological' approach to data analysis, IPA is concerned more with an individual's perceptions of reality, as opposed to aiming for objective statements of an objective reality (Willig, 2001). IPA's focus on personal accounts therefore makes it a useful means of analysis when exploring the meaning people attach to their experiences (Shaw, 2001).

In addition, IPA may involve approaching data collection in relatively flexible and open-ended ways, with the aim of facilitating participants' descriptions of their experiences. This approach therefore has the ability to reveal unanticipated views of the phenomena in question, making it particularly useful for exploratory endeavours (Shaw, 2001).

Participants
Participants were recruited on the basis of being potentially able to provide insights into the research question. This is based on the principles of 'purposive sampling', commonly used as the basis of data collection in IPA (Willig, 2001). Participants had the shared experience of having lived with chronic pain following an accident. 'An accident' was defined as an unexpected and sudden event that was deemed to be 'an accident' by the participant.

Specifically, inclusion criteria for this study were:

- Having lived with chronic benign pain for at least six months
- Having experienced 'an accident' that is attributed by the person to be the 'cause' of their pain.

Exclusion criteria were:
• Previous attendance on a pain management course
• Severe and enduring mental health difficulties
• Being under 18 and over 65 years old.

Recruitment

Two outpatient pain management services in Surrey agreed to help in recruiting participants for this study. However, due to delays in gaining an honorary contract at one of these services (a requirement for researchers within the Trust) and limited time, no participants were recruited from this service.

Two psychologists, a specialist nurse and a physiotherapist who were routinely involved in the screening of referrals to the pain management service were informed as to the aim and purpose of this study and the inclusion/exclusion criteria. Potential participants were then identified at screening appointments: an appointment to assess suitability for the pain management service.

At this point, the aim of the study and the interview procedure were briefly discussed with potential participants and they were given an invitation pack. This consisted of an invitation letter (appendix A), an information sheet (appendix B), a consent form (appendix C), a reply to invitation sheet (appendix D) and a ‘freepost’ envelope. Anybody not returning a reply sheet within two weeks was sent a follow-up letter (appendix E). Those agreeing to take part were contacted by phone and a meeting set up for the interview.

Eight people (three male, five female) aged between 35 and 58 agreed to take part in this study. Basic demographic information can be found in table 1 below. As can be seen from this, five of the participants reported that their pain started as the result of an injury at work, two described pain onset as related to a road traffic accident and one person described a fall on her bicycle. The length of time since their accidents ranged from between three and nine years.
Table 1: Basic demographic data for each participant

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnic Background</th>
<th>Current Marital Status</th>
<th>Qualification</th>
<th>Current Employment</th>
<th>Date of Accident leading to pain</th>
<th>Main site of pain</th>
<th>Type of Accident</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Max</td>
<td>M</td>
<td>50</td>
<td>White British</td>
<td>Married / Cohabiting</td>
<td>None</td>
<td>Not working</td>
<td>Feb 02</td>
<td>Lower Back, Shoulde r</td>
<td>Injury at Work</td>
</tr>
<tr>
<td>2. Lucy</td>
<td>F</td>
<td>46</td>
<td>White British</td>
<td>Married / Cohabiting</td>
<td>GCS E</td>
<td>Full Time Work</td>
<td>May 03</td>
<td>Lower Back, Shoulde r</td>
<td>RTA</td>
</tr>
<tr>
<td>3. Brenda</td>
<td>F</td>
<td>58</td>
<td>White British</td>
<td>Married / Cohabiting</td>
<td>None</td>
<td>Not working</td>
<td>Jun 03</td>
<td>Lower Back, Buttock</td>
<td>Injury at Work</td>
</tr>
<tr>
<td>4. John</td>
<td>M</td>
<td>35</td>
<td>Black British</td>
<td>Single</td>
<td>GCS E</td>
<td>Not working</td>
<td>Feb 03</td>
<td>Ankle, Foot</td>
<td>Injury at Work</td>
</tr>
<tr>
<td>5. Paula</td>
<td>F</td>
<td>36</td>
<td>White British</td>
<td>Single</td>
<td>GCS E</td>
<td>Not working</td>
<td>Jan 97</td>
<td>Hands, Wrists</td>
<td>Injury at Work</td>
</tr>
<tr>
<td>6. Alan</td>
<td>M</td>
<td>45</td>
<td>White British</td>
<td>Married / Cohabiting</td>
<td>GCS E</td>
<td>Not working</td>
<td>Sept 03</td>
<td>Legs</td>
<td>RTA</td>
</tr>
<tr>
<td>8. Jo</td>
<td>F</td>
<td>54</td>
<td>White British</td>
<td>Married / Cohabiting</td>
<td>None</td>
<td>Not working</td>
<td>Jan 01</td>
<td>Neck</td>
<td>Injury at Work</td>
</tr>
</tbody>
</table>

*Participant names have been changed to maintain anonymity.

Sample size

Smith & Osborn (2003) suggest that there is no right answer in deciding on sample size and that this may in part depend on the richness of the cases obtained. Guidelines for studies using IPA generally suggest obtaining a sample size that allows the researcher to retain an overall picture of the individual cases and the location of themes within them (Warwick, Joseph, Cordle & Ashworth, 2004; Smith, 1996). A sample size of around six has been recommended as sufficient to enable an
exploration of the similarities and differences between participants, without becoming overwhelmed by the data (Smith & Osborn, 2003).

**Procedure**

Semi-structured interviews are the most widely used method of data collection in phenomenological research (Willig, 2001). They allow the researcher flexibility in adapting questions to fit with participants' responses and to probing interesting or important areas as they arise (Smith & Osborn, 2003). This approach therefore seemed the most suitable for this study.

An interview schedule was therefore constructed using guidelines presented by Smith (1995) and Smith & Osborn (2003). Initially, the relevant literature was consulted in relation to accident-related chronic pain to help identify key areas of relevance. Broad areas of interest were drawn up and discussed with two clinical psychologists working in pain management. The aim of the discussion was to highlight areas that might be particularly important to cover in order to explore the lived experience of CP following an accident. The main topic areas were then put into a logical sequence and open-ended questions were generated with possible follow-up questions or probes.

The interview schedule was then discussed with the two clinical psychologists as to it's relevance in relation to the research question. The main aims covered by the schedule were to:

1) Obtain an understanding of how people make sense of the onset and persistence of their pain and the consequences of their accident;
2) Gain insight into the kinds of thoughts people were having about their accidents;
3) And to highlight any influence the accident may still be having on coping with pain;

See appendix F for interview schedule.

In line with Smith and Osborn's (2003) suggestions, an overall aim of the schedule was to provide a freedom for participants to recount the experiences they deemed significant.
The first interview served as a pilot run for the schedule. The initial transcript from this interview was discussed with a clinical psychologist in pain management with this in mind. It was decided that no significant changes were necessary and the transcript from the initial interview was retained for subsequent analysis.

The interview
According to their preference, three participants were interviewed at the pain management service while others took place at participants' homes. The schedule was used as a guide to the interview rather than as a strict outline of questions (Smith, 1995) and each interview lasted about one hour. At interview, participants were asked if they had any questions/concerns before starting. They were then asked to complete the consent form they had been sent and a brief background questionnaire (see appendix G). All interviews were audio-taped and then transcribed verbatim with all identifiable information changed.

The researcher found it useful to transcribe interviews himself, as an initial means of familiarising himself with the data and the way in which words were spoken. The verbatim transcripts served as the data for the analysis (see appendix H for an example transcript).

Ethical considerations
This study involved participants talking about their experiences of chronic pain and the accident that they attribute to be the 'cause' of their pain. It was anticipated that some participants may find this difficult or distressing and a number of steps were considered in order to minimise this:

1. Participants were made aware of the content of the interview and that it might be upsetting. Participants were sent an information sheet and signed a content form prior to the interviews. Participants were assured of confidentiality and anonymity and were reminded that they could end the interview at any stage.
2. They were given the telephone number of a clinical psychologist in pain management who they could call before or after the interview should they feel the need.
3. Participants were waiting to attend for pain management. Any issues that arose as a result of the interview could have been addressed when they started to attend.

4. The interviewer was a trainee clinical psychologist in his third year of training, with one year's experience as an Assistant Psychologist working with people with chronic pain conditions.

Another ethical issue was that participants may have thought their care was dependent on participating in this study. It was made clear that their quality of care was in no way impacted by a decision to participate or not.

Approval for this study was obtained from the University of Surrey Ethics Committee and from the relevant Local Research Ethics Committee (see appendix I) and Research and Development Office (see appendix J).

Analysis

Despite being a relatively new and continuously developing method (Shaw, 2001), detailed guidelines for the analytic process involved in IPA are available (Smith, 1999; Jarman, et al. 1997). Transcripts were analysed following guidelines outlined by Smith & Osborn (2003) and Willig (2001). In order to facilitate evaluation of the work and maintain 'transparency' (Smith 1995), steps followed in the analysis are detailed here.

Initially, all transcripts were read through to select one that appeared to be a rich account of living with CP following an accident. The account chosen was from a participant who had seemed to be particularly articulate in her experiences and offered insightful and full descriptions. The transcript was read through a number of times to familiarise myself with it and notes were made on it that included any thoughts, observations, summaries, connections and/or contradictions that occurred during each reading (in the left hand margin). The transcript was then read through again and any emerging themes were noted on it (in the right hand margin). These were usually keywords or phrases that attempted to capture the essence of the text. A section of this transcript may be found as appendix K with examples of notes made on it during
the analysis. The left hand margin of the example section shows preliminary notes made on the transcript and the right hand margin shows any noted emerging themes.

On a separate sheet, emerging themes were then listed (to form a ‘preliminary list’ of themes). This was examined for connections and to see if any themes clustered together or were essentially representing the same phenomena. Themes that did not appear well supported in the transcript were dropped and similar themes may have been combined. Themes that seemed to cluster together well in representing a particular category were placed together under superordinate theme titles. The transcript was continuously consulted when clustering themes, to ensure these were represented in the data. The result of this process was that themes were ordered into a ‘master list of themes’ (see appendix L for the master list of themes to emerge from the first transcript analysed).

Smith, Jarman & Osborn (1999) suggest that one may proceed in a number of ways when more than one transcript is to be analysed. For example, the process of analysis may begin anew for each transcript, generating a master list for each that may then be read together leading to a consolidated list of themes for the group. The procedure selected for this study was to use the master list of themes generated from the first transcript to begin the analysis of the second transcript (as used by Osborn & Smith, 1998). Smith et al. (1999) suggest that this works well with studies that use small sample sizes (up to ten participants) that allow one to retain an overall picture of each individual case.

Thus the procedure involved reading through the second transcript in a manner similar to that described for the first (i.e. repeated readings making preliminary notes, followed by notes of emerging themes), but also using the master list of themes developed from the first transcript, to note any similarities and differences in the second. During this process, examples of themes already identified were noted. Any new emerging themes were highlighted, evaluated as to their prominence and then incorporated into the master list of themes. Again, transcripts were continuously consulted to ensure themes were represented in them. This procedure was repeated for each subsequent transcript, using the master list of themes emerging from the
previous transcripts to begin analysis of the next. After working through each transcript in this manner, a final master list of themes was eventually produced (see Analysis section).

While the above describes (as accurately as possible) the stages of the analysis, it should be noted that the process appears somewhat more linear (for the sake of clarity) than was my experience of it. In reality, the process was more of a repetitive and cyclical one than appears on paper.

The credibility of the study
Osborn & Smith (1998) state that establishing the validity and overall credibility of qualitative research is just as important as with other forms of research. However, they add that because of its different epistemological roots, qualitative research should be evaluated in a manner appropriate to this form of research; the criteria used to evaluate quantitative methods being incompatible. The aim of validity checks on this work is to ensure that the emerging account is "sound" and "warrantable from the data" and "not to prescribe the singular true account of the material" (Osborn & Smith, 1998, p. 69).

Elliot, Fischer & Rennie (1999) have produced a set of guiding principles to consider when carrying out qualitative research. In accordance with these:

- Descriptive data is provided for the sample, enabling readers to evaluate the relevance of findings to them or the patients they work with.
- Verbatim excerpts from transcripts are provided with themes, so readers may evaluate or challenge the fit between the data and interpretations.
- It is noted that any conclusions made as a result of the findings from this study are limited to the group of participants that took part. This is to guard against making any general statements that extend beyond the aims of this study (i.e. about other people with CP, or other contexts).
- Credibility checks were used to minimise bias, or challenge any interpretations that were only minimally grounded in participants' accounts. These checks included the following.
My university supervisor read through two transcripts and commented on themes that had emerged from my analysis.

My field supervisor, a clinical psychologist working in pain management, also read three transcripts and commented on the extent to which themes appeared grounded in the data.

I attended a discussion group of other trainees using qualitative approaches where a number of excerpts from transcripts were discussed with the aim of challenging or testing my interpretations.

Elliot et al. (1999) also suggest that a researcher may use their original participants as a means of checking the credibility of their understandings or interpretations, though it is interesting to note that this method rarely appears in published studies using IPA. It was decided that this particular method did not appear to be useful in the current study. One of the reasons for this is that IPA places a specific emphasis on the interpretative nature of the analysis and it was deemed somewhat unhelpful to add a further level of interpretation to this (i.e. participants’ views of the researcher’s views). In addition, in line with the aim of credibility checks in IPA (i.e. to ensure interpretations link back to the data, not to test for the ‘correct’ interpretation) participants would be faced with a rather difficult task of having to remain focused on checking the researcher’s interpretations, rather than switching back to their previous roles as interviewees and ‘informants’ (i.e. elaborating or correcting their original stories). Another consideration related to the potential for a power imbalance between researcher and participant and the extent to which participants would feel able to comment on the researcher’s views. This cast some doubt on the potential usefulness of such a check.

‘Owning my perspective’

Given the active role of the researcher in making interpretations of participants accounts, Elliot et al. (1999) suggest that researchers aim to ‘own’ their perspectives and to specify their “theoretical orientations and personal anticipations” (p. 221). This is so that readers are helped in understanding or evaluating the interpretations made.
My motivation for wanting to explore this area of chronic pain stems from having worked as an assistant psychologist at an inpatient pain management service in London for about a year prior to training. I recall observing significant variations in people’s stories of pain and in their ways of dealing with this chronic condition. I also noted the very observable differences in a number of patients following their attendance, in terms of improved confidence and mobility. Pain management at this service was provided predominately from a cognitive-behavioural perspective. I was mindful therefore that these experiences could shape my understanding of CP and the experiences reported by participants.

Given my reading of the literature, I had some expectation of clear and explicit links between the accident that represented the cause of pain and coping with ongoing pain. I expected that participants would report some ongoing distress relating to their accidents, if only in relation to its significant aftermath in terms of pain and disability.

I describe myself as a white British/Lebanese male, in my early 30s and I live with a partner. I have never experienced chronic pain or ongoing disability.
ANALYSIS

Overview of Themes
The overall aim of this study was to explore the personal experience of living with chronic pain following an accident. Specific aims were to explore a) how people understand the circumstances surrounding the onset of their pain, b) how they understand the ongoing nature of their pain and c) whether there are links between the accident and current coping with pain. A number of themes emerged from participants' accounts and these were grouped under three main broad headings. These can be seen in Table 2.

Table 2: Themes Emerging from Participants' Accounts

<table>
<thead>
<tr>
<th>1. Making sense of accident</th>
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<tr>
<td>a. Understanding what happened and establishing responsibility</td>
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<tr>
<td>b. Thinking about the accident</td>
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<td>2. Understanding injury &amp; pain</td>
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<td>a. Uncertainty around injury</td>
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<td>b. Assumptions/expectations about injury and recovery</td>
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<td>c. Acknowledging chronicity</td>
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<td>3. Impact of chronic pain</td>
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<td>a. Sense of self</td>
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<td>b. Difficulties maintaining lifestyle</td>
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<td>i. Social difficulties</td>
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<td>ii. Difficulties at work</td>
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<td>c. Increased sense of vulnerability</td>
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Description of Themes
The following section aims to provide a narrative account around these themes using extracts from the transcripts where appropriate. The findings illustrate how participants make sense of their accidents and understand the subsequent development and persistence of their pain. They highlight how participants engage with the medical profession in searching for a solution to their pain, holding assumptions and
expectations of a recovery and treatment process. Disappointment at the failure of repeated attempts emerges from participants’ accounts and how they adapt to a view of their pain as ongoing. The findings also highlight the pervasive impact that living with ongoing pain and restricted mobility following an accident can have on an individual’s life.

1. Making sense of the accident

1.1. Understanding what happened and establishing responsibility

Participants were generally able to give clear accounts of the sequence of events involved in their accidents, leading to identifiable points of injury. In doing so, each participant also gave a description of the factors they believed were responsible for their accidents and the people they blamed. All participants, except Vicky, attributed the cause of their accident to an external factor.

Specifically, John, Alan, Jo, Brenda and Paula described the cause of their accidents in terms of Health and Safety issues at work, while Alan and Lucy attributed a driver of a car as responsible for their accidents. Brenda, for example, relates how, as an auxiliary nurse on a stroke unit, she had tripped over some wires while attempting to move a patient and had hurt her back. She holds her employer accountable for this, given that she had verbally related the potential risk these wires had posed, prior to her accident:

_I blame the hospital a lot, I do. If those wires hadn’t been under the bed, they should have been hooked up_ (Brenda).

Paula’s account is somewhat unique in ascribing responsibility for her accident to an individual; her supervisor at work. She recalls how he had asked her to lift a heavy object despite knowing that she had recently hurt her hands and did not feel able to do the task. She reports still feeling anger and blame towards him, nine years on from the event.

1 Participant names have been changed to maintain anonymity.
All participants except Vicky had been, or were, involved in seeking compensation for losses following their accidents. Over time, this process had the potential to become a source of frustration and anger for participants undermining their accounts of their accidents. Participants describe how they found themselves being blamed for their accidents and how this was in contrast to their accounts. For example, Max describes attributing his accident to the brakes on the fire engine he was driving and to wet weather conditions. This was in contrast to the account put forward by the organisation he worked for:

_They said that because there was nothing wrong with the fire engine, that I must be to blame, for going too fast. But what I can’t understand was that I was on my way to an emergency call. It weren’t as if I just going back to the station_ (Max).

Similarly, Brenda relates how her employer had placed accountability back with her, arguing that she should have made a written account of the dangers posed by the wires, prior to her accident. She described feeling angry about this and somewhat let down by the employers she had worked for, for the last 15 years.

_I felt a bit, well you know, after 15 years you’d expect them to do something. But once it happened, they didn’t really want to know. I might have got my appointments quicker than most people do but no, I don’t know...I thought they’d just given up on me in a sense_ (Brenda).

Her frustration at her employer’s reaction to her accident was exacerbated on finding out that nothing had subsequently been done about the cause of her accident, rendering the event somewhat meaningless:

_I went to a meeting with my Union Rep and I said to them ‘are those wires still under the bed’ and he said ‘yes’. Well to me that is ridiculous. Something should have been done about them. I was so annoyed over it. They haven’t learnt from what happened to me_ (Brenda).
Failure on the part of 'the other' to accept responsibility for the accident was associated with 'disappointment' and 'frustration' and an undermining of participants accounts of what happened. A clear example of this is given by Lucy who describes how the oppositional view adopted by the defendant in her compensation claim, led to a doubt in her mind as to what had happened during her road traffic accident, in which another driver drove into the back of her vehicle:

*It wasn't my fault, but you do start to doubt yourself and ask yourself, 'did I go into her?' Well there was no way I did* (Lucy).

Having their accounts undermined meant that participants were pressed into a position of needing to 'prove' that their pain began as a result of the accident they experienced. In the face of a large organisation, with more resources than themselves, participants related feeling somewhat powerless:

*That wasn't one person blaming me, it was an organisation. It's not as if I can go and have a go at someone. You see what I mean? You've not got someone in your face telling you you're to blame. So I blamed the machine, but there's no way I can prove otherwise. So you gotta forget about it* (Max).

*I can't prove that the accident made me retire. Well they said I could appeal, but I thought what's the point, they're just gonna say the same thing. So I just left it* (Brenda).

**1.2. Thinking about the accident**

All participants described experiencing a period of rumination in the weeks that followed their accidents but that this faded over time:

*Well I used to run through it in my mind. Could I have gone any slower. If I done this that way. If I hadn't let go of the steering wheel, would I have hurt my back. If I'd taken a different route* (Max).
However, Paula, Alan and Lucy also reported experiencing somewhat more distressing images or dreams about the events that took place, for a period of time following the accident:

*For about the first two years, when I was going off to sleep, I would wake up with 'the fall', as if it was real, like it was happening again, but it would only happen as I was going off to sleep. I would wake up suddenly, you know, but I don't get that anymore (Paula).*

*I used to wake up thinking about it. Used to wake up with a jump, thinking about the bonnet. I could see the bonnet of the car coming at me. I only saw the bonnet of the car for a split second but I had that image in my mind a lot after (Alan).*

Paula clarified that her distressing dreams could make matters worse by increasing her levels of tension, but not by increases in pain:

*When I used to wake up like that I used to be very tense, but the pain was there 24 hours a day. It was just the rest of me that felt worst when I felt so tense thinking about the fall. Even the painkillers I was just in pain all the time (Paula).*

Over time, participants described having fewer thoughts about the accident and instead, becoming more concerned with their ongoing pain and the impact of their physical limitations (as opposed to the cause of them):

*I don’t think about the accident at all now, only when I’m asked about it (Lucy).*

*It’s like it’s [the accident] gone. It’s all in the past. There’s nothing I can do about it. My back is still bad and I’ve got to get on with that now (Max).*

Participants described how not thinking about the accident may have been something of a necessity, in terms of coping with the present. They related a degree of anxiety around the prospect of continuing to dwell on it:
If you try to pick apart exactly what happened or think about it too much you'd probably go crazy. You know. What can you do? It happened (Alan).

You have to put it to the back of your mind and not open that little gap, every time you go to a set of traffic lights, or when you are in pain. You can't. Because it would ruin your life I think, if you kept going on and on over it. I just block it off (Lucy).

Brenda and John related how their anger and frustration towards those they held to be responsible for their accidents had made thinking about the accident difficult. John describes actively blocking out thoughts of the accident for this reason:

I've blocked it out. I get too angry. That it could have been avoided... if they had done what they were supposed, I wouldn't be in this situation (John).

John added that he does not see any links between his frustration or anger in this process and his experiences of pain:

Anger doesn't make the pain worse or better. The pain is there regardless. How I feel doesn't affect the pain. The pain affects the way I feel (John).

While describing that they did not think about the accident on a regular basis, those involved in litigation related how this process involved repetitive questioning about the accident and its aftermath and a number of visits to professionals for assessment. This had the potential to be distressing as participants were asked to repeatedly tell their stories and recall their losses:

Every time I go for a medical to do with it [his compensation claim] I have to explain what happened. That can be really monotonous. It makes you think about the accident and the pain and all the things that have changed because of it (Alan).

I had to go and see doctors and go and see other people, or they were coming to see me and write reports on me and I had to talk about it all the time. In the end it became
automatic, I got really bored telling the same story. So in the end I settled out of court because I didn’t feel like I could go on, for another year (Paula).

Lucy highlighted being concerned that she might have to attend court and that this would mean having to think about the accident:

If I have to go to court, well it [the accident] might all come back again and I’ll have to relive it, to explain it all. I don’t think I should be put through it really, you know? Hopefully, I won’t have to (Lucy).

2. Understanding injury and pain

2.1. Uncertainty around injury

While participants were able to describe the sequence of events involved in their accidents, they reported being far less certain as to what had actually happened during their accidents in relation to injury or their bodies. Their descriptions of their injuries varied in detail but seemed relatively vague:

So I went down a hill, on my bike and hit this bump in the road, which made me twist round. And as I twisted I made a huge thump. But I don’t really know what I did and nobody still really knows what I did. (Vicky).

I held on to the steering wheel which put my shoulders out. I thought I’d broken my back at the time but it turned out I didn’t... My spine was crushed in the accident I presume. A crush injury to a disk apparently (Max).

I think my back just jolted and twisted and that was it (Lucy).

Participants related that they were not content with the explanations they had as to the extent and nature of their injuries. For example, Paula related receiving the results of x-rays taken following her accident that showed no noticeable injury or damage to her wrists. She described experiencing increasing levels of pain without knowing what her injury was and she reported feeling frustrated with health professionals over this:
They [medical consultants] didn’t know what was wrong so they gave me any old explanation. It felt like that for a long time at different appointments (Paula).

Uncertainty in relation to injury and pain appears to be fuelled by conflicting or alternative explanations from different professionals. Involvement in litigation contributed to this by encouraging participants to attend assessments with various professionals:

I’ve had so many different opinions. Because I’ve been to see people in different fields and they all give you a slightly different reason (Max).

Over time, these appointments present participants with alternative explanations as to their injuries and pain. Participants described how they were presented with alternative explanations that attempted to minimise or undermine the significance of the injury they sustained during the accident: Max, Brenda, Lucy and Jo were all told their pain may have been due to a general deterioration with age, or ‘wear and tear’, rather than to their accidents and this conflicted with their understanding of the onset of their pain. These ‘alternative’ explanations were met with anger and frustration as they were presented within the context of a litigation process that undermined their accounts and challenged their lived experience:

His attitude was ‘you know, people of your age, if I pulled nineteen people out off the street, they’d all have the same sort of degenerative neck pain to what you’ve got’. And I thought ‘Bollocks to you, I’m sure that’s not right’, cos’ I wasn’t like this beforehand. Maybe it had made it worse, but I wasn’t like it before (Jo).

The day that I hurt my back, the nerve trapped, so it’s nothing to do with wear and tear or my age as far as I’m concerned. They’re saying that in 2 or 3 years time I might not have been able to work anyway, because my back might have been bad. But it was clearly the accident that made it worse. This is what annoys me. The fact that they try to make it sound like, well, she had a back ache years ago so it’s nothing to do with the accident (Brenda).
Brenda relates how an explanation she was given for her pain did not fit with her perceptions of her injuries. This mismatch appeared to contribute to her uncertainty regarding her injury and pain:

*I thought I had broken something. You know at the base of my spine. I really thought I had cracked something. When they said to me it’s a trapped nerve, well a trapped nerve is in the spine and not where my pain is. They tried to explain to me that it throws the pain around there, but to me I always think it’s that bit that I’ve hurt or injured* (Brenda).

### 2.2. Assumptions/expectations about injury and recovery

In relating their understanding of the ongoing nature of their pain, participants’ accounts revealed expectations and assumptions regarding injury and the recovery process (i.e. what their injuries should mean in terms of an appropriate recovery time, or an appropriate level of treatment). These expectations of recovery and treatment appeared to be related to how participants made sense of their pain.

For example, all accounts revealed an expectation that injuries will heal with time, or with appropriate treatment; nobody expected their pain to be an ongoing issue:

*I thought my back was going to get better. I didn’t think I’m gonna have years of back pain. Because of something that happened. I just thought I’ve hurt my back, it will heal. That was how I looked at it. I thought, well it might bloody hurt at the moment, but it will heal* (Brenda).

*I was expecting it to get better, but it was getting worse and worse* (Paula).

In addition, participants revealed expectations of a medical profession that will sequentially assess, clarify and treat, in response to a person’s injury. These expectations are neatly summarised by Vicky:
You know, you think I've got an appointment and you think great they'll be able to tell me what the matter is. And then they'll be able to cure it. I guess that's modern thought isn't it, you sort of think you can cure anything nowadays you know, because medical science has evolved so much (Vicky).

In the context of these expectations, participants appeared to make sense of their ongoing pain as a failure in relation to the expected 'injury-assessment-treatment' process. For example, on being asked about his understanding of why his pain has persisted, Max replied:

Because I haven't been made any better. I would have thought I would have been able to be made better by now. I expected my back to get better after a few weeks basically... But I seemed to be passed from person to person. Any treatment you are referred for, you have to wait and wait. I suppose that's just the way the NHS is at the moment. To me you are injured, you should be seen straight away, I could have got back to work (Max).

Max implies an assumption that had he been seen soon enough, he could have made a fuller recovery. Similarly, John and Paula both described an understanding of their ongoing pain as related to a delay in the treatment of their initial injuries. John described that this delay resulted in his injury being 'left to heal how it was' (John). Their accounts imply an assumption that injuries need to be caught within a certain time and treated quickly:

If they had found it earlier, I probably would have been about 90% better than I am now (Paula).

I had to wait a further six months before I could get a scan. It's like someone with a headache being told to come back in six months for some headache tablets (John).

Max, Paula and John described that they had expected further investigations immediately after their accidents and that they had felt that their injuries had not been taken seriously enough by health professionals. There appeared to be a discrepancy
between their perceptions of the seriousness of their injuries (i.e. Max believed he had broken his spine at the time of the accident) and the level of investigations they received. For example, Max and Lucy relate having asked for particular investigations (i.e. x-rays and an MRI scan) and being told these were ‘not warranted’. They were potentially left feeling as though something important had been missed:

Nobody did any proper checks. I wasn’t in Casualty long enough. They quickly did some x-rays and said that’s it, ‘nothing wrong’...The treatment I was given was not for the injury I had. The treatment I was given was for where you walk down the road and you twist your ankle or something, or a little injury that takes a couple of weeks to heal...All they did was give me painkillers and send me home (John).

The swelling in my hands was amazing. It was obvious there was something wrong with it but the doctors and that weren’t really taking much notice, an x-ray here and there (Paula).

Perceiving one’s initial injury as ‘slight’ may also be related to subsequent difficulties in understanding the ongoing nature of one’s pain. Vicky relates being unsure as to why she continues to experience pain, given that she perceives her initial injury to have been relatively insignificant. She had expected to recover without medical intervention. Having heard a noise during her accident (‘a huge thump crack sound’) Vicky described thinking at the time that she had ‘done something’ to her body. However, she recalled feeling a little stiff but ‘OK’ and was able to cycle home to have a bath, expecting that this would help to relieve the ‘stiffness’ that she felt:

You don’t tend to think you’ve done yourself a huge damage because, well, all I did was, I was only on my bike, I didn’t even get knocked off, I didn’t fall over, I just twisted (Vicky).

Similarly, Brenda and Jo described heading home following their accidents, to rest as a means of facilitating recovery. They too expected their pain to fade fairly quickly:

I always thought I could walk things off (Brenda).
It is possible to speculate that the way participants make sense of their injuries and their pain may change over time and in the context of ongoing pain. Injuries initially considered ‘slight’ at the time of an accident may be re-interpreted in the light of ongoing pain as being more serious than initially thought. Vicky’s account hints at this, as she relates her desire to know what a noise she heard (from her hip) during her accident meant, in terms of injury. It is possible that this noise had gained significance in the context of her ongoing pain:

*I know how my body moved, but I still don’t know what caused that noise and that would be good to know, but nobody can tell me* (Vicky).

### 2.3. Acknowledging chronicity

For all participants, their accidents mark the beginning of a struggle between their expectations of what would be an appropriate recovery or treatment process and the lived reality of a pain that is intractable. Participants related how their positions or attitudes towards their pain changed as their conditions persisted over time. Despite failed attempts at a successful treatment and the duration of their pain, participants describe continuing to hope that a solution will be found and an increasing desperation to try any potentially useful treatment. They also reported finding it difficult to understand why a solution had not yet been found. Having exceeded their expected recovery time, or having made failed attempts to be free of pain, participants described a gradual realisation that their pain may be ongoing. They related significant moments or events that contributed to this sense of chronicity. Max described one such moment, in being told that there were few feasible medical options left for him to try.

*They [medical consultants] said it wasn’t worth having the operation until it was that bad that you are stooped over. I said well right then, I won’t have an operation. You just have to learn to put up with the pain then. And adjust* (Max).
Brenda highlights the struggle and confusion in facing the prospect of an enduring pain, while her expectations and hope persist of a more favourable ‘injury-treatment-recovery’ process:

*I just think I've got to live with it. Accept it. But what do you do. It's something you got to live with. You either accept it or not. I've accepted that I've got the pain and I've got to get rid of it. But I hope I won't always have it. Surely if it's a trapped nerve they can do something for it. It just seems it's such a bloody long time doing it. I don't know. I can cope with it better now. I just hope I don't have really bad days now* (Brenda).

Participants described a realisation that doctors don't have all the answers, bringing with it a degree of anxiety as hopes or expectations of recovery are further impeded. However, it also appears to be related to adopting a more active view of self in the process of recovery:

*To think that if the doctor doesn't have the answers, who does? You don't want to be left like this, do you? You want it to be over with. But I know I've got to look after myself and I know this now. I am worried and I do have some doubts. But I'll have to deal with it. The doctor can't do it all* (Alan).

*You think well you're a doctor you know best, but you know your body better than the doctor knows your body so, you have to deal with it if you know something's not right* (Paula).

Participants described having no choice but to adapt to their pain and their physical restrictions. They related struggling through aspects of life on a daily basis and adapting where possible. They referred to a necessity to ‘just get on with it’. This appears to refer to a process of struggling through each day or with each demand placed on them, as best as possible and adapting to the pain.
I just go day to day, hour to hour. I don't know how people get by but they do. You just plod on. You adapt... I don't know. It's like a challenge. I have no choice but it's a challenge (Alan).

I sort of just carried on. There were days when I couldn't bring myself to do anything at all... I think you just push forward when you have to. You either sink or swim really. You must come to a crossroads or a fork in the road and decide which way to go. I'm not sure where my point was, but I must have decided at some point that I had to push on (Vicky).

3. Impact of chronic pain
Participants related that pain had placed significant restrictions on their lives. They described overwhelming struggles to maintain their lifestyles as they were, prior to the accident. Significant changes were specifically described in relation to how participants saw themselves and how they interacted with the external world and others.

3.1. Sense of self
Participants described changes in their views of themselves as a result of their pain and physical restrictions.

They compared themselves before and after the accident and described feeling as though they had become 'different' people, that they had experienced 'complete change' since the accident. Participants related a notion of themselves as 'on hold', with their views of themselves dominated by the daily experience of pain and disability in their lives. The result was a feeling of having lost aspects of themselves:

I'm not the same person. And if I'm in pain I can only think about pain stuff. I can't do or think much else. And I get sad about that (Alan).

I felt like I was losing my self and me. I wasn't the same person at all. I had lost my spark, if you like. My style of dress changed. I didn't make an effort anymore... No spark there at all (Vicky).
Participants referred to difficulties trying to maintain the roles that had formed an important part of who they were. For example, Max describes how experiencing increased pain prevented him from fulfilling his role as a Chelsea Football Club supporter (who ‘used to attend most games’), or as a supportive husband:

*My wife plays in concerts, she’s a violinist and I haven’t seen her play since before the accident. You can’t fidget about at a concert so I haven’t seen her play again* (Max).

John explains that his restrictions have impacted on his capacity to fulfil his role as a father to the extent that he would ideally like to. This ideal self is compared against his perceived actual self:

*I also don’t feel like I can be as good a father to my son as I could be. I can’t run around. I feel like a prisoner instead, when I am here [at home] (John).*

John highlights his struggle to accept his physical restrictions as being part of his identity. He compares himself to the person he was and the person he still wants to be:

*To me, I think my mind still doesn’t realise I can’t do things. I still think I can do things but I can’t. I was a people person, life and soul of the party. That was me. To be like this isn’t me. That part of me still wants to do things, but I end up in more pain because of it (John).*

Participants described that their pain impacted upon the way they see themselves in relationships with significant others. Vicky describes having been quite a ‘gregarious’ person prior to the accident, being assertive in relationships. She compares this with being less assertive and confident in relationships now. Others, she relates, tend to take on more of a carer role now which ultimately pushes her into a more submissive and dependent role.
She's my younger sister and I was used to taking the lead on things, but we've switched and she takes more of a kind of carer role now, so things feel a little different (Vicky).

3.2. Difficulties maintaining lifestyle

3.2a. Social difficulties
Participants described how their physical restrictions meant that they did not feel they could take part in activities on an 'equal' basis with others, or at their pre-accident levels of participation. Because of this, they described decreased enjoyment of social activities, feeling like a burden on others. They therefore withdrew from social situations and experienced fewer opportunities for interaction:

I just get pissed off that I can't say yes when I'm asked to go [to play golf]. They still ask me. It's the social part after that I miss too. Lots of social activities I miss. But it's in my head that I can't do them, so that's it (Max).

Vicky's account hints at a tension between wanting to maintain social contacts while feeling unable to do so. She describes making plans and then cancelling them at the last minute. Contributing to this is a sense of having nothing to talk about, except for pain:

Everybody else, has done something, been on holiday or done something, whatever. They've been getting on with their lives and have got loads to talk about but I've not got a lot to talk about because I haven't been up to much at all, taking my tablets, sleeping...so you lose a dimension because you lose things to talk about (Vicky).

Participants' accounts portray a sense of isolation and an impression of feeling left behind, their lives in some way 'on hold' while others 'move on' with theirs. Alan, for example, describes how his children have their own lives to lead and that his wife needs to focus on her career training, so that 'everybody's busy really'. He related feeling unable to talk to anyone about this pain, even family members:
It brings people down around you. I've got to a stage where I don't talk about it, even if I'm in a lot of pain (Alan).

Participants generally reported that their close relationships with friends and family, had been supportive and understanding, in the immediate aftermath of their accidents and in the longer term. Participants often related a partner as having been a vital part of how they managed their struggles with pain. However, subtle changes in close relationships were noted by Vicky who observed a shift in the balance of power in her relationships. She describes feeling less equal and less able in relationships in comparison to before:

It was much more of an equal relationship before the accident. I don't feel like it is quite so equal anymore because I feel less in the friendship and I can't pick myself up to what I was in the relationship (Vicky).

Outside of their closer relationships, participants related greater difficulty in communicating their pain and disability. They related that their pain and their situations were not well understood by others, further fuelling a sense of isolation. Vicky talks about not being able to find the right words to communicate accurately her situation to others, without going into detail as to her post-accident operations and decreasing abilities over time. She describes the need for a precise 'package of words' that will explain to others exactly what she has been through and why, for example, she needs a degree of flexibility at work.

Vicky's need to present an accurate picture to other people appeared to be related to feeling a pressure to 'justify' her level of distress or disability in comparison to the severity of her accident:

People assume that I got knocked off [her bike] and then I have to say that I didn't get knocked off, that this is what happened, but because the accident wasn't that bad, it's hard to explain why I'm still in pain. So I have to explain it all and it gets tedious explaining it again and again (Vicky).
Vicky therefore describes a threat to the legitimacy of her pain arising out of a mismatch between the severity of her accident and the expectations of others as to what her level of suffering should be. Feeling that one’s pain or disability was not being believed was also related to having exceeded an expected recovery time, or to the invisible nature of pain and disability:

*Because it’s gone on for so long, you wonder sometimes if they think you’re just making it up* (Alan).

*If you got a broken arm people can see there’s something wrong with you. If you’re just in physical pain all the time but there’s no band aid shall we say, they just think that you’re putting it on* (Jo).

Participants described variability in the way other people responded to their difficulties. However, they also point out that the impact other people’s responses can have may also vary, depending on factors such as their current mood. For example, while reporting a general preference for responses that involve ‘empathy’ as opposed to ‘pity’, Vicky suggests that this will depend on the situation:

*Sometimes, you can just move on with the conversation after pity, ‘oh you poor thing’ and then move on and you don’t have to dwell on it. But if somebody’s being a bit more empathetic then you tend to get a bit more pulled in. You can’t quite pull yourself out of it as quickly* (Vicky).

3.2b. Difficulties at work

Participants described how maintaining their occupational roles, at a pre-accident level, had become increasingly difficult. They described feeling as though they had become a burden on their colleagues and felt guilty at not doing as much work as others:

*In the end I had to go sick because the blokes were carrying me more and more... they were doing more and more of my work. I was getting out of loads of things. All the*
mundane jobs. Nice of the blokes but it started to get to a point where I was getting embarrassed about it (Max).

Ability to fulfil one's occupational role appeared to become a marker or gauge of recovery success. Taking early retirement, or leaving employment, was then described as a significant point in realising the potentially longer-term prognosis of their pain. It was for some the start of a period of depression and 'hitting rock bottom'.

Vicky describes a complete change in her life after becoming unable to travel to work because of her pain and related physical restrictions:

*I was off work for 18 months and I had a completely different way of life to what I was used to. It was a much slower pace of life and I would always make sure I could get out of the house if I could, if I was physically able. I would see a whole different set of people by walking into town than I would normally see (Vicky).*

For Max and Brenda, leaving their jobs meant taking early retirement from posts they had held for many years. This therefore represented a hugely significant change, involving the loss of the futures they had planned:

*I probably would have gone on until I was 65 or so. Because I was quite active, I don't think I would have left work at 60 (Brenda).*

Participants described how they would have appreciated a greater degree of flexibility in their employers and that they did not feel that their employers understood the full impact that pain can have. As Vicky summarises:

*I would like them to understand how debilitating constant pain is on people. I would like them to understand how medication makes you feel, how it feels to be in a fog and how you need a bit of leeway, at work, to take it home, or different working hours, different ways of doing things. I think maybe I would like them to walk around with a stick, outside at rush hour and for them to feel invisible at rush hour (Vicky).*
3.3. Increased sense of vulnerability

Participants related a general avoidance of activities they deemed would increase their pain, or that might lead to further damage. They describe acting to protect themselves from further damage or pain:

*It's just normal now, like habit. I'll always find a corner to sit in where I feel I know I won't get knocked... I do everything I can not to get knocked* (Paula).

*I'm frightened of pushing the pain to the extent that it is bad again* (Brenda).

In particular, participants related an increased sense of vulnerability or threat in certain situations related to the accidents they experienced and this was related to an avoidance of these situations. This appears to be associated with a lack of confidence in mobility and a fear of pain/re-injury. However, John, Paula and Alan also report memories of the accident playing a part in their fears or concerns in certain situations.

The clearest example is presented by John, who relates having developed a fear of stairs as a result of his accident (which involved falling on stairs at work):

*The only time I think about the accident is when I see stairs... when I stand at the top of the stairs I get flashes of what happened. Makes me feel insecure on the stairs. I avoid stairs as much as possible* (John).

He adds that his fear of stairs is related to a fear of falling as a result of being less able to stop himself falling because of his physical restrictions. He also reported that this has been missed by his GP, where time is limited to talking only about the pain and pressing issues.

Paula highlights an increased sense of vulnerability in walking and a fear of her accident occurring again and causing injury. The perceived ease with which her accident occurred feeds into her sense of vulnerability:
I'm really careful now with my walking. I'm like always carefully watching where I walk (Laughs). Because it took just a second to not look and to trip over the flooring... what I felt like at that time, I never want to feel that again (Paula).

While Alan initially reports not being bothered by memories of the accident, he does report an increased awareness of possible threat near roads. His accident involved being knocked off his bicycle by a driver and he describes concern about his mobility near roads and an increased awareness of the potential for harm:

I don't think about the accident but I find it difficult to walk anyway, so I'm fearful of falling over, or not being able to get out of the way of a car. The lady who was driving wasn't going that fast but you can still feel the force cars have... For about 2 months afterwards I used to think about it a lot and especially at night. I'm still dubious around roads. I now know the impact of what a car can do to you if it hits you. I can feel the power of them when they go passed me, so I'm worried when I'm out. I haven't been back to where the accident took place, though I don't feel the need to (Alan).

While feeling confident in driving, Lucy describes also avoiding the road where her RTA took place and that that road is the only place where she thinks about her accident.

The only time I think about the accident is when I have to drive down that road. I avoid it if I can (Lucy).

Summary
The participants in this study described being predominantly concerned with their pain and related difficulties and not with the accident itself, which they generally described as an event in the past. Where thoughts about the accident were reported, these were related to angry rumination or blame as to the cause of the accident (i.e. that it could have been avoided) and how it had been dealt with by those responsible.
In most cases, participants had entered a process of seeking compensation from those they felt were responsible. They described this generally as a stressful process of repeated assessments that forced them to think about the event itself and about their subsequent losses. Involvement in litigation meant participants were presented with challenges to their accounts of their accidents and their explanations as to why their pain developed. This contributed to an uncertainty participants already felt regarding the extent and nature of their injuries and led to feelings of frustration and anger and a powerlessness to prove otherwise.

Participants were generally at a loss to explain the persistent nature of their pain. They reasoned that their pain must be related to injuries that have failed to heal, or that healed incorrectly. Their accounts revealed assumptions around what their injuries should mean in terms of recovery and treatment. Participants generally appeared to expect their pain to fade with time, as their injuries healed, or when the appropriate treatment or cure was applied. Participants held expectations of a medical profession that will clarify injury and sequentially provide a fix or cure. Ongoing pain was then described in relation to a failure in this process.

With the repeated failure of treatments to alleviate pain and having exceeded their expected recovery times, participants were again and again faced with the prospect of having to live with a pain that is intractable. They related increasing despair at their failed attempts to be free of pain, while maintaining hope of ‘a cure’. They described a gradual realisation that their pain is not going away and that the medical profession may not hold all the answers. At the same time, the medical profession remained their main source of hope.

Participants related how their pain had impacted on all areas of their lives. They described efforts following their accidents to maintain their lives as they had been pre-accident (i.e. going back to work, attending weekly darts match, etc). As these attempts failed, participants described realising the fuller extent of the limitations the pain was imposing on them.
Participants highlighted a particular difficulty in communicating their pain situations to other people, fearing that they would not be believed. They felt other people would judge that they should have recovered from their accidents by now. As a result of these difficulties, participants relate feeling increasingly isolated. They describe how the people around them appear to be 'moving on' with their lives, while their lives remain 'on hold', filled with little more than their struggles with pain.
DISCUSSION

Overview
The overall aim of this study was to develop a better understanding of the personal experiences of people living with chronic pain following an accident.

Analysis of the accounts of eight people living with chronic pain as a consequence of an accident, revealed a number of themes that were grouped under 3 main headings: Making sense of the accident, Understanding pain and injury and the Impact of pain. These will be discussed in relation to the existing literature. Methodological issues in relation to this study will be then discussed. Finally, the clinical implications of this study and directions for future research will be highlighted.

Discussion of themes

Making sense of the accident

'Processing' the event
Participants shared similar ways of relating to their accidents. All described their accidents as events 'in the past' that cannot be undone. Each reported no longer thinking about their accidents on a regular basis. Instead, they related that the 'damage had been done' and the persistence of their pain was their predominant concern.

The participants in this study may be viewed as no longer being particularly distressed by their accidents. Indeed, Ehlers & Clark (2000) suggest that the metaphor of trying to put an event 'in the past' is one that is often used in relation to speaking of recovery and one that represents an aim in treatment relating to adjusting to traumatic events.

Participants did report experiencing more frequent thoughts about their accidents in the weeks and months that followed. They described thinking about the chain of events that had occurred and questioning how things might have been different (i.e. 'if
only I hadn’t ...’). Three participants in this study related relatively more distressing intrusive images and dreams in the aftermath of their accidents.

These findings are consistent with studies that have shown repeated or intrusive thoughts to be common immediately after a sudden unexpected event (e.g. Ehlers & Steil, 1995). For example, Delahanty, Heberman, Craig et al. (1997) found that all of 130 MVA victims experienced intrusive thoughts (as assessed by the Impact of Events Scale) at three weeks following their accident. A potentially useful way of understanding this has been put forward by Horowitz (1986) who suggests that people have a need to integrate new information ('a completion tendency') to achieve a 'fit' with their pre-existing representations of the world. Repeated or intrusive thoughts serve then to facilitate the ‘processing’ of new (trauma-related) information.

Blame, anger and litigation

Blame and attributions of responsibility featured as central in participants’ accounts of their accidents. Janoff-Bulman (1985) has suggested that following traumatic events, people make ‘causal attributions’ which provide explanations of their experiences, in order to “satisfy the need to re-establish a view of the world in which events make sense”(p. 26).

Similarly, DeGood & Kieman (1994) describe the need to establish responsibility or fault after an accident, as a ‘natural human tendency’ to understand the reasons for events out of our control.

Blame was attributed to external sources, or ‘others’, in all but one of the participants’ accounts. Where blame wasn’t attributed to an external source, the accident was understood in terms of being more of a random event, or ‘just one of those things’. All participants who held somebody else responsible had entered into a litigation process.

Appraisals of blame and unjustness, have been related to the generation of anger in CP sufferers (Fernandez & Turk, 1995). Fernandez & Turk suggest that anger is a salient feature of the CP experience that can be intensified if “damage is seen as the result of something intentional and preventable” (p.173). Participants in this study reported
anger and frustration at the preventable nature of their accidents and at the failure of those they held accountable to accept their responsibility for the accident.

Two of the participants had previously complained to their employers about a potential hazard (i.e. loose wires, uneven steps) that later led to their accidents. They felt that if they had been listened to prior to their accident, the event may never have occurred. They therefore held their employers responsible for their accident. However, a failure on behalf of their employers to accept responsibility then served to increase their anger and frustration.

Interestingly, DeGood & Kiernan (1994) observed that where perception of fault was reported to be with the person's employer, rather than 'other', greater levels of distress were reported; patients in their study reported feeling unfairly treated by their employers following their accidents and by the compensation system. Two participants in the current study highlighted a sense of powerlessness against a large organisation that is intent on dismissing their claims. This sometimes placed participants in an impossible position of having to 'prove' their pain began as a result of their accidents.

Obtaining agreement as to responsibility for one's accident was not always a simple process for the participants in this study and was complicated by involvement in the legal process. Consistent with Romano's (1990) findings, as mentioned in the introduction, the compensation process was described as stressful by the participants in this study.

The legal process appeared to have a broad influence on the experiences of living with pain, by influencing how participants made sense of their accidents (i.e. in terms of the inevitable polarisation of blame) and how they related to those they held responsible. It threatened the way they made sense of their injury and their ongoing pain. In addition, their accounts and understandings were dismissed during this process, contributing to a sense of not being believed and challenging the meaning of their pain.
Similar to the process described by Mason, Turpin, Woods, et al. (2006), involvement in litigation involved participants having to repeat the details of their accidents and subsequent losses, in various assessment situations. They described distress as they were reminded of their losses and unable to avoid thinking about their accidents. Mason et al. (2006) suggest that the legal process may become an obstacle to adapting to events, as it encourages repeated event recall, rather than a natural adaptation.

In a review of studies exploring the relationship between chronic pain and compensation, Mendelson (1994) concludes that while involvement in litigation has been shown to be somewhat detrimental to treatment outcome, the majority of studies have shown individuals seeking compensation to be undistinguishable from those not seeking compensation, in terms of pain severity and distress (see Mendelson, 1994). He recommends both receive the same treatment. Given the potential for added stress by being involved in a legal process, it would seem that this group would benefit from increased support.

**Making sense of pain and injury**

The participants in this study related a lack of confidence in the explanations they had regarding their injuries and the ongoing nature of their pain. However, all linked the development and persistence of their pain to an injury sustained during their accident.

Osborn & Smith’s (1998) participants related an uncertainty as to the cause of their pain and a search for an explanation. They describe their participants being unable to account for the persistence of pain in “any manner which was meaningful to them beyond the notion that ‘there was something wrong” (p. 69).

They report their participants as lacking any useful framework to explain the nature of their pain and turning to “whatever common-sense concepts they have to hand” (p.75).

Similarly, participants in the current study expressed uncertainty as to why they were experiencing ongoing pain. They reported receiving conflicting explanations as a result of attending various assessments. However, in attempting to make sense of their ongoing pain, they referred to the ‘injury’ they associated with the onset of their
pain and their expectations and assumptions regarding what injury should mean in terms of recovery.

From a social constructionist perspective, Eccleston, Williams & Stainton-Rogers (1997) highlight that “implicit within our understanding of pain is the need for it to make sense. And to make sense of pain means finding a story that works” (p.700).

Broadly speaking, the participants in this study shared an understanding of their ongoing pain as a failure in the healing of their injuries and pain remained indicative of damage. Any challenges to their understanding of their ongoing pain (i.e. x-rays showing no damage) were met with anger and frustration and participants maintained the view that pain indicated some physical injury or damage, yet to be fully uncovered or treated. This is consistent with previous studies that have highlighted how people make sense of their pain as a sign of physical damage or malfunction (i.e. Aldrich & Eccleston, 2000; Bendelow & Williams, 1996; Eccleston, et al. 1997).

Eccleston et al. (1997) report findings from an exploration (using a Q-sort task) of the understandings that patients and professionals have relating to the causes of chronic pain. Four accounts of the causes of CP emerged from their analysis, which they labelled: the patient’s account, the professional’s account, the scientist’s account and the alternative practitioner’s account. The ideas expressed by participants in the current study, closely resemble those that emerged as exemplars of ‘the patients account’ of the causes of CP in Eccleston et al.’s (1997) study: that is, participants shared the view that pain always has a physical origin, even if doctors cannot diagnose it and serves as a signal that something is wrong.

In addition, participants in the current study made sense of their ongoing pain as a failure to receive adequate treatment, or treatment soon enough. Eccleston et al. (1997) found a similar blaming of the medical profession by their participants. They suggest that patients may deflect blame away from the self and attribute responsibility to medicine. In this way, pain retains its meaning as a signal of injury or damage, rather than becoming senseless (i.e. if pain does not equate to injury, then it does not make sense). Participants in their study were reported to be resistant to explanations
of their pain that did not link it to a physical disorder "loss of meaning for pain is strongly resisted in repositioning it as diagnostically meaningful" (p.706).

They suggest that challenges to a patient's accounts of their pain serve to undermine the legitimacy of their suffering, implicating the individual in his / her own suffering. This may help to understand the anger and frustration described by participants in this study, when their accounts of pain are threatened by alternative explanations advocated during the litigation process. A commonly used argument to arise within the legal process is that pain is due to 'wear and tear', rather than to injury and this was met with anger by participants and may have been related to an undermining of the legitimate nature of their complaints. In addition, the implications to the self of understanding pain as 'wear and tear', or deterioration due to old age, are perhaps harder to bear, or more permanent than if pain is seen as an injury. Working with those who are involved in a legal process may therefore require a particular sensitivity to the impact of the various threats they face in relation to legitimising their pain and making sense of it.

Participants in this study described finding it difficult to understand, given that the cause of their injury is known, why treatment has not yet been successful. They were concerned with finding a cure for their pain and related a faith that the medical profession has the answer to their pain. Given that the majority of people recover from injury (Mason, et al. 2006), it is perhaps not surprising that people hold an expectation of recovery with appropriate treatment or time. In addition, faith in the medical profession is one that is dominant in western modern society (Kleinman, 1988). As Eccleston et al. (1997) point out: "Western medical culture is one where cure and the modern triumph of science over embodiment are regularly portrayed. Stories of medicine as scientific, powerful, technical and efficient are legion" (p.706).

However, participants in this study related some ambivalence or scepticism and this might be related to their repeated failed attempts with various medical treatments. Participants described losing faith in the power of doctors and the medical profession, while hopeful that they might one day be provided a cure or a more permanent relief.
Bendelow & Williams (1995) suggest that it is possible that some participants have expectations of the medical profession that are too high, given the chronic nature of their conditions. They add that medicine may create an overdependence on it and passivity on behalf of patients. Interestingly, participants’ accounts described disappointment in the medical profession, while at the same time acknowledging a possible need to become more active in their own care. However, losing faith in the medical profession was also related to an anxiety in relation to the prospect of there not being a cure or explanation out there. Acknowledging the limits of medicine and becoming more active in one’s care, may therefore be resisted.

Adjusting to chronicity
Having exceeded their expected recovery time, or experienced failed treatment attempts, participants described being faced with the prospect of an intractable pain and they described beginning to confront the idea of having to learn to live with it. Participants described making adaptations in their lives and learning to work around the pain. They spoke of having to ‘accept’ the presence of their pain, but at the same would speak of searching for a cure, or considering an operation.

None of the participants described engaging in activities despite their pain, or of acknowledging the ineffective nature of trying to avoid or control pain; as suggested by McCracken, Carson, Eccleston, et al.’s (2004) definition of ‘acceptance’ of CP. McCraken & Eccleston (2005) report on an accumulating database to suggest that acceptance, as defined, is related to improved levels of functioning in CP sufferers.

Instead, participants in this study related trying to avoid activities that were related to an increase in pain. They generally tried to control pain by learning the limits of what they can do and adapting to this. In so doing, the participants in the current study resembled those described by Bendelow & Williams (1995), as displaying features of ‘resignation’. That is, participants who describe their lives as dominated by pain, who see no hope for a future and who report missing out on meaningful activities as a result of their pain.
Participants in this study described failed treatments and significant losses (e.g. employment) that represented significant events in their realisation that their pain may be ongoing. They nevertheless maintained a search for a cure and did not openly describe the possibility of a meaningful life in the presence of pain.

**Impact of chronic pain**

Participants in this study related how pain had impacted on their lives in many ways. They described changes in their views of themselves and their relationships with others and difficulties struggling with daily life. The findings are consistent with prior research showing CP to have a pervasive impact on many interrelated areas of a person’s life (Pincus & Morley, 2000; Osborn & Smith, 1998).

**Struggling with daily life**

Participants in this study told of how they had, following their accidents, attempted to maintain the roles they had fulfilled prior to the event. Some for example returned to work relatively soon after their accident. In so doing, they reported being increasingly presented with the restrictions that their injury had imposed on them. Becoming increasingly aware of these limitations, participants reported feeling a burden on their colleagues and to a lesser extent on their close relationships.

Feeling unsatisfied with their ability to participate in activities on an equal basis, or at a pre-accident level, participants withdrew from meaningful social activities, reducing opportunities for social interaction and increasing a sense of isolation. With their lives restricted by pain, they reported being unable to be the people they wanted to be, or had once been and they spoke of becoming different people. This is now a familiar pattern in the literature on CP (Pincus & Morley, 2000; Osborn & Smith, 1998).

**Perceptions of self**

Pincus & Morley (2000) suggest that feeling restricted in relation to activities that are held to be important by an individual will have a significant impact on their sense of identity. In addition, they highlight that having few replacement sources of self-esteem or self-worth may be particularly devastating. In a similar manner to the participants in Osborn & Smith’s (1998) paper, the participants in this study compared
themselves now, with how they had been prior to their accidents. They also appeared to nostalgically recall the people they had been and their abilities pre-accident.

This may be understood in terms of making sense of experience in relation to one’s life story, or narrative. For example, Kleinman (1988) has suggested that people order the experiences of their illness into personal narratives, in order to make sense of the distinctive events and give coherence to the course over time, of one’s condition. Similarly, Risdon, Eccleston, Crombrez & McCracken (2003) suggest that: “A core component of identity is the management of its coherence over time and the ability to project the idea of oneself in the future” (p. 384).

Since their accidents, participants spoke of themselves as having been ‘left behind’, while others ‘moved on’ with their lives. They related a sense of their lives being ‘on hold’, or themselves ‘not moving forward’. This way of relating their conditions suggests that CP may have a disruptive influence on one’s sense of self as progressing through time. Crossley (2000) remarks that the experience of CP, or illness, may represent a disruption in a person’s basic sense of time. The idea of time standing still is also discussed in relation to reactions to trauma (Herman, 1992).

Speculatively, in the present study, a perception of the self as stuck in time or ‘standing still’ is implied through participants’ accounts of their lives as having changed to an irreversible extent, and that they can no longer pursue their expected future goals or meaningful activities. One participant related a reduction in activities to the point of not knowing what day it was. A disruption in one’s sense of moving through time may be related then, to a sense of monotony, or everyday feeling the same, with reduced interactions in a ‘moving’ world.

People reported a sense of their lives being dominated by pain and having nothing to offer in relationships, with nothing else to talk about except pain-related experiences. This may be understood in relation to Pincus & Morley’s (2000) ‘schema-enmeshment’ model. This model proposes that adjustment to pain is related to the degree to which pain, illness and self schemas overlap. The aim of treatment is then to facilitate a separation of identity from pain.
Not being believed

An interesting aspect of the social difficulties participants related was the pressure they described to have to justify their levels of suffering to others. Despite having a clear point of onset and knowing the cause of one’s pain, participants related a sense of not being believed by others. One participant in particular (Vicky) spoke of the need to explain accurately, the sequence of events leading to her current disability. She spoke of a need to justify her disability, given the perceived insignificance of her accident.

Feeling that one’s pain was not being believed was related to having exceeded an expected recovery time, a mismatch between the seriousness of accident/injury and subsequent disability and/or the invisible nature of pain. One participant, for example, spoke of feeling the need to ‘wear a sign’ informing others of her pain. She related not wanting to wear a neck support, but she perceived others would expect this of her.

This is consistent with Osborn & Smith’s (1998) findings that participants felt “vulnerable to the judgements of those around them” (p.72) on the basis that their pain was invisible and unjustified in the context of having no apparent reason for pain/disability.

As Kleinman (1988) has said: “If there is a single experience shared by virtually all CP patients it is that at some point those around them – chiefly practitioners, but also family members – come to question the authenticity of the patients experience of pain” (p.57).

However, in seeking compensation for their losses, participants in this study were faced with an additional, more ‘formalised’, questioning of the legitimacy of their complaints and were presented with ‘evidence’ to support a dismissal of their claims. For example, one participant related that her employer had used the fact that she had had a number of days off work over the last 15 years, due to back problems, to dismiss her account of the consequences of her accident.
Major Research Project

Roy (2001) relates that there is a general consensus that malingering is rare and not easy to spot. On the basis of this, he then queries why so many patients seeking compensation end up having their 'veracity questioned' and feeling frustrated. He concludes that this will continue to be the case where diagnoses around a person's pain conditions remains unclear and where there is a lack of objective measurement to justify the level of disability being claimed.

*Increased sense of vulnerability*

All participants in this study related an avoidance of activities thought to increase the likelihood of pain, or further injury. This is consistent with Vlaeyen's (2003) observations that a fear of pain is one of the most salient fears involved in CP.

Vlaeyen (2003) proposes that an injured patient becomes involved in a vicious cycle of increasing avoidance, disability and pain. Negative appraisals of pain (as signalling damage) lead to an increased fear of pain which in turn motivates avoidance. Over time this leads to increasing muscle de-conditioning.

As mentioned earlier, participants in this study showed a tendency to make sense of the ongoing nature of their pain, with reference to the injury that was associated with onset and a failure somewhere in an expected healing process. Perceptions of injury and/or a permanent damage (as signalled by pain) appeared to be particularly salient in the participant’s accounts obtained. This is consistent with Turk et al.’s (1996) speculation that the experience of injury may facilitate beliefs relating to a need to prevent further damage, or increases in pain, leading to an avoidance of activities.

Vlaeyen (2003) postulates that people might fear an increase in current pain, or pain later, or they may fear re-injury. The participants in this study also reported a desire to avoid pain at the level of intensity felt at the time of the accident and a desire to avoid the consequences of an increase in pain (i.e. having to stay in bed for days).

The current study also found that some people are reminded of their accidents when in certain situations, like being on the stairs, or near roads. One participant described an increasing fear of stairs since his accident. He relates this to a decreased confidence in
his mobility and to 'flashes' of his accident when on the stairs. For another participant, the ease with which her initial accident occurred meant that she had an increased perception of a similar accident occurring again and this contributed to avoidant and guarded behaviour.

Studies have shown that phobias can develop following accidents (Kuch, Evans, Watson & Bubela, 1991). However, the participant reporting a fear of stairs also related that this had not been spoken about with his GP, due to a lack of time and a prioritising of medical aspects of his pain. Interestingly, Kuch, et al. (1991) suggest that some accident phobias may remain 'clinically silent' in patients with CP, who are inactive and who do not therefore encounter their feared situations.

Ehlers & Clark (2000) suggest that intrusive images or sensory impressions relating to a traumatic event, like the flashes reported by the participant above, are often experienced as happening in the 'here and now', rather than as a recollection of a past event. As such, they suggest that these feed into a person's sense of current threat and anxiety. Thus, memories (or sensory impressions) of a previous accident, together with a decreased confidence in physical ability, may contribute to a perceived likelihood of another accident occurring and a fear of re-injury.

Evaluation

Research design
The approach used in this study allowed participants a freedom to express themselves, without too many restrictions upon them. It was possible to develop insights into the experience of CP following an accident, using participant's own words and through a detailed engagement with their accounts; the end product being a co-construction of these. As a result of the flexible nature of IPA, it was possible to gauge the confusion participants felt in the face of an intractable pain that was inconsistent with their expectations of what their injuries should mean in terms of a recovery process.

The methodology allowed for an exploration of the ways in which people make sense of their ongoing pain, making use of the 'common sense concepts' available to them.
and how involvement in a legal process can impact on this, bringing with it an additional 'formal' dismissal of the legitimacy of their suffering. It is acknowledged that the findings of this study are limited to the participants involved. The intensive involvement in participant's accounts means that sample sizes using IPA are generally kept small enough to be manageable (Smith & Osborn, 2003). The aim of this study was to achieve an account of the experiences and perceptions of individuals who have been living with CP following an accident, rather than to make statements that attempt to generalise to the CP population.

A potential shortcoming in the design of this project may be related to the assumptions IPA makes around language, in that peoples' experiences of the world, their beliefs and perceptions, are assumed to be accessible in what they say (Willig, 2001). Language is thought to describe experiences. However, Willig (2001) reports that it is possible to view language as constructing reality, rather than describing it and to think of language as adding meaning. From this perspective, it is impossible to gain access to a person's experiences and the analysis in the current study could be seen as lacking a focus on the way people talk about their experiences. By way of a resolution on this issue, Osborn & Smith (1998) suggest that both are relevant approaches that depend on the orientation of the researcher.

The sample
One of the people given an invitation pack at their screening appointment returned their reply slip with a note saying that she thought she would find talking about her accident and her subsequent losses, too distressing. In addition, all participants reported having put the accident 'in the past'. It is possible then that only people who did not mind talking about the experiences of their accidents may have taken part. While this is likely to represent the majority of individuals attending pain management courses with CP as the result of an accident, the study's findings may not apply to individuals who are continuing to be distressed by memories of their accidents. Using IPA to explore the experiences of CP sufferers who are currently more distressed by their accidents, or who meet criteria for PTSD, could be a useful means of exploring any interactions of current coping with pain and memories or thoughts about the accidents.
All of the participants in this study were able to offer descriptions of their experiences and their thoughts and feelings around some of these. However, it was apparent that some accounts were richer in detail at times, or in the level of insight they provided. These transcripts may have been favoured sometimes during the analysis as the aim of using IPA for this study was to capture detail in the experiences and meanings associated with CP following an accident. Willig (2001) suggests that articulating one’s experiences to meet the requirements of IPA can be a demanding task for participants. Some of the experiences of people who were less able to put particular thoughts and feelings into words may therefore have been missed.

One participant remarked that he generally found it easier to talk about his pain to people who he knew had been through similar suffering. It is possible then that participants’ accounts may have looked somewhat different, had the interviewer been a CP sufferer. Knowing that the interviewer was going to be a psychologist, may have influenced the way in which participants expected to talk about their experiences. While participants were instructed that they should feel free to talk about whatever they feel is relevant, they may have been motivated to let me know about particular aspects of their experiences, like their struggles with treatment as opposed to any positive experiences they have had, for example.

Making interpretations
IPA acknowledges that researchers are actively involved in shaping the analysis, by making sense of and interpreting participants’ accounts. However, as Willig (2001) points out, while clear guidelines generally exist for using IPA, fewer guidelines are available that “show us how exactly the researchers’ own conceptions are implicated in a particular piece of analysis” (p. 67).

Throughout this project, using this approach required a self-monitoring to remain aware of what were my pre-conceptions, or ideas and what was actually linked back to the participants’ accounts. Knowing how far to go beyond the descriptions of participants was initially difficult. Larkin, Watts & Clifton (2006) refer to researchers needing to achieve a ‘balancing act’, between description and interpretation. Wanting
to represent a participant's individual account, while also wishing to make interpretations based on similarities with others, was another related balancing act. Working through these issues (and other concerns) was helped by reflective discussions with supervisors and with colleagues pursuing qualitative approaches and with practice in engaging with transcripts. Of course, the final decision in accepting an interpretation rests with its traceability back to the participants' accounts (Larkin et al. 2006).

Clinical implications and directions for future research
The participants in this study were far more concerned with their current pain and their restricted abilities to pursue meaningful activities, than they were with the accident that represented the start of their pain.

Instead, the accident appeared to be having an ongoing influence indirectly, through the process of seeking compensation and becoming involved in a stressful legal process. The experience of injury during the accident also provided participants with a possible, though uncertain, explanatory framework for the ongoing nature of their pain. Possible implications of this for clinical practise and future research are discussed below.

1. Fear of re-injury and avoidance
The findings suggest that avoidance of activity due to a fear of pain or re-injury appears particularly salient in this group. This may be related to participants making sense of their ongoing pain in relation to injury and perceiving themselves as damaged. Their experience of injury may represent a source of 'evidence' to support pain as a signal of damage. In addition, studies have shown that CP sufferers may be quite resistant to alternative ways of viewing ongoing pain that potentially undermine the legitimacy of their suffering, or threaten to make their pain senseless. Asking people to pursue meaningful activities in the presence of pain, as suggested by several authors in relation to encouraging acceptance, appears to be a tall order then and inconsistent with the notion that pain signals damage.
Efforts to achieve a shared understanding of ongoing pain that does not undermine or implicate patients in their suffering may be useful. Models, developed for each person, that work with their understandings of pain (i.e. as related to their injuries) but that are also able to encourage re-engagement in activities would seem ideal. Further explorations (i.e. group comparisons) of fear of pain according to the type of pain-onset, may be useful in confirming the relationship between an increased fear of pain/re-injury in the context of having had the experience of an accident or an injury.

2. Ongoing influence of accident
The findings of this study suggest that accidents may be having an ongoing subtle influence in certain situations. Participants in this study reported experiencing images, or sensory impressions in certain situations that are related to their accidents. This is despite reporting that they did not think about their accidents on a regular basis. These intrusive images, together with perceiving oneself as physically less able, may contribute to a sense of vulnerability in certain situations (as the occurrence of a similar event is deemed possible, or even likely).

Health professionals working to encourage CP sufferers to re-engage in activities that are thought to be avoided because of pain, may need to be aware of the subtle influence that images, sensory impressions, or attributions about their accidents, may also be playing. Asking people with CP following an accident about intrusive images, or 'vibes', in accident-related situations may be useful in uncovering any factors that may be contributing to avoidance and to a fear of re-injury. In addition, ongoing fears/phobias relating to accidents may have been easily missed by referrers, if exclusively focussing on injury and medical treatment. The person may also themselves be unaware of any accident-related fears if opportunities to encounter feared situations are fewer because of reduced activity levels.

Further research as to the relationship between intrusive images and cognitions while in accident-related situations and fear of pain / re-injury may be useful here, to highlight any subtle influence of the accident on avoidance of activities, in sufferers of CP following an accident.
3. Impact of legal process and not being believed

Entering into a legal process is increasingly easy to do and many participants referred to their decision to pursue compensation as 'worth a try'. In doing so, they are faced with 'formal' challenges to the legitimacy of their suffering and to their understandings/accounts of their pain. They are presented with alternative and conflicting explanations for their pain, like 'wear and tear' and 'deterioration' which can result in uncertainty as to the meaning of pain and threats to their views of themselves (i.e. as 'able but injured').

No evidence was obtained from this study to suggest that involvement in litigation should mean exclusion from treatment. In fact, it would seem from this study that these participants are in need of support to deal with the stresses involved with this process and with the consequent undermining of the legitimacy of their suffering. In working with people involved in litigation, a sensitivity to their perceptions of not being believed and the threats they face in relation to the legitimacy of their pain, would seem useful in efforts to establish trust. In addition, helping patients to achieve some understanding of the results of the various assessments they have had may lessen the uncertainty they face in relation to understanding their pain. Again, establishing a model that makes sense of ongoing pain which is careful to avoid subtle blaming, or the undermining of the legitimacy of their suffering, appears to be a useful aim.
Conclusion

The aim of this study was to explore the personal experiences of CP following an accident, from the perspective of the individual sufferer. The rationale for this was based on the findings from quantitative studies that suggest that CP sufferers are generally worse off in relation to levels of disability and distress when pain-onset is related to an accident. Adopting a qualitative approach to this allowed for a detailed analysis of accounts provided by people with experience of CP that has developed as the result of an accident.

The findings of this study suggest that accidents leading to CP may be quite unremarkable events that are not in themselves related to subsequently high levels of distress. However, accidents may have a more indirect or subtle influence as appeared to be the case in this study. For example, the experience of an accident may encourage a perception of oneself as injured, thereby reinforcing a view that pain equates to damage and injury. This may then lead to an avoidance of activities that are thought to be potentially damaging. People may also experience intrusive thoughts, or images, in situations related to their accidents and this may contribute to a sense of vulnerability and further fear/avoidance.

This study is consistent with others that have shown how people make sense of their situations using ‘common sense’ concepts available to them. People with CP following an accident may search for an explanation as to why their pain persists past an expected period of recovery. Expectations of what an injury means in terms of what would be an adequate treatment, or a helpful recovery process, become important in make sense of the ongoing nature of their pain (i.e. as a failure to receive adequate or suitable treatment). Expectations and hope of a cure appear to persist over time, despite failed attempts at treatments and an increasing disappointment with the medical profession. These expectations may hinder a more useful acceptance of pain.

People living with CP after an accident may also have the additional stress of being involved in a legal process that presents them with various explanations for their pain.
Research has shown that CP sufferers are liable to feelings of not being believed by others and the legal process appears to represent an additional and more formal, challenge to the legitimacy of their claims. Involvement in litigation may be related to polarised views of blame and feelings of injustice, especially where responsibility is not being accepted by those thought to be accountable and this may generate an ongoing anger.

The themes emerging from this study highlight the impact that CP can have and how people try to make sense of their accidents and the development and maintenance of their pain conditions. Taking account of these themes may help when working with these individuals to develop ways in which they might usefully come to understand their situations and the chronic nature of their pain. Ways of understanding chronic pain that incorporate injury/damage, but that are also able to encourage re-engagement in activities in spite of pain will be likely to be especially useful for this group.
References


Appendix A

15th May 2006 (Version 2)

Dear Sir/Madam,

We are writing to you to ask if you would take part in a research study currently being conducted at the Centre of Pain Education (COPE) and sponsored by the University of Surrey. The aim of the study is to improve our understanding of the experiences of living with chronic pain as the result of an accident. We wish to interview about ten people who have experienced an ongoing pain condition as the result of an accident. This interview should last around an hour. You are one of the people being invited to participate in this research because at your recent assessment at the Pain Clinic, it was thought that you fit the criteria to take part in this study. While the Pain Clinic have given you this invitation, no other information about you (or any of the people we are inviting) has been obtained by this study.

Participation in this study is entirely voluntary and before you decide to take part it is important that you read the attached information sheet so that you understand more about the research.

Please take time to read the information carefully. If you have any queries please feel free to contact us on the numbers given below.

Thank you very much for your time.

Yours sincerely

Tarick Ali
Trainee Clinical Psychologist
Department of Psychology
University of Surrey

Dr Claire Copland
Chartered Clinical Psychologist
COPE Pain Management Programme
020 8296 4315

We welcome comments about our service
If you have anything to say please ring 020 8296 2503
www.epsom-sthelier.nhs.uk
Appendix B

Epsom and St. Helier University Hospitals
Cheviot House
Sutton Hospital
Cotswold Road
Sutton
Surrey SM2 5NF
Dr Claire Copland
020 8296 4315
15th May 2006

Information sheet (Version 2)

The personal experience of living with chronic pain after an accident.

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. A telephone number, e-mail address and postal address are provided above should you wish to 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.

Background Information & Aims

Some people develop chronic pain conditions over time and with no obvious cause. Others can remember exactly when their pain conditions began – like after an accident of some sort. Some studies have shown that people with pain conditions that start as the result of an accident may have slightly different experiences, compared with people whose pain conditions develop gradually.

This might be because the person has to deal with both the event of the accident itself, and its consequences (like ongoing pain). Accidents may bring sudden changes to a person’s life and adjusting to this can be very stressful. Less research has been devoted specifically to the experiences of people with ongoing pain conditions develop as the result of an accident.

Our aim in this study is to gain a deeper understanding of what it is like to live with chronic pain, while also living with the consequences of a sudden life-changing event like an accident. We want to gain knowledge of this in the words of people who have experienced it. The results of this research may help staff working on pain management programmes to better understand the difficulties facing people with accident-related pain.

Why have you been chosen?

We are aiming to interview about 10 people who have developed ongoing pain following an accident.

You have been invited to participate in this study because at your recent appointment at the Pain Clinic, it was thought that you fit the criteria for this study (i.e. you have been suffering with ongoing pain as the result of an accident).

We welcome comments about our service
If you have anything to say please ring 020 8296 2508
www.epsom-sthelier.nhs.uk
Do I have to take part?

No. It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive in any way.

What does the study involve?

This research involves one interview on one occasion. The interview will last no more than one and a half hours. Interviews can take place at your home, or at Sutton Hospital (your travel expenses will be paid). If you have indicated on the reply sheet that you would like to take part, you will be contacted by telephone for an interview time to be arranged.

The questions you will be asked in the interview are about your experiences of living with pain and the accident that led to your pain condition. The interview will focus around three main areas and the main questions that might be asked are as follows:

1. Your understanding of the accident and its consequences
   - What is your understanding of why pain developed following your accident?
   - What is your understanding of why your pain has persisted?
   - How do you feel about the way other people have responded to your pain since the accident?
   - Apart from physical problems, have there been any other consequences of the accident?

2. Thoughts about the accident and pain
   - Do you still think about the accident?
   - When do you find yourself thinking about the accident?
   - Do you think about the accident more at certain times of pain?
   - What types of thoughts do you have / did you have about the accident? For example some people say they think about how the accident could have been avoided?

3. The influence of the accident on coping with persistent pain
   - How do you think the accident might still be influencing your pain now (or physical health)?
   - Some people develop pain without really having a recognised 'cause' for it. Do you think your experience now would have been different had you not known the cause of your pain?

Everybody's answers to these questions will be different and the interview is meant to be very flexible. There is no rigid structure to how the interview will go.

The interviews are tape recorded. They are then typed up with all identifiable information removed. These transcriptions become the data for the study and each is allocated a fake name. The tapes are then destroyed.

What are the possible risks or disadvantages of taking part?

Some people may find it upsetting when they start to talk about their pain and how it started. You are free to stop at any point during the interview without giving an explanation. You are also under no obligation to discuss anything you do not wish to.
If you become in any way concerned (before or after the interview) you may contact Dr Claire Copland at C.O.P.E., on 020 8296 4315. There is also a COPE helpline that you should have been given information about at assessment. Another option you have is to wait and talk to staff members when you start attending for pain management at COPE.

Are there any possible benefits?

We should make it clear that there are no intended benefits to you from taking part in this interview. However, it might be that some people find it useful just talking about their experiences. The information we get from this study may help us to treat future patients living with pain better.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. However, if a disclosure is made during the interview that is deemed to put you or other people at risk, the information may be shared with team members at COPE.

Any information collected about you will have your name and address removed, as well as all identifiable information, so that you cannot be recognised from it.

It is up to you whether your GP is informed about your participation in this study. If you would like them to be informed, we will send them a letter explaining you have agreed to take part and a copy of this information sheet.

What will happen to the results of the research study?

The results of this study will be written up and published in relevant health publications, accessible to anyone. A summary of the results will also be written and sent to you if you so wish. The findings might also be discussed at conferences in order to circulate them amongst health professionals. However, all identifying information will be removed and you will not be identified in any report or publication.

As mentioned above, this research intends to obtain information from an 'insider's perspective'. Therefore, quotations from interviews form a large part of the write up. However, all identifiable information will be removed from the transcripts so that nobody will be recognisable from the data (i.e. made-up names will be given to each participant).

Who is organising and funding this study?

This research is being sponsored by the University of Surrey.

Who has reviewed this study?

The study has been reviewed and approved by the London-Surrey Borders Local Research Ethics Committee and the University of Surrey Ethics Committee.
Further information

Please feel free to contact us at COPE on 020 8296 4315 if you have any questions at all. We would be delighted to discuss any queries or concerns you might have about taking part in this study.

Thank you very much.

Tarick Ali
PsychD Clinical Psychology
University of Surrey
Guildford
GU2 7XH

Dr Claire Copland
Chartered Clinical Psychologist
Centre of Pain Education (COPE)
Cheviot House
Sutton Hospital
Sutton SM2

You will be given a copy of this information sheet and a consent form to keep
## Consent Form (Version 2)

Please read and complete this consent form. This will be collected from you at interview.

**Title of Project:** The Personal Experience of Living with Chronic Pain After an Accident

**Name of Researchers:** Tarick Ali & Dr Claire Copland

<table>
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<tr>
<th>1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. I have been given adequate time to consider my participation.</th>
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<td>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 in any way.</td>
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<td>3. I understand that sections of my medical notes may be looked at by the named researchers above, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.</td>
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<td>4. I agree to take part in the above study.</td>
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1 copy for participant; 1 for researcher; 1 to be kept with hospital notes.

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We welcome comments about our service. If you have anything to say please ring 020 8296 2508

www.epsom-sthelier.nhs.uk
Reply to invitation sheet

The personal experience of living with chronic pain after an accident.

If you would like to take part in this study, please complete the following so that we might contact you to arrange an interview:

Name: _______________________________

Contact number or e-mail: _______________________________

Whether you have decided to take part in this study or not, we would like to thank you for your time in reading the information we sent you.

Please return this sheet in the stamped addressed envelope provided.

Thank you very much.

Tarick Ali
PsychD Clinical Psychology
University of Surrey

Dr Claire Copland
Chartered Clinical Psychologist
Centre of Pain Education (COPE)

We welcome comments about our service
If you have anything to say please ring 020 8296 2508
www.epsom-sfhelier.nhs.uk
Dear

Thank you for reading the information sheet we sent you for the research project “The personal experience of living with chronic pain after an accident: an insider’s perspective”.

If you have already sent back the reply sheet for this project, thank you for your time. If you have not, we would still very much appreciate your help with this research.

You can contact us at COPE, on 020 8296 4315, should you have any questions.

Your participation in this research is entirely voluntary and if you have decided that you do not wish to take part, we respect your decision and we will not contact you again regarding the above research study.

Thank you again for your time.

Yours sincerely,

Tarick Ali
Trainee Clinical Psychologist

Dr Claire Copland
Chartered Clinical Psychologist
Appendix F

The Interview Schedule (Version 1)

This interview schedule is intended as a guide for the interview only.

Preamble

"You indicated at your assessment at COPE that your pain started following an accident. I have been given no more information about you than that.

The study that we are doing is aimed at getting a more detailed picture of what the experience of living with chronic pain as a result of an accident has been like for you. Everybody's experience will be different and we would like to hear about your experiences, in your own words.

There is no rigid structure to the interview, so please feel free to talk about anything you think is relevant. Over the next hour or so, I would like to ask you about how you have come to understand the experiences you have had, your thoughts and feelings towards the accident now, and the influence that the accident may still be having on your coping with persistent pain. Does this sound OK? Before we start it is helpful for the readers of any reports that we write about this research to have a little background information on the people that we interviewed:"

[Ask participant to complete the Background Information Questionnaire]

Understanding of pain – onset and persistence.

"I would like to ask you a few questions about your understanding of how your pain developed and the consequences the accident has had for you"

1. What is your understanding of why pain developed following your accident?
   What explanations have you been given for your pain?
   Do these explanations make sense to you?

2. What is your understanding of why your pain has persisted?
   What explanations have you been given as to why your pain has persisted?
   Do these explanations make sense to you?
   What is your understanding of persistent pain?

3. Apart from pain, have you experienced any other physical problems? Including pain, which is the most problematic for you?

4. Apart from physical problems, have there been any other consequences of the accident? Which is the most problematic consequence for you?

Thinking about the accident… and pain

"I would like to ask you about the kind of thoughts you have about your accident now"

5. a. Do you still think about the accident?
   When do you find yourself thinking about the accident?
   Are there times when you think about the accident more?
Do you notice any changes in your pain when you think about the accident?

b. You said that you don’t think about the accident now – Did you think about it in the past?
   
   How has your thinking changed over time?
   Have changes in your thinking influenced your pain?

6. What types of thoughts do you have / did you have about the accident? For example some people say they think about how the accident could have been avoided?
   
   Do you blame anyone for the accident?
   Do you think about who is responsible for the accident?
   Do you feel like you could have done something differently?
   
   Does thinking these types of thoughts influence your pain in anyway?

7. What do you think about when you experience heightened pain (i.e. on bad days with your pain)?
   
   Do you think about the accident more at certain times of pain?
   Do you try and avoid thinking about the accident when in pain?

Influence of the accident on coping with persistent pain

“I would like to understand more about how having had an accident might affect how people cope with their pain - even years later”

10 a. Does the accident still have an influence on your pain (or physical health) now?
   
   How do you think the accident might still be influencing your pain?
   How does the accident influence how you cope with pain?
   Did the accident ever have an influence on how you cope with your pain?
   How has the influence of the accident on your pain changed over time?

b. You said that the you feel that the accident has little influence on your pain now. What has helped this?

11. Some people develop pain without really having a recognised ‘cause’ for it. Do you think your experience now would have been different had you not known the cause of your pain?

12. How do you feel about the way other people have responded to your pain since the accident?
   
   What have been the reactions of partner? family? friends? professionals?
   Are there differences in how people responded immediately and how they have responded in the longer-term?
   Would you like them to have responded differently (at different times)?
Appendix G

Participant Number: 1.5th My 2005 (Version 1)

Background Information

The following information is collected so that people who read the final report can know more about the people who have taken part. However, the information that you give cannot be used to identify you in any way.

1. Age? ___________

2. Gender? (circle one) Male / Female

3. How would you describe your ethnicity? (please tick)

- White British
- Irish
- Other

- Mixed: White & Black/African
- White & Black/Caribbean
- White & Asian
- Other Mixed Background

- Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Black or Black British
- Caribbean
- African
- Other Black Background

- Other Ethnic categories
- Chinese
- Any other categories

4. Current Marital Status?

- Single
- Married/Co-habiting
- Other (please specify) ___________________________

5. What is your highest qualification? (please tick):

- None
- GCSE/O level
- A level(s)
- Diploma
- Degree
- Postgraduate

6. What is your current employment status? (please tick)

- Full time work
- Part time work
- Studying
- Not Working because of pain / medically retired
- Not Working for Reasons other than pain
- Other ___________

What is your job now or what was your last job? _____________________________________

6. Date of accident that led to development of pain? ____________________________

If more than one accident, list dates: _____________________________________

7. Duration of pain? ___________ Years ___________ Months

8. Main site/s of pain ____________________________
Appendix H

Transcript 1: ‘Max’ (December 2005)

Interviewer: Right. So the tape’s now on. Are you happy if we make a start, you feel OK with everything?

Max: Yeah. Fine.

Interviewer: OK. Great. Well like I said. There’s no rigid structure to the interview so please free to say anything you feel is relevant. Hmm. Perhaps I could start then by asking what your understanding of why your pain developed is?

Max: Urh. Well I know really. I had an accident in a fire engine, where we went up and down. Basically, I held onto the steering wheel which put my shoulders out. I thought I’d broken my back at the time but it turned out I didn’t. I got taken by an ambulance to hospital. I asked for x-rays and they said ‘no no you don’t need them’. After about two hours lying on a trolley, they checked me over. ‘No you don’t need an x-ray’. They just gave me loads of tablets.

Interviewer: Hmm. Yeah.

Max: I was off duty for the next four days. I went back on duty after four days. I was aching everywhere. You think to yourself, you’ll fight through it. And they put me straight onto night duty and I was on night duty for about three weeks. And basically, I learned to live with the pain as it didn’t seem to be getting any better after three or four weeks. I was back on full duty at this time. The blokes were helping me out at work.

Interviewer: Hmm. Right.
Max: In the fire brigade, when you drive you don’t really do much else really. I got in touch with the doctor who sent me to a specialist at Epsom and I started with a physio straight away. And then with a physio at work also so there was a period where I was doing twice a week physio. Basically I just got used to the pain. There was a level I could manage. Over the course of time I was having the physio and that was making things worse. At the start of physio I was leaving and then hurting for just a day or two and then it would get back to normal. But what was happening was the more that we were doing it, the more it was hurting. Basically, I was hurting until the next time we did it. I was actually getting worse and worse. In the end I had to go sick because the blokes were carrying me more and more and more. I had to make the decision, coz I would be about 9 months away from completing 30 years service now, but I was doing less and less at work. But that was bad on the blokes really. They were doing more and more of my work. I was getting out of loads of things. All the mundane jobs. Nice of the blokes but it started to get to a point where I was getting embarrassed about it.

Interviewer: And how far from retiring did you say you were?

Max: At the time of the accident, I’d less than three years to do. I’d struggled on for a while, but there was no way I was gonna be able to stay for much longer, you know and then, I’d been waiting for different appointments for all these different things and everything takes three months in the NHS. It’s like three months for the appointment, then three months for the MRI scan, then three months for the results, another four months to have injections in me spine and now I’ve ended up on this pain management course.

Interviewer: You said you were holding on to the steering wheel during the accident, can you say a bit more about what happened?

Max: Well basically we were on our way down a hill on an emergency call, it was in the wet and the brakes didn’t work how they usually did, in my opinion because I’ve done that road so many times. We’ve hit a speed table and the vehicle lifted up in the air and came down sharply. I kept hold of the steering wheel to try to keep it straight
and pull up, so basically we got shook up and down. I thought I'd broken my back. Pain all over, as if my spine had broken. I was in agony.

Interviewer: While you were driving?

Max: As we pulled up, I knew I was in pain. Just seconds after I realised how much pain I was in. Maybe a slight delayed reaction. And that is it really.

Interviewer: What explanations have you been given for the pain?

Max: That is was due to the accident. Or not necessarily so. Apparently they've delved into my medical files and I've got... I’ve had a few back injuries in the past. It could be part of an old injury, or due to one of them from before the accident.

Interviewer: From a previous injury?

Max: Or they’re saying it’s generic... is that the word, like wear and tear basically.

Interviewer: So like general wear and tear?

Max: Yeah. But I had no problems with my back for years. When I did I was back at work within a few days so.

Interviewer: What do you think of that explanation then? General wear and tear?

Max: I’m not happy with that at all.

Interviewer: It doesn’t make sense to you?

Max: No, No. Everyone’s got wear and tear haven’t they. As they get older. No. To go just like that, like my back did, well I know it was due to the accident, coz I was in the accident, with three others.
Interviewer: What do you think happened to your body then?

Max: My spine was crushed I presume. A crush injury to a disk... apparently... but another lot of x-rays and an MRI scan two years after the accident, they can’t tell from that whether it happened on the accident, or previously. If they’d done the MRI scan previously, just after the accident, but there’s a waiting list. You can’t just go and have an MRI scan (laughs). If I’d had x-rays on that day, on the first day, they just sent me home on that day, saying you don’t need them, the first set of x-rays I had was about three months after and they found, trapped nerves, my back was constantly in spasm.

Interviewer: So you said you didn’t kind of buy into the whole idea of wear and tear, how did you feel about the idea of a crushed spine, did that make more sense to the way you were feeling?

Max: Yeah it does, that’s what I thought it was.

Interviewer: Ok. Because having seen a few specialists, I was wondering if you’d had different explanations for what was going on?

Max: Exactly. I had different explanations.

Interviewer: And do you feel like you’ve had an adequate explanation for why the pain persisted?

Max: Urrhm. Not adequate, No. I’ve had so many different opinions. Because I’ve been to see people in different fields and they all give you a slightly different reason. But, No I don’t think I have been given an adequate explanation.

Interviewer: Mmm I see.

Max: I expected my back to get better after a few weeks, basically. But I seemed to be passed from person to person. Any treatment you are referred for, you have to wait
and wait. I suppose that’s just the way the NHS is at the moment. To me you are injured, you should be seen straight away, I could have got back to work.

Interviewer: So what’s your understanding of why the pain hasn’t gone away?

Max: Because I haven’t been made any better. I would have thought I would have been able to be made better by now. I expected my back to get better after a few weeks basically. But the injections in the spine haven’t worked and I’ve been sent onto a pain management course to learn to manage the pain. We were told when I had that interview – I was up there a few weeks ago…they explained it better, you know, that you are going to have it for the rest of your life and you just got to bear with it and try some different things, some exercises and to try and make it more bearable. But I don’t think it will be more bearable than I’m doing now because, I do my own thing, I walk about a lot, I don’t sit down, I’ll be up again in a minute, I go for walks down the road just to, that relieves it for me – short walks.

Interviewer: Apart from physical problems, have there been any other consequences of the accident?

Max: What do you mean?

Interviewer: Well, urhm, has the accident impacted on your life in other ways except physically?

Max: The accident completely changed my life, but that’s because I can’t do as much physically….which is a bummer. I was depressed for a long time, but I’m over that now. Now that I’m retired at least there’s a bit of closure on it.

Interviewer: What do you mean?

Max: The job wouldn’t let me go you see. They tried to get me to do other bits and pieces, a different job basically! I can’t, because I don’t drive, I can’t sit down long enough. I can't work a computer. I’ve had to get the boy to look some stuff up for me
on the computer because I don’t have an idea about anything else in my life really. No there’s that really. I do me walking. Obviously there are things I’d like to do and I can’t, which I’m pissed off about. I’m a Chelsea supporter and used to go to most games and the last game I went to, I think was just after I went sick. Over two years ago, me mates said come on lets go and see a game... anyway, drove up there and we had a drink b4 hand so I could stand and walk, but when we got in the stadium and sat down, I had to get up after about 15 minutes. I had to go down to the concourse downstairs and watch them on the screens down there. I haven’t been back since cause I couldn’t sit in them little seats. So uncomfortable.

Interviewer: Yeah they are uncomfortable seats...

Max: Yeah, I was in real pain so I haven’t been back since. So there’s that...

My wife plays in concerts, she’s a violinist and I haven’t seen her play since before the accident. You can’t fidget about at a concert so I haven’t seen her play again.

Interviewer: Sounds like it’s had an impact on all parts of your life...

Max: O everything yeah. Well, as I’ve said to them, maybe if I could go to a Chelsea game, that would be great. To sit down for an hour and a half. And if I could watch me wife in concert. Other than that I’m not too bothered.

Interviewer: They sound like really clear goals to have?

Max: Yeah, yeah. I’ve had to drive this week and that’s why I’m really feeling it at the moment. Because I’ve had to drive every morning because my wife’s in hospital. I had to go up there to drop some stuff off. But I don’t usually drive. I’m usually the passenger, sitting in the front, which isn’t too bad. We have to miss all the bumps. I can’t go over bumps. It’s like on the train... obviously if I have to go for interviews, I come up to the hospital and that does me in when I get there because you don’t realise how painful...well you don’t...you’re sitting on the train, or standing and it’s when you get off the other end, you feel the pain, coz of all them bumps and jerks your going over, you don’t realise them at the time. It takes it out of your body when you
go to get off the train. I’m in pain now. Basically, I try not to take public transport, or go anywhere in the motor unless I have to.

Interviewer: It seems like the main consequences of your accident have been related to the physical problems you’re experiencing now... like it doesn’t sound like you’re having images of the accident or flashbacks...and that type of thing?

Max: Oh no, no, no. I didn’t kill someone or nothing like that. There were no other people injured as such. I didn’t hurt anyone.

Interviewer: Well I guess I’d like to ask you a bit more about the kinds of thoughts you’re having about the accident. Do you still think about the accident?

Max: Not at all. Only when I’m asked. I did. But now I don’t think about it all.

Interviewer: Right. How’s your thinking changed about it?

Max: Well it’s like I’ve basically given up on it. It’s like it’s [the accident] gone. It’s all in the past. There’s nothing I can do about it. My back is still bad and I’ve got to get on with that now.

Interviewer: You mean you’ve put it in the past?

Max: Yeah I realised I had to get on with my life. I can’t do things like I used to.

Interviewer: When you used to think about it, what kinds of things were you thinking?

Max: Well I used to run through it mind. Could I have gone slower. If I done this that way. If I hadn’t let go of the steering wheel, would I have hurt me back. If I’d taken a different route. Coz there was another route to where we were going. There were two routes (laughs). So, its things like that. Other than that, there’s nothing more I could have done. It was just one of them things.
Interviewer: It sounds like you were replaying the accident afterwards...

Max: Yeah. It gradually stopped.

Interviewer: Some people wonder how the accident could have been avoided, like you just said and some report feeling to blame. Did you feel any blame towards...

Max: Oh no, no. well only... I don’t actually blame... where we hit the second speed table, it turns out it shouldn’t have been there. It was too close to the other one. But as for blame, no.

Interviewer: I guess... did you mention something about the brakes earlier?

Max: Yeah. They took the machine away. And they said there was nothing wrong with them. Well I accepted that. But then I found out that about two months later there were two other incidents, with that particular machine, not the same one but that model, same year, in London, in the same situation, going down hill in wet conditions, they had exactly the same problems, where the drivers reported the brakes aren’t working properly.

Interviewer: Yeah. Right.

Max: So... I can’t prove anything.

Interviewer: Does that annoy you a little bit?

Max: Yes. That does annoy me. That did for a long time actually. It’s very frustrating. Without a doubt.

Interviewer: Have you made any attempts to pursue someone taking responsibility for what happened?
Max: Oh yeah. My union got in touch with the solicitors and I’ve got a claim going against the council and straight away they said about the bumps being too close together. They admitted responsibility anyway. That’s still in the pipe line. I might get a few grand back in lost earnings. I’m still being paid by the brigade, but I’ve lost over-time. I don’t expect to make any money from it. The solicitors will probably. I didn’t even want to go down that road. But it’s all free. If you don’t win, you don’t pay anything. I would have retired in ten months anyway so I haven’t really lost too much in lost earnings really. Only a few grand overall. So I don’t know what will happen with it in the end but we’ll see. I’m not too bothered.

Interviewer: It’s not playing on your mind.

Max: No. Whatever I get I’ll spilt between me kids anyway. That’s about it. Like a bonus.

Interviewer: Do you think thinking about the accident might say increase your focus on the pain?

Max: Well I don’t really think about the accident now so anyway. Perhaps it did but I don’t know. It might have done then, but not that I was aware of. I only thought about how things might have been different for a while. Like what if I’d gone a different route.

Interviewer: And those things don’t play on your mind now.

Max: No. Coz I know I was doing the right thing really. I was on the way to an emergency call and I was going fast, in those conditions, but no faster than I’d always gone. I was going slower than I normally would, because of the conditions. The others were in the back but they wouldn’t have noticed much about the accident. They would have just gone up and down. When you’re sitting in the back there’s not a lot that you can see. The guy next to me was the officer in charge, he said something like ‘it’s not stopping’, something like that and that’s it.
Interviewer: Do you think there might be any ways in which the accident still has an impact on the way you cope with your pain now? Or has an influence?

Max: Well I don’t think so. I mean the accident was the cause of the pain so it must play a part. But that’s all I can say about that really. I’m in pain because of the accident.

Interviewer: What things have helped?

Max: The sun helps. (laughs). I find it hard in the winter. If the cold is getting into me back perhaps. Last few weeks have been... then again, perhaps that’s psychology. I don’t know. People say the cold has an influence, but I don’t know. I know I feel in more pain and I think it’s because of the cold. Obviously I’m not going out so much now when it’s cold and not going on my 15 minute walks that help. Whereas in the summer, I go out nearly every hour or other hour. There’s that to it I suppose I hadn’t thought about.

Interviewer: Ok. You said that the accident has little influence on your pain now and we were talking about what you think helped and we talked about part of what helped might have been that you didn’t feel to blame for what happened to you or that no one blamed you.

Max: The job blamed me. The actual fire brigade blamed me. Well they did back then. They said that because there was nothing wrong with the fire engine, that I must be to blame. For going too fast. But what I can’t understand was that I was on my way to an emergency call. It weren’t as if I was just going back to the station.

Interviewer: Yeah

And I’ve been driving 26 years, a fire engine for 26 years and I think I’ve only had one accident before.
Interviewer: That’s a good number after 26 years. How did it feel that they were blaming you.

Max: Disappointed yeah. That wasn’t one person blaming me, it was an organisation. It’s not as if I can go and have a go at someone. You see what I mean? You’ve not got someone in your face telling you you’re to blame. So I blamed the machine, but there’s no way I can prove otherwise. So you gotta forget about it.

Interviewer: I wonder if your colleagues helped you with that. Like by not blaming you.

Max: I just got on with things really.

Interviewer: Some people develop pain without really having a known cause... they just develop pain gradually and it gets worse and worse. Do you think that your experiences would have been different if you hadn’t known the cause of your pain?

Max: What if I hadn’t had the accident?

Interviewer: Yeah, if you didn’t know why you were in pain?

Max: Well you’d go to the doctor first of all and find out why you’ve got it. And then I guess go through the same process that I have. Depends on what they say has happened. If all of a sudden you pick up pain, you’d think there was something wrong with you wouldn’t you? Like cancer or something else.

Interviewer: I guess when people develop pain gradually without a cause, those are some of the thoughts they might have.

Max: Well you might think it’s much worse than it is. That’s why you go to the doctors straight away usually. But I know what I’ve got wrong with me which must help, rather than not knowing. It’s just a shame they can’t do nothing about it.
Interviewer: Do you think that makes a difference to how you respond to your pain? That you’re in pain but you know why? Do you think that helps?

Max: Not really. I don’t really think about it.

Interviewer: Having a recognised cause seems to help some people. How do you feel others have responded?

Max: Really good really. Those that are close to me, really good. Wife and I have had our rows obviously. Loads of rows, coz she’s got bad shoulders. That’s what she’d had done in the hospital. So she’s limited in movement. It’s hard for her, but you have to work together don’t you. The kids have been great really. Though I have had a go at them loads of times. They have been good. And I’m getting older too (laughs). I think I’d be more pissed off if I was like this and only 20 say and I had years and years to go. But I’m 50 now. I think if I was younger it would be totally different.

Interviewer: Friends?

Max: They’ve been good too. Giving us lifts places. Run me to the hospital. Luck we’ve got me mother and father in law across the road so that helps. They do a lot for us.

Interviewer: Professionals?

Max: Most have been good. Except obviously those who aren’t on my side. The ones in the job.

Interviewer: So when litigation comes in to it, it changes?

Max: Yeah, once money is involved you get biased opinions. Probably on both sides. If one side’s for you and the other is against you, you probably don’t get the truth. Bias on one side or the other. The only one you’re going to get truth from is like where I went to see the specialists at Epsom hospital, the consultant with the results of
the MRI scan. He told me about the crushed disc, this that and the other. He's not on any side. I'm hearing it from him which I prefer. I'd like to think I got the truth from him. But overall, all the professionals I've seen, like at COPE, they all seem nice enough wherever I've been. You've got to get on with it really, at the end of the day.

Interviewer: Have professionals tended to ask you questions about the accident, as well as the pain?

Max: Yeah some have. Not many. At COPE, one of the people asked a few questions.

Pause to light cigarette.

Max: I tend to smoke more now. Actually, I don't smoke in the house, I go outside, but as you're here and it's so windy and my wife's out, I'll take advantage and smoke (laughs).

Interviewer: You have to make the most of it before she gets back (laughs).

Max: I'll open the windows later before she comes home.

Interviewer: Were there any differences in how people responded immediately after the accident and how they reacted in the longer term?

Max: Urhm. Well of course after the accident you had loads of people ringing up and getting in touch. Job wise, in the job and friends and relatives. Since then, all me friends and relatives have been really good. Very supportive, so it hasn't changed much really. Only from certain people in the job.

Interviewer: They were in touch early and not so much later on?

Max: They were only in touch early and then not at all later on. Basically they wanted to know for the job how I was and what was going on and then you don't hear from them again. Just to check in really. People have been very good really.
Interviewer: Any support you didn’t get that you would have liked?

Max: I would have liked more input from the benevolent fund. They’re supposed to get in touch and they didn’t. In the end, my friend called them, but they are informed anyway and then eventually they did ring me up but by then had the arse and I said no I’m not interested.

Interviewer: Hmmm. You’d have liked them to be contact earlier.

Max: I thought they would have been in touch, without someone else ringing them. It was other people in the job actually, that were more annoyed than me that they hadn’t been in touch. Other than that no.

Interviewer: Does the benevolent fund offer social support – like the British legion?

Max: Similar. Like welfare that you pay for every month as you work.

Interviewer: Are there local organisations for retired fire fighters?

Max: Well I’ve just joined the retired fire-fighters organisation but all that is, it’s nothing, it just keeps you in touch, like an address book really of everyone else. You don’t get anything out of it.

Interviewer: You don’t meet up?

Max: Only once a year, they organise a lunch. It’s not free (laughs).

Interviewer: OK. We’ve been talking for an hour so I don’t want to keep you. I get a sense that the accident was fairly clear cut and you know what happened and no-one else was injured. It didn’t take too long to put the actual accident into the past.
Max: No. I’ve just got on with it really. Yeah. I cant do a few things because of it, like gardening and all the other social stuff I used to do. Used to play golf and catch up with the lads. But I’m never gonna play golf again obviously.

Interviewer: Does that make you think about the accident, when you get asked?

Max: No, I just get pissed off that I can’t say yes when I’m asked to go. They still ask me. It’s the social part after that I miss too. Lots of social activities I miss. But it’s in my head that I can’t do them, so that’s it.

Interviewer: Was there a point when you thought that?

Max: Well I thought that my back would actually get better. Not worse. I actually thought that it would.

Interviewer: Do you remember that turning point?

Max: Urh...I think that was around the time when I went sick because it was getting so bad. The other blokes were supporting me more and more. Then I had me MRI scan and the result. They talked about injections in the back and having an operation. That it could cure it but I would undoubtedly have pain elsewhere for the rest of my life. So in their opinion they said it wasn’t worth having an operation until it was that bad that you are stooped over. I said well right then, I won’t have an operation. You just put up with the pain. And adjust.

Interviewer: I guess you were presented with this choice that wasn’t really a choice...

Max: No it wasn’t a choice at all. Full stop - you cant do certain things anymore. Like climbing ladders. No, I’ve accepted it all now. I do me best around the house. I try. They’re certain things I can’t do with the Hoover because of the bending down and going round the sides. Can’t lift it to take it upstairs. The pain is terrible. The silly little things you just cant do.
Interviewer: Even the little things can have a big impact on you.

Max: It would be nice just to get back upstairs and Hoover. If anything does come out of me doing this course, you know at COPE it’ll be good. When I try, the pain isn’t bad bad but I know I’ve got to put the thing down otherwise, because it’s going to get bad, if you see what I mean.

Interviewer: What goes through your mind when you feel the pain?

Max: You don’t think your back is snapping when you lift something, but you know you shouldn’t be lifting it because your back is starting to tense up. It’s hurting so you put it down quickly.

Interviewer: Do you have any thoughts of the accident when that happens.

Max: No, no. Not at all. Just think to put it down (laughs).

Interviewer: Ok well thank you. I’m really grateful to you for taking the time to take part in the study, especially as it’s coming to Christmas. Well I won’t take up any more of your time. Thanks again.

Max: That’s fine.
Appendix I

London - Surrey Borders Research Ethics Committee
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12 January 2006

Mr Tarick Ali
Trainee Clinical Psychologist
Surrey Borders NHS Trust
Department of Psychology,
University of Surrey, Guildford
Surrey
GU2 7XH

Dear Mr Ali,

Study title: The personal experience of accident-related chronic pain: an interpretative phenomenological analysis.

REC reference: 05/Q0806/84

Amendment number: 1
Amendment date: 23.12.05

The above amendment was reviewed at the meeting of the Sub-Committee of the Research Ethics Committee held on 11 January 2006.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

- Request to add Kingston Hospital, Pain Management Service as a research site
- Ann Gold's CV – local collaborator

Research governance approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval of the research.

An advisory committee to South West London Strategic Health Authority
Statement of compliance

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

REC reference number: 05/Q0806/84 Please quote this number on all correspondence

Yours sincerely

Sheree Leehane
Committee Co-ordinator

An advisory committee to South West London Strategic Health Authority
Dear Dr Ali

Re: Accident related chronic pain: An IPA – Version 1

Thank you for your application for R&D Trust Approval, which was received on 5th September 2005.

The R&D Office has checked and can confirm the following documentation has been received:

**Document: Local Research Project Registration Form**
**Version:**
**Dated:**
**Received:** 5.9.05

**Document: Investigator CV**
**Version:**
**Dated:**
**Received:** 5.9.05

**Document: Investigator CV**
**Version:**
**Dated:**
**Received:** 5.9.05
Document: Protocol/Study Design
Version:
Dated:
Received: 5.9.05

Document: Clinical Trial Agreement
Version:
Dated:
Received:

Document: Form of Indemnity
Version:
Dated:
Received: 5.9.05

Document: Researcher's Agreement
Version:
Dated:
Received: Pending

Document: Letter from Sponsor (if not the funder, the applicant's employer)
Version:
Dated:
Received: See RRF

Document: Statement regarding compensation arrangements
Version:
Dated:
Received:

Document: Comments from Statistician
Version:
Dated:
Received:

Document: REC Application Form Parts A & B
Version:
Dated:
Received: 5.9.05

Document: REC Application Form Part C
Version:
Dated:
Received: 5.9.05

Document: A summary, synopsis or diagram (flowchart) of protocol in non-technical language.
Version:
Dated:
Received:
Your application will now be reviewed and you will be contacted should any issues be raised or further information be requested.
Applicants should expect an R&D Review decision within 35 working days from the date of this letter, excluding any time taken by you (or your solicitors) to fully respond to any issues raised or requests for further information.

Kindly note you will also require a favourable Research Ethics Committee opinion in order to commence this research study.

Please quote the following R&D Registration Number in all future correspondence:

Yours sincerely

[Signature]

Mrs Y. Real
Research & Development Business Manager
## Appendix K

<table>
<thead>
<tr>
<th>Preliminary notes</th>
<th>Section of Vicky’s Transcript</th>
<th>Emerging themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Identity/ change</td>
<td>Tarick: OK. If I might start then by asking, what’s your understanding of how your pain developed?</td>
<td></td>
</tr>
<tr>
<td>- Clear on sequence of events: unremarkable event, no distress.</td>
<td>Vicky: Yeah. Well. I had an accident. I was on my bicycle in Richmond Park, I used to be quite a keen cyclist, and I came over a bridge and had to brake quite suddenly and the bike stopped but my leg, well it didn’t. So I went down a hill, on my bike, and hit this bump in the road, which made me twist round. And as I twisted I made a huge thump. But I don’t really know what I did and nobody still really knows what I did.</td>
<td></td>
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<tr>
<td>- Unclear as to actual damage at the time</td>
<td>Tarick: Hmm. Right.</td>
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<td>- Nobody clear as damage at the time</td>
<td>Vicky: I think basically, I completely ruined my tendon around my hip, and I damaged the inside of my hip as well. I’ve had two, no, three procedures, well two were operations, and one was an investigation. The first operation was to cut the tendon because I’d come to a complete halt at the time and couldn’t walk anymore. So they cut the tendon which helped me a lot with my mobility as it actually released the hip. It had been like, so tight where it was holding the hip in place if you like. But with the mobility came a lot of pain, and then I had to have more investigations, and then a further operation inside my hip where they had cleaned the spur. They are still looking into why I’ve still got this ongoing pain, so I don’t really know either. But it also affects round my back. I’ve also got a slipped disk, that comes and goes, which I feel is from this, but they won’t give me a link. The doctors won’t actually give me a precise link to it but I think it’s because I’m holding myself in a particular way so my whole body posture is out of alignment, and so every now and again that goes.</td>
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<tr>
<td>- Has some explanation as to injury</td>
<td></td>
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<tr>
<td>- Search for answer or fix.</td>
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<tr>
<td>- Operation (mobility Vs pain)</td>
<td></td>
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<tr>
<td>- Still no answer as to ongoing pain, despite investigations &amp; ops.</td>
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<tr>
<td>- Own explanation Vs. experts.</td>
<td></td>
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<tr>
<td>- Experts can’t explain</td>
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Uncertainty as to injury

Search for fix/cure.

Disappointment in medical prof.

Uncertainty re. ongoing pain.

Conflicting explanations (Self Vs. Medical)
<table>
<thead>
<tr>
<th>- 'Feels linked...': own explanation</th>
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<tbody>
<tr>
<td>Tarick: So, you link your back pain to the accident too.</td>
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<tr>
<td>Vicky: Well, because it sort of started at the same time as after the accident. I mean, there may not be a link at all, it might just be co-incidence, I’ve got no idea, but often, if I’ve over done it with my hip my back will go. It feels as if it is linked.</td>
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<tr>
<td>Tarick: it feels like it is linked, but you haven’t had that confirmed.</td>
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<tr>
<td>Vicky: No, I haven’t had that medically confirmed</td>
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<td>Tarick: have you been happy with the explanations that you have been given. Do they fit with what you feel or think?</td>
</tr>
<tr>
<td>Vicky: hmm. The tendon explanation - I could understand that completely. It wasn’t a problem. I understood where it was, what it did, why it was causing me pain, and why they had to cut it. That was fine. The hip, hmm, I don’t feel as if I have a full explanation for that. I don’t feel like the consultant really entirely understands what has actually gone on. There was this, well he said that the bone had become pitted and grew a spur, and also they say that I’ve got a very deep socket, so the bone at the top of my leg rubs against the socket, and has started to wear away. They are not sure whether that was caused by the accident, or whether it was something that was there that was then exacerbated by the accident. So it’s, uh, so they keep coming up with these various explanations but I don’t know. I can understand why the wearing away would make it hurt, but I don’t understand why the bone went wrong, why the spur grew, or the bone pitted, and I don’t really understand what I did when I had the accident</td>
</tr>
<tr>
<td>Tarick: so they don’t really know if it was something that was made worse by the accident, or whether it was brought on by the accident</td>
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<table>
<thead>
<tr>
<th>- Varying uncertainty.</th>
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<tbody>
<tr>
<td>- Extent of 'fit' with own understanding.</td>
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<tr>
<td>- Experts don’t understand - can’t give me an answer.</td>
</tr>
<tr>
<td>- Uncertainty as to how accident led to injury/pain.</td>
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<tr>
<td>- Pre-accident functioning.</td>
</tr>
<tr>
<td>- Confused re. pain.</td>
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<tr>
<td>- Various explanations.</td>
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<thead>
<tr>
<th>Own understanding</th>
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<tbody>
<tr>
<td>Uncertainty as to injury</td>
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<tr>
<td>Disappointment in medical profession</td>
</tr>
<tr>
<td>Uncertainty as to ongoing pain</td>
</tr>
<tr>
<td>Various explanations</td>
</tr>
</tbody>
</table>
| - Huge noise?  
  Retrospective recall of damage  
 - Immediate response to rest. |
<table>
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<th></th>
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<tbody>
<tr>
<td>Vicky: All I know is that I did something on that day that made a huge noise, when I did it, and urhm, I got back on my bike and went home actually (laughs). I came home thinking 'ooh that's a bit painful', so I got in the bath, went to bed, and I got up the next day and thought 'ooh, I can't actually move now (laughs)'. The adrenalin must have just carried me home I think.</td>
</tr>
<tr>
<td>Expectation of recovery (with rest)</td>
</tr>
</tbody>
</table>

| - Effort to get on with daily life.  
 - Gradual process of realisation pain not going away.  
 - Failure in recovery efforts |
|---|
| Tarick: You just headed for home.  
 Vicky: Yeah, I just wanted my home.  
 Tarick: It sounds like you were thinking 'I'll just go to bed and sleep this off' then?  
 Vicky: Yeah and for a while as well, I just carried on. I mean I was very very stiff, and I eventually went to see an Osteopath, and had a bit of treatment with him. It just sort of carried on and on and on. And then eventually I went to the doctor, and eventually down to the consultant room, through various steps.  
 Tarick: So it was a gradual process, to getting any investigations?  
 Vicky: Yeah.  
 Tarick: Did you go the Osteopath straight away?  
 Vicky: Well no, I thought 'I've hurt myself but it will go away'. I suppose that's the natural thing to hope for. You don't tend to think you've done yourself a huge damage because, well all I did was, I was only on my bike, I didn't even get knocked off, I didn't fall over, I just twisted, but the noise kept coming back. This huge thump, crack sound. Ooh. I thought 'ohh I've done something'. Actually I did at the time think 'I've done something' but it didn't actually hurt. |
| Gradual Realisation of ongoing pain  
 Expectation of recovery (with time). |

| - Expected pain to go away - limited treatment seeking  
 - Pain doesn't make sense: damage not in line with severity of accident |
|---|

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<table>
<thead>
<tr>
<th>Theme</th>
<th>Summary</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>-Mystery/meaning of noise/damage done</td>
<td>don’t remember it hurting me at all, but I remember the noise, and I don’t know, I got off the bike and stood up, and checked everything, thought ok I feel alright, I’m alright. Got back on the bike and got home, and that was it. I don’t remember pain at all, not at all. Whether I was in pain and blocked it out or whether it just wasn’t there I don’t know.</td>
<td>Uncertainty as to injury. Trying to make sense of ongoing pain.</td>
</tr>
<tr>
<td>-Struggle to make sense of the severity of post-accident pain/consequences.</td>
<td></td>
<td></td>
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<tr>
<td>-Acute injury based response.</td>
<td>Vicky: Yeah. I don’t remember if it was that day, but I remember definitely the next day. Because I got in the bath that day just because I felt it would do me a bit of good. But it was the next day when I really felt it.</td>
<td>Expectation of treatment process</td>
</tr>
<tr>
<td>-Attempts to recover in line with perceived severity of accident.</td>
<td></td>
<td></td>
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<tr>
<td>-Trying to make sense of pain in terms of damage</td>
<td>Vicky: Well I just thought I must have done more than I realise, and then I think I just carried on. Don’t even think I took any pain killers. I thought I’m a bit stiff. Like they always say – ‘exercise is bad for you’ (laughs). So I just carried on. And like I say, eventually I went to see the Osteopath, rather than go to the doctors, because I thought it was stiff and he might help and that would have been about four days after I think. I can’t actually remember how long it was after that I went to see the doctor.</td>
<td>Expectation of recovery</td>
</tr>
<tr>
<td>-Struggling but maintaining daily life</td>
<td></td>
<td>Search for pain relief/cure</td>
</tr>
<tr>
<td>-Assumptions of injury &amp; treatment seeking.</td>
<td></td>
<td></td>
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<tr>
<td>-Gradual realisation pain not going away</td>
<td>Vicky: It was in 2001. So it was really a gradual realisation that this thing wasn’t going to go away. And my mobility went down gradually, it was quite a decrease. Although I had become stiff straight away, and found it difficult to walk, it sort of came back during the day and went up and down, so I</td>
<td>Realisation of ongoing nature of pain.</td>
</tr>
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</table>
- Loss of physical abilities/disability
- Fear of disability
- Faith & disappointment in medical profession.

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<tr>
<th>Physical/Mobility Restrictions</th>
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| carried on for quite a long time before it sort of started getting worse and worse and worse. And I would just sort of grind to a halt basically. I would be walking along and then feel that I just couldn’t physically go any further. That was really frightening, really scary. My body just stopped and I couldn’t move my leg. It was so gradual the whole thing though. It wasn’t like I woke up one morning and thought that’s it. I think because I was going through the medical profession and everything takes so long. You know, you think I’ve got an appointment and you think great they’ll be able to tell me what’s the matter. And then they’ll be able to cure it. I guess that’s modern thought isn’t it, you sort of think you can cure anything nowadays you know, because medical science has evolved so much.
### Appendix L

**Master list of themes from Vicky's transcript**

<table>
<thead>
<tr>
<th>Understanding injury and pain</th>
<th>Location of relevant excerpts</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Uncertainty as to injury &amp; why pain persists</td>
<td>‘I don’t really understand...’ (3:21)*</td>
</tr>
<tr>
<td>- Conflicting explanations/Lack of explanation</td>
<td>‘these various explanations’ (3:18)</td>
</tr>
<tr>
<td>- Search for a cure/fix &amp; hope/faith/disappointment in medical profession.</td>
<td>‘you think they can cure anything...’ (6:22).</td>
</tr>
<tr>
<td>- Expectations of recovery / gradual realisation pain not going away or acceptance.</td>
<td>‘thought it will go away’ (5:2)</td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>Impact on Identity</th>
<th>‘I’m a different person’ (23:13)</th>
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<tbody>
<tr>
<td>- Impact on sense of self</td>
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<tr>
<th>Social Difficulties</th>
<th>‘It’s hard to explain..’ (14:15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Communication Difficulties/not being believed</td>
<td>‘I’ve really pulled back..’ (18:15)</td>
</tr>
<tr>
<td>- Social withdrawal</td>
<td>‘I feel less in the friendship..’ (17:15)</td>
</tr>
<tr>
<td>- Changes in relationships</td>
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<tr>
<th>Change in maintaining lifestyle</th>
<th>‘I have a special desk now..’ (14:18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Adjustment/Change</td>
<td>‘Cant do as much now’ (11.22)</td>
</tr>
<tr>
<td>- Loss/Physical restrictions</td>
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</tbody>
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*(3:21) = page 3, line 21 of the interview transcript.