

DClinPsy Portfolio

Volume 1 of 2

A portfolio submitted in partial fulfilment of the requirements of the University of Hertfordshire for the degree of DClinPsy including thesis entitled:

Experiences of Causing an Accidental Death: An Interpretative Phenomenological Analysis Study

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CHAPTER ONE: ESSAY 1

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

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1. Introduction

I feel it is necessary to begin by sharing my own position on this topic. I believe that evidence based practice (EBP) is hugely important to maintain the integrity of our profession, and our client's trust. However, I believe that non-positivist paradigms are not favoured within the current climate of EBP. Whilst positivist understandings of what constitutes knowledge are the dominant force within EBP, I would like to argue that it is not the only means to construe knowledge. Whilst highlighting the importance of EBP, I aim to look more critically at the evidence base (EB) from which our current clinical practice guidelines have emerged.

I will begin with a justification for the adult mental health (AMH) focus, before explaining my understanding of EBP, with a critical consideration of whose evidence it is to which we refer. Following this, I will consider the historical power and effect that the positivist paradigm has had upon EBP in clinical psychology, with a critical evaluation of the RCT's (randomised control trial) gold standard. The essay will then focus on the difficulties that clinical psychologists face when translating research into practice. I will then reflect on what has been omitted from research measurement. This will inform my discussion of qualitative approaches in clinical practice and the absence of such knowledge in the EB. Finally, I will discuss how we as trainees and clinical psychologist can help shape the future for EBP.

1.1 Justification for an Adult Mental Health focus

The essay will concentrate on AMH settings for several reasons. AMH serves perhaps the largest demographic within mental health services (18 years of age to working age adults). The demand for this service exceeds the current availability of resources (Mace, Moorey, & Roberts, 2001). Financial cutbacks in the NHS have

led to an increased scrutiny of psychotherapeutic services. As a direct result the service is under pressure from the government to demonstrate psychotherapeutic efficacy and cost effectiveness. A second rationale for my focus upon AMH is driven by the literature relating to adult diagnosis and psychotherapy, in which EBP is a dominant focus. Thirdly, government initiatives such as the National Service Framework (NSF) cover targets and standards that address mental health difficulties across the lifespan. Yet, this trend is not reflected in the practice guidelines for clinicians, as outlined by the National Institute of Clinical Governance (NICE). The focus within the NICE documents sways heavily towards diagnosis in AMH. Child and adolescent services appear to have only a small amount of clinical guidance. Similarly, older adult guidance and recommendations are sparse when compared to AMH. I shall use examples from AMH settings to illustrate the issues I have chosen to highlight.

2. What is EBP and whose evidence is it?

Within the realms of health care there has been a significant movement since the 1980s towards EBP. EBP is concerned with ensuring that clients receive treatments of proved efficacy (Bower, 2003). The most commonly cited definition of EBP is from Sackett, Richardson, Rosenberg, & Haynes, (1997). They describe EBP as:

“...The conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients, based on skills which allow the doctor to evaluate both personal experience and external evidence in a systematic and objective manner...” (p, 71).

This widely used definition stresses both the formal research element and the practitioner's own personal clinical experiences. We would expect to see the plurality of this definition reflected in the hierarchical descriptions of applicable

legitimate evidence, which are outlined by the National Service Framework for Adult Mental Health (DOH, 1999a). Unfortunately, this is not the case. The RCT and a systematic review are considered as the best forms of evidence. Relegated to the bottom rung are the opinions of the experts and of the service users. This position sits somewhat contrary to the current service user movement, particularly within AMH. It appears that the subjective opinion of this highly political movement does not fit the desired objective and systematic method of obtaining evidence as set out by the DOH (1999a).

Whilst acknowledging that the opinions of clients/patients are important, Deale, Chalder, Marks, & Wesseley (1997) suggest that clients/patients are not good indicators of whether an intervention is doing what it says it is doing. For example, Deale and colleagues conducted an RCT to investigate the efficacy of CBT versus relaxation therapy for adults with chronic fatigue syndrome. The relaxation therapy provided a control to account for therapist time and an explanation for symptoms. Relaxation therapy was found to be popular, achieved low attrition rates, and scored highly on satisfaction ratings. However, the therapy did not work when assessed against the criteria targeted, i.e.: to help fatigued patients to get back to work and reduce functional disability. CBT, on the other hand, showed greater effectiveness in relation to these outcomes. This example demonstrates the difficulties of using clients' opinions. Deale *et al.*, (1997) suggest that they did not provide a good measure of outcome because the treatment was not doing what it set out to achieve.

The current importance of EBP has escalated within the last decade. Policy makers, service purchasers, service providers, insurance companies, researchers, academics, clinicians, and the clients all have a stake in EBP. EBP provides a means to identify and improve the quality and provision of mental health care. This is a priority for the second phase of the NHS Modernisation Plan (DOH, 2002). However, the increased financial strain on the NHS has led to an increased need for accountability in psychological services to demonstrate effectiveness and

efficiency (Roth & Fonagy, 1996). The implications for clinical psychologists are profound. The research evidence obtained will ultimately shape the types of services that therapists will be able to provide and influence economic decisions regarding purchasing and funding. Those psychotherapies with large amounts of research and hence, evidence supporting their effectiveness, will inevitably be considered as the safer option financially (Winter, 2006, as cited in Loeventhal & Winter, 2006).

The shift to EBP has been an important contingent in the survival of psychotherapies against the dominant pharmacotherapy industry. EBP has meant that inequalities in practice can be identified and reduced. EBP provides a means to regulate and diminish ineffective, outdated practices that may be detrimental or harmful to the client (Bower, 2003). EBP creates a space to share knowledge, and generate discussions about what evidence can be considered to indicate best practice.

It is important to acknowledge that EBP is not a solid fixed opinion but is rather a fluid, flexible movement that evolves with the generation of new evidence. For example, 'debriefing practices' for Post Traumatic Stress Disorder (PTSD) were once routine practice in AMH services. The majority of evidence at one point in time suggested the benefits of this treatment. Others however, (Bisson, Jenkins, Alexander, & Bannister, 1997) found empirical evidence to the contrary. Nevertheless, the majority of evidence firmed up the opposing side of the debate, thus accepting debriefing as best practice. The emergence of new RCT research design and systematic reviews demonstrated that 'debriefing' was in fact ineffective and counter-productive (Wessely, Bisson, & Rose, 1998a, in Oakley-Brown, Churchill, Gill, *et al.*, Cochrane Database). The new evidence brought about change in NICE practice guidelines and hence clinical practice. The above example illustrates the process of adding, disproving and changing the EB, which then informs practice.

Clinical psychology has emerged as a practice based on empiricism. The evolving nature of our profession would not exist as it does today if it was not for the empirical evidence on which we justify our practices. In the same vein that it has driven the need for EBP, it has also driven a need to be more critical about the evidence that is considered truth.

3. The power of empiricism: the size of its effect

Over the last 40 years, research and evaluations of psychotherapy have provided an evidence base upon which effectiveness and efficacy has been reviewed. From the collated research findings (evidence), decisions and judgments are made about what therapies are believed to be most effective and for whom (Roth & Fonagy, 1996). The evidence from empirical research provides the foundations and is a driving force for government initiatives such as the NSF and Clinical Governance. It seems that the value of empirical research past and present is at its most influential.

In 1996, the government commissioned a book called, 'What works for whom? A critical review of psychotherapeutic research' (Roth & Fonagy, 1996). In brief the book outlines a systematic review of the research literature that had investigated the effectiveness of various psychotherapies in relation to specific diagnostic categories, as identified in the DSM-IV-TR (2000, American Psychiatric Association). A number of recommendations followed outlining what the literature suggested to be the most effective type of therapy and for which diagnostic group. It seems that the implications of this book have been far reaching for both the clinician and the purchasers of services. For the clinician, therapeutic style seems to dictate. For example, cognitive behaviour therapy for depression proved 'clearly effective' opposed to psychodynamic psychotherapy, which has limited support for its efficacy (Roth & Fonagy, 1996). For the purchasers, the book could act as a quick pocket reference guide for buying in the most effective therapy at the cheapest cost to suit their population demand. However, can we take the

knowledge and recommendations of this book without question? The purchasers will not ask why psychodynamic therapies are deemed as less effective or why there is limited evidence to support their therapeutic intervention. One possible explanation could be the conflicting methods of obtaining data for evaluation. The psychodynamic paradigm is not congruent with empiricist principles, and thus steers away from imposing quantification within their practice. Hence, limiting the production of quantifiable evidence sought for evaluation. Further discussions regarding this point are addressed later in the essay. It seems that the banner of scientific authority and the government agenda from which the book was written may over ride any doubt in the validity of Roth & Fonagy's (1996) conclusions.

Historically, EBP in clinical psychology has emanated from a medical philosophical epistemology governed by scientific principles, assumptions and discourses. The prestige and value of science within western societies is well established and held in high regard. Empiricism is the corner stone of traditional sciences. Integral to the empiricist philosophy are a number of assumptions and methodological principles including objectivity, control, quantification, reductionism and determinism. For a philosophy that promotes transparency i.e., creating an objective window of reality; one which is value-free and free from bias (Morgan, 1998). It seems odd that such assumptions should exist because they are all values. It appears that each scientific value is creatively re-categorised as a non-value, (Slife, Wiggins, & Graham, 2005). All philosophies have values; to ignore them or re-categorise them does not mean that they do not exist. Despite some of the fundamental problems underlying the scientific assumptions and the lack of empirical evidence for empiricism (see, Slife, Wiggins & Graham, 2005, Sheppard, 1997), the popularity of this type of knowledge dominates. This has largely affected and shaped the belief that scientific knowledge equates to superior evidence.

As a critical clinical psychologist one must consider how the knowledge used in the decision-making processors is derived, where does the evidence come from? More importantly, do the conditions from which evidence is obtained translate to

clinical practice? By stepping back and considering the broader issues involved with research we can begin to consider a more critical view of what is presented as evidence and its implications for the practice of clinical psychologists in AMH.

4. RCTs: questioning the gold standard

The current climate of empirical investigation is flourishing; particularly through the endorsement of its superiority from the DOH. At the forefront encapsulating methodological rigor is the RCT. The RCT research design emerged from the medical paradigm to detect the active ingredients in new pharmacotherapys (Shapiro & Shapiro, 1997). The demonstration of specificity was paramount to reveal the benefits of an active substance over and above other factors such as hope or psychological processes. Statistical significance, and more recently confidence intervals and effect size (Kazdin, & Bass, 1989), are considered the hallmarks to which specificity can be accredited. The research design consists of a number of elements including, randomisation, double blind and a control group. Essentially, the active drug (independent variable) is administered blind (both the researcher and participants are unaware of the drug being received/administered) to one of the two groups of participants (dependant variable). The placebo group acts as a control to determine whether any changes or benefits can be attributed to the physiochemical properties of the hypothesised drug.

The application of this scientific research design was cast upon psychotherapy treatment evaluations. Rosenthal & Frank (1956 as cited in Wampold & Bhati, 2004) proposed that the design could be translated by using a matched control group to participate in a placebo therapy. This group theoretically would not be expected to produce the effects of the therapy being evaluated. They concluded that this design would exclude common factor within therapies and establish specificity. The rationale presented by Rosenthal & Frank (1956) seems plausible. A working example could be the delivery of CBT for generalised anxiety disorder, compared with a placebo controlled therapy group. If CBT produced a favourable

statistically significant outcome, one could conclude that CBT (challenging irrational thoughts and creating a shift in core schemas) would be the active ingredient responsible for the benefits of treatments.

However, Wampold & Bhati (2004) have identified two fundamental problems with the RCT design when applied to the realms of psychotherapy research. Firstly, the nature of delivering a psychotherapy protocol ultimately means that the therapist cannot be blind to the therapeutic condition. Furthermore, a psychologist carrying out a treatment that is known to be ineffective may produce cues to the participants aligned with that knowledge. Similarly, a clinical psychologist with a particular theoretical orientation e.g.: social constructivist who may be involved with the delivery of a manualised CBT placebo (incompatible with constructivist philosophies), may unwittingly demonstrate an allegiance effect to their desired therapy.

With regard to the statistical analysis of results and the requirements to report effect size, Roth & Parry (1997) found that many studies, including those in reviews, use the minimum number of participants in order to detect an effect size. Thus, sample sizes are generally small, questioning the applicability of findings to broader populations (Cohen, 1988). One could also argue that the use of highly sophisticated statistical tests draws the attention further and further away from the phenomena under investigation, thus becoming reductionist. These criticisms raise an important awareness when considering the principles on which our current practice guidelines are based.

RCTs investigating treatment effectiveness are interested in causal relationships, where outcome is often measured in terms of symptom reduction. However, psychological therapies do not always work towards the reduction of symptoms. Some promote personal growth or the development of skills acquisition. For example, client centred therapy and strategic/solution-focused therapy found in AMH services. The difference in therapeutic goals (outcome) suggests that those

therapies that are more symptoms focused and prescriptive, such as CBT, have a greater chance and opportunity to demonstrate their effectiveness (Bower, 2003; Parry, 1992). This may in part may explain why some psychotherapy have a larger empirical evidence base than others, a question I proposed early. Furthermore, manualised treatments such as CBT or Linehan's (1993) Dialectical Behaviour Therapy (DBT) stem from a positivist paradigm that supports a linear process to therapy, one that lends itself easily to quantitative evaluation. Therefore, perhaps the process of therapy in relation to measurement may also shed light on the absence of evaluative research for therapies that subscribe to an alternative to the positivist paradigm.

If we consider the theoretical conceptualisation of systemic therapy, we will see a very circular means to thinking and working, where changes in one system influence and create change in relating systems. If the process of change is circular, at what point should measurement occur? This is the challenge that many systemic therapists face. Yet, there is a great pressure from the NHS for family therapy teams and systemic therapists to show the effectiveness of their work (Vetere & Dallos, 2003).

The aims of RCTs are to identify specificity. Imposing prescriptive manualised psychotherapy is a means to standardise treatment, which ultimately dictates both delivery and content. Extremes of this can be found in books such as, 'The Complete Adult Psychotherapy Treatment Planner' (Jongsma & Peterson, 1999, cited In Winter, 2006). This branded commodity describes 'treatment plans that satisfy all of the demands of managed care companies'. For example, psychoticism can be dealt with in a 25-point plan and spiritual confusion in a 24-point plan. The USA seems to lead in the development of manualised empirically supported therapies. However, reviews and books such as Roth & Fonagy's (1996) "What works for whom?" indicate a shift towards this type of prescriptive therapeutic practice in the UK. This 'flat pack' form of psychotherapy is not compatible with all approaches to therapy.

Client centred therapy and solution focused therapy are common approaches to working in AMH settings. Rosenbaum (1994) construes therapy as a dynamic change process, where the therapist responds to the client and the client responds to these changes and so on and so forth. The 'treatment' is constantly being constructed and reconstructed through dialogue. Bohart (2000) talks of a meeting of two complex systems (the client and the therapist) who interact and form another complex system. Within and between each system occurs a learning and change process. It is clear that an approach to therapy would not lend itself to manualisation. If anyone were brave enough to take on such a challenge, we would be confronted with a massively complex manual detailing a schematised list of decision rules (Bohart, 2000).

5. Difficulties that the clinical psychologist faces: translating the research to practice

The body of research sets the clinician's expectation for treatment outcome. How relevant is the EB to clinical practice? There are a number of difficulties when juggling the interests of the researcher's agenda (internal validity) with the clinician's agenda (external validity). Critics suggest that the samples found in experimental research are not representative of those seen in everyday clinical practice (Harper, Mulvey & Robinson, cited in Bayne & Horton, 2003). They propose that these clients are seldom referred or self-referred. Furthermore they suggest that they are usually a highly homogenous group in relation to diagnostic categorisation. Dimcovic (2004) suggests that they are frequently highly functioning individuals who present with isolated problems rather than the more complex Axis I – Axis 2 disorders. Whilst this may be the case for some research trials, I feel that this criticism is not strictly true for all. By simply reflecting on my own clinical and research experiences, I can find support both for and against this criticism. From my own experience of working with women diagnosed with Borderline Personality Disorder, I believe Linehan's (1993) work was very

challenging and very representative of the clients found in our AMH services in the UK. On the other hand, reflecting upon my involvement in an RCT concerning AMH difficulties following general intensive care treatment, I was confronted with the fact that almost one third of admissions did not fit the inclusion criteria. Ultimately, this 'tidying up' of the sample produces an unrepresentative sample. This latter example illustrates the problem regarding external validity and efficacy research.

Furthermore, within AMH clients are encouraged to voice a preference as to their treatment approach (Bradley, 1997). The randomisation into treatment groups removes the clients' opportunity for choice and preference. A further difficulty concerns the highly skilled therapist selected to conduct therapy trials. For example, in a recent lecture by Dr Julia Renton she spoke of an RCT investigating the effectiveness of early cognitive therapy intervention for adults with psychosis in a CMHT setting (Morrison, Renton, Williams, Dunn, Knight, *et al.*, 2004). The results looked impressive, however, when questioned about the particulars of the intervention delivery, it was revealed that all therapists had postgraduate qualifications in cognitive therapy, obtained from specific prestigious institutes (not just any old CBT training), and the treatment was delivered in its purest form. This example raises question of how generalisable these results would be to routine clinical practice, where most therapist do not have additional CBT training, particularly in its purest form. Equally, clinicians in the UK, including myself as a trainee are becoming more and more eclectic in their practices. Formulations help the clinician to consider all aspects of the client. Biopsychosocial-spiritual and historical factors can inform the choice of therapeutic approach and strategies. Thus, enabling clinicians to construct individually tailored treatment (Parry, 2002), rather than adhering strictly to one approach that is often driven by a diagnostic label (Miller, Duncan & Hubble, 1997; Johnstone, 2000). It seems that integrative practices are at odds with manualisation, thus strict adherence to manualised practices (as used in RCTs) becomes redundant in clinical settings (Roth & Parry, 1997).

The difficulties that clinicians face have been partially acknowledged, bringing about new challenges to researchers. The movement of practiced based evidence has allowed findings to emerge from routine service settings. For example, sampling therapy as it happens and developing research designs which incorporate patient preference (Ward, King, Lloyd, Bower, Sibauld, *et al.*, 2000, as cited in Barkham & Mellor-Clark, 2003). These changes in research design enhance external validity and are broadly known as pragmatic RCTs. This type of design resembles a more realistic reflection of clinical practices, rather than those contrived situations found within strict positivist RCTs.

Despite these encouraging progressions in research, the strict positivists RCTs are still considered superior. They continue to use these methods and systematic reviews to find superior therapies for specific diagnostic categories. However, large-scale reviews such as Grissom (1996) demonstrate that therapies do not vary in their effectiveness. So where does this leave the clinician? What are the important factors if the treatment itself is not the active ingredient?

6. What is not being measured? : Communalities verses uniqueness

The 'dodo bird verdict' regarding comparative treatment outcomes (Luborsky, Singer, & Luborsky, 1975) is reiterated again and again in the literature. This suggests that perhaps we need to refocus and consider what is not being measured in RCTs. The psychologist (their skills, knowledge, experience, warmth, hope, enthusiasm and charisma) may be presenting as a confounding variable in 'scientific terms'. Yet, they have been deemed irrelevant in many RCT therapy efficacy trials (Wampold, 2001a; Luborsky, Crits-Christoph, & Woody, *et al.*, 1986). The recognition of such omissions highlights the commonalities across therapies such as the therapeutic alliance and the extra-therapeutic factors rather than the differences. Miller, Duncan, & Hubble (1997) propose that research literature reveals four common factors to all forms of therapy regardless of theoretical orientation

(dynamic, cognitive, etc.), style (individual, group, families, etc.), dosage (frequency, number of sessions), or speciality (problem type, professional discipline, etc.). The four factors and their relative contributions to change include: i) extra-therapeutic (40%, incorporating all the characteristics and resources of the client and her/his environment that aid recovery, in spite of any formal intervention; (ii) the therapeutic relationship (30%); (iii) placebo, hope, and/or expectancy (15%) and; (v) structure, model, and/or technique (15%).

It is clear from these investigations and several meta-analyses (Durubeis & Feely, 1990; Elkin, 1994 as cited in DOH, 2003) that the skills of the practitioner and the therapeutic alliance contribute to the variance found in study outcomes. Thus, RCTs may falsely conclude the superiority of one type of treatment over another.

In light of such critiques, we must maintain a certain degree of caution when reading and implementing the Clinical Practice Guidelines (DOH, 2003). We must not forget that it is positivist methodologies, which underpin all of the recommendations in the Clinical Practice Guideline documents. The methodological limitations reveal gaps in the knowledge base (i.e. non-specific factors). These gaps may never be uncovered by scientific enquiry. It feels as if we need to be asking a different question, not *what* therapies work, but rather, *how* and *why* therapies work?

7. Qualitative approaches to clinical practice, why not a qualitative approach to research?

Qualitative research and alternative therapeutic paradigms aim to explore the client's frame of reference, gain an understanding of how clients construe their world, their experience, their narratives, and their reflections. Bohart (2000) considers therapy as an interpersonal dialogical process between the client and

therapist. This process promotes change, with any specific standardised treatments coming secondary. Qualitative methodologies support a practice-based approach to evidence. Case studies, diaries, case-notes and in-depth interviews create an opportunity to understand the meaning of key events that occur in therapy (McLeod, 2003). This contextual approach to therapy (Howe, 1989) may shed light on questions such as how the therapy operates. What can be changed to make therapy more effective? Moreover, what was helpful or unhelpful in the therapeutic process? Through gaining an understanding of these aspects recommendations can be fed back to therapist and their teams. In my experience of conducting qualitative service evaluations within an adult inpatient setting, it helped to improve understanding of the therapeutic outcome through sharing clients' perceptions of therapy with clinicians. The process also facilitated an enhancement of the client's experience of therapy.

Qualitative research is not without its own limitations. For example, Howe's (1989) work within an AMH setting looked at the clients' experiences of family therapy. Howe used interview data to gain a rich source of information. However, Howe did not check out his own interpretation of the findings with an independent-rater, nor did he check the accuracy of his interpretations with the participants. These steps within qualitative research are thought to enhance the reliability and validity of the researcher's conclusions (Finlay, 2002). This example illustrates how alternative methodologies can reveal information that would be unobtainable via the use of quantifiable psychometrics. These often impose categorised structures usually constrained by a dominant medical discourse. It seems that, quantitative measures potentially ignore experiences outside of those imposed limits. The critique illustrates that qualitative methodologies are also interested in gaining evidence that is reliable and valid. However, the role of researcher is considered as an integral part of the data construction, acknowledging and reflecting upon that role adds to the validity of the data (van Manen, 1997).

The above examples demonstrate the complementary contributions that alternative methodologies can offer when evaluating psychotherapy (Roth & Parry, 1997). It is important to acknowledge that the EB on which current EBP is constructed does not include any evidence established through qualitative methodologies (Fonagy & Roth, 1996). To exclude these valuable forms of obtaining evidence because they deviate from scientific principles is not in my opinion a good enough reason. However, we are unfortunately held within a climate that considers scientific evidence as the only valid source of evidence.

It seems that we must surrender to the positivist drive to evaluate psychotherapies, despite the clash of theoretical paradigms. To avoid 'throwing the baby out with the bath water' we must work with it rather than fight against it. A good current working example in AMH is the emerging EB for constructivist therapies such as Personal Construct Psychology (PCP). Coordination by the Research Subcommittee of the Experiential Constructivist Therapies Section of the UKCP (Winter, 2006), together with encouragement from leading therapists and academics has led PCP clinicians to be encouraged to collect outcome data. Through adopting methods such as the CORE System (1998) of standardised audit and evaluation (Winter & Watson, 2000, as cited in Winter, 2006), it may be possible to generate empirical data on treatment effectiveness. I have witnessed the effective use of this audit tool to support other approaches, such as systemic working in CMHTs. By adopting these outcome measures we are able to preserve these valuable forms of psychotherapy.

8. What can clinical psychologists do to shape the future of EBP?

As a trainee, and for those more established clinical psychologists in routine practice, we must become proactive in conducting research and not 'shy away' from our commitments to personal and professional development. We hold the key to the flaws and difficulties when implementing research findings into practice. If we do not own our role as reflective-scientist-practitioners (Harper, *et al.*, 2003 in Bayne & Horton, p.161) and find empirical solutions to evaluate non-empirically driven practice, we will run the risk of following in the steps of our USA

counterparts, delivering a branded 'flat-pack' therapy. Ultimately, we will lose our freedom to be creative, innovative therapists.

In practice, we must keep abreast with new EB developments through resources such as 'Evidence Based Mental Health Journal', which help digest the academic jargon into language for the practitioners. However, it is also important to maintain a critical understanding of positivist research because it is based upon the medical model and as a result may discredit psychodynamic, family and experiential therapies (Messer, 2001, in Messer & Wampold, 2001). If each therapy requires manualisation then perhaps it should guide rather than dictate choice (Winter, 2006). Alternatively, by providing guidance for empirically supported principles, such as the therapeutic relationship and working within the client's frame of reference, the practitioner could be demonstrating working in an empirically supported manner (Grawe, as cited in Bohart, 2000).

9. Conclusion

The importance of providing high quality care that is cost effective is a goal that all stakeholders endeavour to achieve. The role of EBP has provided an important foundation from which we practice and it will continue to grow in strength. However, I do not believe that the current dismissal of evidence obtained from outside positivist paradigms is satisfactory. Perhaps, with the continuing debate and high quality qualitative research and reviews we will help to carve out a place for alternative sources of evidence, creating a complimentary landscape alongside the dominant positivist paradigm. Despite this epistemological clash, it is important that therapies such as those from constructionist orientations, systemic therapies, and psychodynamic therapies embrace the need to work towards finding empirical solutions for evaluating their therapies. This approach is the only way forward in preserving the valuable work that these types of therapy can offer to individuals with mental health difficulties.

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CHAPTER TWO: ESSAY 2

Discuss the use of systemic and psychodynamic approaches for people with learning disability. What are the potential dilemmas and challenges faced by clinical psychologist when using these two approaches with learning disabled people, and how can they be addressed?

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1. Introduction

“The NSF for Mental Health applies to all adults of working age. A person with a learning disability who has a mental illness should therefore expect to be able to access services and be treated in the same way as anyone else.” (Department of Health [DoH], 2001, pp.73).

Psychological therapies including psychodynamic and systemic approaches are readily available in most NHS trusts to those people who do not have a learning disability (LD). However, despite the recognition within the National Service Framework for Mental Health that “most psychiatric disorders are more common amongst people with learning disabilities [pwld] than in the general population” (DoH, 1999, p73), the provision of psychotherapies for pwld is far from ideal (Baum & Lynggaard, 2006). Over the last two decades researchers and clinicians such as Baum and Lynggaard (2006), Hodges (2003), Fidell (2000), Beail (1998) and Sinason (1992) have demonstrated that pwld suffer from a full range of mental health problems and benefit from psychodynamic and systemic approaches. Normalisation and the central values of the “Valuing People” document (DoH, 2002) emphasise the entitlement to services for pwld which are already available to the general population.

To explore why there seems to be an inequality in providing such therapeutic approaches, I will first consider the historical context of therapies for pwld’s in the UK and how this has been challenged to help shape our present constructs and services. I will discuss a number of themes that can be addressed using psychodynamic approaches and look critically at the challenges and dilemmas faced by clinical psychologists who choose to work from this framework. I will then address a number of themes related to working systemically and discuss how we,

as clinicians, can address the challenges that this approach reveals. In the latter part of this essay, I will address evidence-based practice as this major challenge stretches across both therapeutic approaches. I will make some recommendations for how clinical psychologists can move forward through these challenges. The psychodynamic section of the essay will consider more individual therapeutic issues, whilst the systemic section will focus more on broader issues.

2. Therapeutic history and learning disability

The historical literature regarding pwld appears to be saturated with stories of vulnerability, loss, marginalisation, oppression and abuse (Sinason, 1992). From these social, political and cultural experiences have emerged narratives, which have influenced our understanding of LD. They have created an ethical awareness that has led us to examine and challenge our epistemologies, practices, beliefs and therapeutic approaches when working with pwld (Dagnan & Chadwick, 1997; DoH, 2001).

Perhaps the most fundamental shift has been the movement away from the dominant medical model. This model has construed LD as a psychiatric condition related to biological/brain dysfunction. With this underlying assumption came an array of misunderstandings about pwld. For example, limitations in intellectual abilities and limited verbal ability led to assumptions that talking therapies would not be fruitful. In addition, Mason (2007) talked about diagnostic overshadowing which viewed mental health problems as part of the person's disability. This prejudice seemed to absolve the clinician of their responsibility to address the difficulties faced by this client group. Thus, the mental health needs of pwld were largely ignored.

These collective assumptions led clinicians to defer to traditional behavioural therapies or pharmacotherapy to treat pwld. The movement away from this reductionist stance has allowed attitudes and thinking around LD to change from a knowing position to a more curious stand point and a new wave of understanding.

Whilst challenges do exist in providing alternative psychotherapeutic approaches, these challenges do not rule out accessibility for pwld. Instead, it creates challenges for clinicians to be creative, flexible and person-centred and to provide opportunity and access to therapies such as psychodynamic and systemic approaches.

3. The use of psychodynamic approaches

For the purposes of this essay, I will consider both the psychodynamic and psychoanalytic literature. Although, I recognise that they are distinct psychotherapeutic models, they originate from a common theoretical orientation and so will be treated as one. Psychodynamic approaches have been used within a range of psychotherapies including, music, art, drama and individual talking therapy. In this section I will discuss theoretical developments: the use of techniques such as transference and counter-transference; defences and secondary handicap; dilemmas of making interpretations. I will also discuss common issues addressed using psychodynamic approaches such as abuse, bereavement and loss. Within each section I will discuss the potential challenges and dilemmas that these issues may raise and consider how these can be overcome.

3.1 Theoretical development

As clinical psychologists we have to challenge dominant assumptions and consider alternative theoretical positions. Sinason (1992) has been an influential figure in the area of psychodynamic working with pwld. A core assumption within this framework is to view emotional intelligence as separate to cognitive development. For example, one could have a severe cognitive impairment yet have an age equivalent emotional development and vice-versa. Sinason is not suggesting that these two domains are completely independent, or that changes in one may not affect the other, rather she recognises that emotional intelligence and cognitive intelligence can exist independent of each other. This basic assumption opens the

gate to explore the emotional needs of pwld. By doing so it challenges the dominant behavioural approaches which effectively deny personal agency; deny emotion, and tell us little about the internal world of pwlds (Stenfert-Kroese, 1997).

3.2 Therapeutic techniques: transference and counter-transference

In challenging the second most cited misconception i.e: the verbal ability prerequisite, Sinason (1992) and Hodges (2003) propose that even those with severe and profound LD - who are less able to verbalise their emotions - can be helped within this approach. By using counter-transference, the clinician can become aware of the clients feelings and internal conflicts, by noticing and thinking about how they make the clinician feel. The counter-transference over time can also help to construct a picture of the client's emotional and relational difficulties over time (Simpson & Miller, 2004). This skill, together with transference (whereby clients bring their unconscious unprocessed feelings and experiences to the therapy room and re-enact them in the session) enables the clinician to make interpretations of the client's emotions and internal constellations (Hodges, 2003). Focusing on the 'here and now' also avoids the need for abstract thinking over time. However, it may be challenging for the clinician to separate and manage their own emotions (Hodges, 2003). Regular supervision is imperative to help the clinician reflect and overcome such challenges.

3.3 Defences and secondary handicap

Sinason (1992) describes the process of 'secondary handicap' as occurring when the primary or original disability is exaggerated as a way of defending the person against the painful feelings of difference, thereby exerting some control over their disability and making others feel stupid for not realising the exaggeration. This process may be conscious or unconscious. Sinason (1992) also talks about secondary gains, whereby symptoms are used to their advantage, thus recognising the process of secondary handicap.

As therapy progresses a common dilemma for the clinician is when to challenge such defence mechanisms. When the pwld shed their secondary handicap and become more aware and able to express their feelings they are likely to become more in touch with their realities. Sinason (1992) suggests that this can lead to further mental health problems such as depression. It is therefore, important for the clinician to have adequate time to work with this client group. Ending therapy too soon may leave the person without adequate defences and may have a devastating effect for him or her.

3.4 Making interpretations

The usefulness of making interpretations seems intrinsically linked to the dilemma of challenging defence mechanisms. Rycroft (1968) proposes that correct interpretations are those which explain the material and are formulated and communicated in such a way that they make sense to the client. The aims of interpretations are to increase self awareness and therefore facilitate integration by making the unconscious conscious (Rycroft, 1968). It is a dilemma for the clinician to make a judgement about the utility of an interpretation for the pwld. Consideration of the person's level of acceptance and the strength of the therapeutic relationship are important factors to consider. Hodges and Sheppard (2004) also suggest that counter-transference feelings can help decide whether an interpretation is appropriate or whether an interpretation was helpful or necessary.

3.5 Abuse

Research has shown high prevalence of abuse experienced by pwld (Brown, 1999). Abuse may include neglect and discrimination or be of an emotional, physical, sexual, verbal or financial nature (Emerson, Hatton, Bromley & Cain, 2001). The experience of abuse is not surprising given the way in which pwld are often thought of as different (Hodges, 2003). Hodges describes how pwld have

become a receptacle for feelings of hatred, not just among families but society at large. She describes how society projects feelings of inadequacy, ugliness and insecurity into this population, who represent disability.

The abuse of pwld is becoming increasingly acknowledged. However, it remains a very painful issue for the individual to explore and think about. It can be equally as painful for the therapist to allow themselves to think about the abuse suffered by their clients. I recall an experience of working with a lady who had a mild learning disability who had experienced sexual abuse. My therapeutic task when meeting with this client weekly was to foster a process of sitting with and being with the client; containing, holding and witnessing her experiences. This provided an opportunity for a trusting non-abusive attachment to develop. Theoretically, this process of thinking about and tolerating her experiences may have allowed the client to introject this capacity (Corbett, Cottis & Morris, 1996).

3.6 Bereavement and loss

It is an unfortunate reality that pwld are likely to experience multiple concurrent losses (Hodges, 2003). To confound ordinary life-span losses, pwld also have to contend with the absent losses, the 'what might have beens' if they did not have LD. Theoretical concepts such as 'internalisation' and 'containment' (Bion, 1962; Winnicott, 1962) are important to consider when working from a psychodynamic perspective. Bion (1962) suggests that after the birth of a child with LD, the mother may mourn for the loss of the idealised child. During this time the mother must process and deal with her own emotions, leaving her unavailable to contain the child's emotions. Thus, the process of introjection - of retaining and tolerating emotions - does not happen. As mentioned above, the therapists must provide a containing and supportive environment for such processors to develop. In my experience, this is not always easy when working in the NHS, where the availability of therapeutic spaces can be limited.

Emotions linked to grief, bereavement and loss are often manifested in challenging or disturbed behaviour. It is often the change in behaviour which evokes a referral rather than the underlying emotional issues and conflicts. This is demonstrated in research by Hollins & Esterhuyzen (1997) who found that carers of parent-bereaved pwld did not attribute difficult behaviour to the bereavement, despite being aware of the person's loss. Other studies (Bicknell, 1983; Oswin, 1981) show similar findings indicating that there is a tendency to minimise or ignore the impact of loss when experienced by pwld. It can be challenging working alongside other professionals who have narrow behavioural views, which ultimately invalidate the pwld's experiences.

Working with abuse and loss are common distressing issues experienced by pwld and can be challenging for the clinician, particularly if one allows oneself to experience all of the client's projections. To overcome this difficulty the clinician needs adequate self-care. Support can be achieved at multiple levels: good supervision; training; and personal therapy, can help overcome the challenges of working with abuse and bereavement.

4. The use of systemic approaches

Pwld do not exist in isolation from human and organisational systems. They often live within a complex network of family, carers and support staff who frequently have competing ideologies about the type of care that should be offered (Petty, 2002). This has historically left pwld unheard and passive recipients of other peoples' choices. Petty goes on to suggest that the resulting anger, frustration and resentment about their situations, and attempts to express this, have repeatedly been viewed negatively and within the individual, rather than a product of the dynamics within the system.

The traditional medical reductionist view led to behavioural or pharmacotherapy interventions as the treatments of choice (Emerson, *et al.*, 2001). While behavioural intervention in LD is effective in the treatment of challenging behaviour, it can have

significant limitations in the family setting. Families can sometimes find it difficult to make life-cycle transitions or respond to other stressful life events and become stuck in patterns of interaction that include the presenting behaviours (Rhodes, 2003). Fredman (2001) suggests that therapists offering interpersonal rather than individual approaches create movement away from a pathologising model, and also facilitate a stance of “working with” rather than “working on” their clients. A second assumption within the systemic paradigm is the concept of circularity; this gives an alternative to the linear cause and effect explanations of presenting concerns. Identification of circular patterns that connect symptoms with relationships and communication is a method of organising events/behaviours (Watzlawick , Beavin and Jackson, 1967).

Despite the mass of research into systemic family therapy with the general population, there has been little published in relation to pwld (Baum and Lynggaard, 2006). However, the acknowledgement of its utility was reported some 30 years ago by Russell-Davis (1967). Russell-Davis stressed the role of psychosocial processes in the family perpetuating the effects of LD, and emphasised the value of family work for bringing about major changes in the patterns of interactions in the family.

The use of systemic approaches can be beneficial in addressing a number of issues. I will briefly comment on a number of these themes, including issues arising from: life-cycle transition; the professional system; double bind and overprotection; and parenting patterns.

4.1 Life-cycle transition

The family life-cycle transition theory (Carter & McGoldrick, 1989) identifies a sequence of cyclical transitions that families negotiate, such as the birth of a child or leaving home. Life-cycle transition issues can pose complex difficulties for pwld and their families, particularly around the transition to adulthood (Todd & Shearn, 1996). Young adults with LD often leave home long after that which is socially

expected, thus many transition points are out of synchrony with same age peers or siblings (Vetere, 1993; Carter & McGoldrick, 1989). Furthermore, Fidell (2000) suggests that parents of young people with disability often have less experience of change than their peers who have children without LDs. She states that parents of pwld frequently have little idea of their adult offspring's roles or needs. Thorn, Yavanoff and Irvin (1996) discussed the importance of roles and suggested that both the pwld and their family are critical in directing transition planning. This ultimately enhances opportunities to attain ambitions and desires, such as leaving school, employment and leaving home. This aim is supported by person-centred planning within the system of pwld, which has become an integral part of standard practice to ensure individual participation in life planning (DoH, 2002).

4.2 The professional system

Difficulties during the childhood and adulthood transition can also be reflected in issues relating to the professional system with which the family interacts. The transition between child and adult services is not always smooth and in my experience can be problematic. Fidell (2000) draws our attention to the caution needed during this transition, she suggests that professional systems have a potential to be intrusive not only because of the large numbers of professionals involved but also in the extent to which they are involved in launching decisions. This ultimately may disempower and undermine pwld and their families' abilities to support and guide decisions.

4.3 Overprotection vs risk and the double-bind

Pote, King and Clegg (2004) and Goldberg, Magrill, Hale, Damaskindou, Paul & Tham (1995) have investigated the difficulties families experience when trying to balance protection and risk. Goldberg *et al.* (1995) propose that families with an LD member work to overprotect the person from the perceived consequences of their disability. This may result in the parent restricting the life of the pwld. The double-bind manifests itself in the parents desire for their children to grow-up and

flee the nest, allowing the parents to progress through their own life stage i.e: to be alone again, yet, at the same time they rarely allow the LD person the autonomy to make independent decisions to facilitate personal growth.

4.4 Parental patterns: the eternal child and captive parent

The issue of overprotection seems enmeshed in the concept of the eternal child (Todd & Shearn, 1996). Todd & Shearn (1996) found that some parents tended to view their relationships with non-disabled offspring as developing normally. However, their relationship with their child with LD seemed to stagnate; they described a point of frozen animation occurring somewhere during infancy or adolescence. Therefore, parents may complain about the person being like a two year-old, but persist in treating and interacting with the person as if they were two years-old.

The infantilising of pwld can also generate the captive parent (Goldberg et al. 1995; Todd and Shearn, 1996). These researchers identified a group of parents whose dominant identities were encompassed in being parents to the LD person. Grant (1990) found that carers were reluctant to pass on what they saw as their caring responsibility to others. Grant (1990) hypothesises that this is possibly due to the feelings of competence and self-sufficiency that the parenting role provides. Losing their parenting role would be a significant loss of self-meaning and would be difficult to replace.

4.5 Challenges and dilemmas of using a systemic approach

The techniques and ways of working systemically with ordinary families do not necessarily transfer neatly when applied to pwld. The challenge for the therapists is to refine and adapt our practice to offer creative solutions to overcome potential challenges and dilemmas. There are a multitude of potential difficulties. However, due to the word constraints, I will discuss dilemmas relating to: engagement; the expert therapist verses a collaborative stance; flexibility and adaptation of

therapeutic skills; challenges in deciding upon which family therapy (FT) model to use; and the importance of flexibility in the therapeutic approach.

4.6 Engaging the client and their family

Perhaps the initial dilemma is deciding upon whether to include the pwld, even if they do not understand the proceedings (Fidell, 2000). I think that the client should always be included. Exclusion would surely perpetuate their experiences of discrimination and disempowerment. Their inclusion would also allow the therapist to observe patterns of interactions that surround the reported presenting problem. Fidell (2000) also suggests that like children clients with LD, adults with LD often give spontaneous and unguarded accounts of the problem. The client's view point is valuable and adds to the rich co-constructions of knowledge.

Expectations of FT are particularly important to discuss; what the family actually want may be very different to what the referrer may think is the concern. This incongruence may create a dilemma. This may be further complicated if the referrer feels that the family needs therapy, but the family feel they do not. In such instances the therapist must question who is the customer? To help overcome such incidents the therapist could invite the referrer to attend along with the family or ask the family to attend a one off session to help in an assessment in the hope that they find the experience useful.

The initial engagements and meetings with clients and their families will inevitably reveal dominant discourses and power differences within the family system. More often than not, the dominant view within the family is that the pwld is the most powerful in the system, particularly where challenging behaviour is the presenting problem (Fidell, 2000). However, Fidell (2000) suggests that the common lived experience of pwld reveals that they feel powerless even when they are behaving 'badly'. Nonetheless, the client's behaviour is experience by others in the system as powerful. It is a challenge for the therapist with their additional power that they bring as the therapist, together with their wish to empower the client, to observe

and explore the power shifts in therapy and consider how these relate to outcome. Fidell (2000) recommends that simply listening intently to the pwld encourages others in the system to do the same. This technique is important in changing perceptions and therefore, balancing out power.

A second dominant discourse within the family may be one of incompetence relating to the pwld. The challenge for the therapist is to address this view and illicit an alternative view from the family. Baum & Lynggaard (2006), suggest that using genograms can be a helpful tool to address this difficulty. Most pwld can give information about their family and this can be empowering for them, as well as displaying competency to their family.

A third dominant discourse may be one of 'blaming' and 'scapegoating' of the pwld. Fidell (2000) suggests that FT could provide an opportunity for further stigmatisation. Clients with LD are already construed as different and potentially difficult and when problems occur these beliefs are strengthened. The therapist is faced with a dilemma, s/he may unwittingly collude and reinforce the stigmatisation, or work to empower the pwld, giving them an equal voice alongside other family members. However, this latter position could lead to a further dilemma of alienating other family members and risk the termination of therapy, as it is usually the family who bring the pwld to therapy. It is here that the role of the reflecting team can help to ensure that all views have been heard.

4.7 Should the therapist take an expert stance or a collaborative stance?

Given the life-long nature of LD, many individuals and their families will have had years of experience interacting with health care professionals. These experiences, helpful or unhelpful, are likely to enter the therapy room. It is important for the therapist to explore these, as well as their expectations of FT. Sloper (1989) proposed that parents of pwld want therapists to meet the needs of the whole family and to treat family members as competent people. Afterall, they are likely to have experienced and overcome many adversities without professional

intervention. On the other hand, Odell and Quinn (1998) suggest that clients must also believe that their therapist is an expert who can help them overcome their difficulties.

Balancing these two stances can be a challenge. In my own practice I gravitate towards a collaborative stance; this position helps to acknowledge the families' own strengths. I think that establishing this position in the first session sets a precedent for what follows, in terms of continued engagement and success in therapy. This view is supported by Cardone & Hilton (2006), who state that working collaboratively is central to "inclusion, empowerment, engagement and person-centred practice". These values guide government policies and practice in the UK.

Scior & Lynggaard (2006) suggest a number of techniques that demonstrate collaborative practice. For example, inviting the pwld to teach them, thus showing the clients how their knowledge can be used to help the professional learn about challenging their sorts of problems. This technique would also provide opportunities for empowerment.

4.8 Adaptive therapeutic skills

The therapist must give the pwld a voice in the system. Some pwld may not be used to having a voice, particularly in the presence of their carers. It is therefore important to work at the pace of the client (Cardone & Hilton, 2006; Petty, 2002). Regardless of potential cognitive limitations and verbal skills, the therapist must encourage participation. To overcome such difficulties the therapist could adopt questions such as 'how will I know when you are feeling stressed?' or 'tell me when you want to end the session'. These types of statements and questions encourage ground rules which may empower clients (Brechin & Walmsley, 1989).

The value of narrative techniques within systemic therapy has been explored by Lynggaard & Scior (2002). The therapist's aim would be to help the family to construct, live and circulate new narratives by drawing upon the system's strengths, abilities and resources. The emphasis is to avoid the use of labels in favour of

externalising or naming difficulties in terms of what they mean to the client's life (White & Epston, 1990). Other useful methods such as drawing and role play can help to simplify questioning and increase meaning in the sessions. However, one must not assume that narrative techniques will work for all pwld. A blanket approach would lead to de-individualisation which contradicts the philosophy of person-centred care (Lynggaard & Scior, 2002).

4.9 Which FT model? And flexibility in the therapeutic approach

The literature offers a flurry of explanations in favour of one school of FT over another. Vetere (1993) recommends a structural model whereby the child parent hierarchy is paramount. However, the utility of this model is questionable when applied to adults with LD who should have equal rights and responsibilities as other adults in the system. Fredman (2006) also suggests that second order cybernetics (ie: Structural and Milan) are guided by normative models of the family, with an almost implicit assumption of equal power for all in the system.

Similar to Fidell (2000) and Fredman (2006), I align myself with a third wave social constructionist stance of FT. Here, we assume that there is no essential truth, rather a co-construction of knowledge. Therefore LD is not an objective phenomenon, but a social construction. Within this framework power differentials and dominant social discourses are monitored and alternative narratives about competence, resources and ability are co-constructed.

Whilst the therapist may hold a particular FT orientation s/he may be challenged by the needs of the client. Strict adherence to one particular therapeutic approach may not suffice. It is a challenge for the therapist to be eclectic and provide a combination of therapies such as systemic and behavioural to best meet the needs of the client. For example, Rhodes (2003) proposed a model which integrates family management with family therapy. However, when and to who do we offer such integrated approaches are not known. It is only through research that such questions of best practice can be answered.

5. The major challenge: evidence-based practice (EBP)

Perhaps the most fundamental problem faced by therapists using psychodynamic and systemic approaches is the limited evidence base (EB). The current growing gap between commissioners and providers is forcing clinicians to provide only those therapies which are evidence based (Mason, 2007). Providing such services is integral to clinical governance; however the lack of evidence does not mean that alternative therapies are ineffective (Roth & Fonnagy, 1996).

Addressing the question about the usefulness of an approach will depend upon the epistemological perspective and method that is adopted. Government policy such as the NICE guidance is currently guided by a modernist paradigm, whereby the randomised control trial (RCT) is deemed the gold standard for investigation. Unfortunately there are no such studies investigating the efficacy of systemic therapy with pwld (Baum & Lynggaard, 2006). The Beail and Warden (1996) and Beail (1998) psychodynamic evaluation studies demonstrate the effectiveness of psychodynamic therapy with pwld. However, literature reviews, such as Beail (1995), elaborate on numerous methodological problems when conducting RCTs with this client group. Regardless of these methodological challenges, Oliver, Piachaud, Done, Regan, Cooray, Tyrer (2002) suggest that more basic issues, such as capacity and consent may impede the development of the EB.

Postmodern research approaches, such as qualitative methods can reveal descriptive accounts in support of systemic approaches (Arkless, 2005) and psychodynamic approaches (O'Conner, 2001; Willner, 2005). Such methods can tell us about the personal utility of therapy or reveal important implications for how clinicians can improve their practice (Arkless, 2005; Gilbert, 2004). Furthermore, the literature indicates that there is a lack of outcome measures appropriate for this client group (Hatton, 2002). Particularly due to acquiescence and the propensity to provide socially desirable answers, this problem is evident in both research and clinical settings. However, developments in dichotomous scales have allowed

acquiescence response bias to be examined (Wright & Stone, 1979). Nonetheless, there seems to be an argument for greater creativity with outcome measures, for example, using projective tests such as the 'Draw a Person' (DAP) assessment. It seems that using multiple complimentary methodologies may be the way forward for outcome research.

The scientist-practitioner model feels like it is under threat. Conducting research in the NHS is a real challenge. There is little or no allocated research time and the emphasis is on creating a flow of clients through the system. Financial, ethical and logistical constraints mean that not all studies can achieve methodological rigour (Kendall, Butcher & Holmbeck, 1999, Willner, 2005). Thus, the lack of evidence would suggest to purchasers and some researchers that alternative therapies are neither effective nor efficacious. For example, Sturmey (2005a; 2005b) takes a strong view against the use of psychotherapies with pwld, he states that the lack of evidence supports his view. So how can we move forward beyond RCTs and conduct research with no extra resources? Beail & Warden (1996) suggest that we need to turn to more naturalistic studies of normal clinical practice; share resources; and pool our outcome data with colleagues who have similar interests in working with pwld. Practice based evidence (PBE) seems to be the way forward.

Writing this essay has allowed me to reflect on my experiences of working therapeutically with these approaches and with pwld. I think that as clinical psychologists, we need to actively share our formulations and consult to other professionals to help them think more systemically and psychodynamically when working with pwlds (Petty, 2002). Despite the challenges and dilemmas talked about throughout this essay, the real challenge for clinical psychologists is to be flexible, creative and innovative clinicians. In a similar vein, these principles apply to our research skills. The limited resources and funding in the NHS are not going to change overnight, we need to use what we have and produce more practice based evidence.

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CHAPTER THREE:

SMALL SCALE SERVICES RELATED PROJECT

An evaluation of a seven week parallel psychoeducational course for people in the early stages of dementia and their close relatives.

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1. ABSTRACT

This audit evaluates outcomes of a parallel psychoeducational group (PPG) for people with a recent diagnosis of dementia and their close relatives (carers). Outcomes measured included: 1a) Factors associated with psychological adjustment among carer's of people with dementia including: self-efficacy; depression; anxiety; strain; and dementia related knowledge (biomedical, coping and service related); 1b) Effectiveness of the group for people with dementia (pwd) with regards to their acceptance of illness and coping style, and 2) The carer's and pwd's general satisfaction with the PPG. Quantitative findings from the audit indicated that the PPG was limited in its' effectiveness in relations to outcomes 1a and 1b. However, qualitative findings measuring outcome 2 suggested that all participants found the PPG to be a positive experience. Results are discussed with regard to methodological, service implications and wider research.

2. INTRODUCTION

Dementia is a disease of the brain characterised by a collection of symptoms, including a decline in memory, reasoning and communication skills (Alzheimer's Society, 2007). As the disease progresses, symptoms often become evident through changes in personality, behaviour and loss of functional abilities (American Psychiatric Association, 1994). The most common dementias are Alzheimer's disease, Vascular Dementia, Dementia with Lewy Bodies and Fronto-Temporal Dementia.

Dementia affects 700,000 people in the UK (Alzheimer's Society, 2007). This represents 5% of the total population aged 65 and over, rising to 20% of the population aged 80 and over. In the UK, two-thirds of all people with a dementia live in their own homes, an arrangement that often results in 'informal' caregiving by family and friends. This currently saves the UK £6 billion pounds a year (Alzheimer's Society, 2007). It is estimated of the 5.5 million informal carers across the UK (Population Census and Surveys, 2003), at least two thirds of a million provide care for people with dementia (pwd) (Alzheimer's Society, 1992), presenting multiple social, emotional, physical and financial demands for the carer (Charlesworth, 2006; Pfeiffer, 1990).

The clinical and research literature suggests that carers of older people with cognitive impairment are more susceptible to depression and other mental health problems (Charlesworth, 2006; Gilleard, Belford, Gilleard, Whittick & Gledhill, 1984), compared with carers of people who have only physical impairments (Tennstedt, Cafferata & Sullivan, 1992). The capacity of the informal carer to maintain a healthy lifestyle and to identify and initiate coping strategies to assist maintaining this, is fundamental to ensuring the well-being of the individual with dementia (Morris, Morris & Briton, 1998, In Mockler, Riordan, & Murphy, p310).

The role of informal caring was acknowledged by the Department of Health (DoH) in The National Service Framework (NSF) for Older People (2001); Caring about Carers Legislation (2004) and the Carers Equal Opportunity Act (2004). These documents propose that services should develop to provide more community orientated services to support carers and increase carer well-being. The NSF for Older People (2001) specifically suggested the use of psychoeducational approaches to facilitate this and has more recently been supported by the Alzheimer's Society (2007), who emphasised the need for guaranteed carer support packages.

Clinical Psychology has an important role in the delivery of such services to carers of pwd through the provision of '.....effective approaches to [helping people cope] with personal stress as well as practical and problem-solving help' (British Psychological Society, 2002, p.10).

2.1 Brief review of psychoeducational approaches for carers of pwd

There have been a number of meta-analyses and systematic reviews examining the efficacy of group interventions for carers of pwd (Brodaty, Green, & Koschera, 2003; Peacock & Forbes 2003; Pusey & Richards, 2001; Cooke, McNally, Harrison & Newman, 2001; Sorensen, Pinquart, Duberstien, 2002; Thompson & Briggs, 2000). Many of these reviews have examined both the content and mode of intervention (individual or group).

Pusey & Richards (2001) review of 30 studies demonstrated that interventions that included educational, problem-solving and behavioural-management components were more effective than those offering emotional support alone. However, they concluded that there was insufficient evidence to support one mode of intervention over another. Cooke *et al.*, (2001) reviewed 40 interventions for carers of pwd. They found that only one third of the studies showed statistically significant findings. They concluded that interventions for carers that included a social support

component or a combination of social and cognitive components (e.g. problem solving) were most effective.

Both Cooke *et al.*, (2001) and Pusey & Richards (2001) found that the majority of group interventions for carers of pwd were 'deemed to be psychoeducational' (i.e. typically based upon principles of Cognitive Behaviour Therapy) with a focus on information giving, and developing the carers' self-care and stress management techniques (Depp, Krisztal, Cardenis, Oportot, Mausbach, *et al.*, 2003). The literature reviewed suggests that such interventions are more efficacious, as measured through reduced rates of depression, increased knowledge and self-esteem in carers of pwd compared to those attending support based groups (Sorensen *et al.*, 2002; Depp, *et al.* 1993; Knight, Lutzky, Macofsky-Urban, 1993).

Despite the number of reviews examining the efficacy of psychoeducational groups for caregivers, the conclusions drawn are often equivocal. This is in part due to methodological limitations including a lack of reliable and valid measures to assess such interventions (Peacock & Forbes, 2003; Pusey & Richards, 2001; and Thompson & Briggs, 2000).

In response to this particular methodological problem, recent researchers have commented on the value of qualitatively evaluating psychoeducational groups (Nathanwi, 2006). In an earlier study using this methodology, Thompson and Briggs (2000) found that carers who had attended a psychoeducational group reported an increased sense of self-confidence and a reduced sense of isolation through being given an opportunity to discuss concerns that they would have otherwise not addressed.

A further limitation of the research produced to date is its lack of grounding in a clear theoretical framework (Lavoie, Ducharme, Levesque, Herbert *et al.*, 2005). The most widely cited model from which the complexities of care-giving for pwd have been explored is the Stress Process Model (Perlin, Mullan, Semple & Skaff

,1990). This biopsychosocial model incorporates contextual factors (e.g. the relationship between the caregiver and pwd); primary stressors (e.g. functional impairments associated with dementia); secondary stressors (e.g. conflicts associated with familial and intrapsychic strains involving self-efficacy); mediators (e.g. coping and social support); and outcomes of stress (e.g. the well-being of the caregiver; mental health and burden/strain).

Following this model, Pfeiffer (1999) developed a practise based stage model of caring for pwd. In Pfeiffer's first stage, he identifies carer's needs to include information about the disease; knowledge about community resources; availability of treatment interventions; whether they require emotional support from health care professionals and/or peer support from others in a similar situation. Pfeiffer also identified what services are most appropriate for each stage and possible adverse outcomes for the carer at each stage.

The use of these types of models to guide research would assist interpretation and clinical application of results obtained, as well as allow new models to be developed as more knowledge is generated (Schulz, 2001).

2.2 Brief review of psychoeducational approaches for PWD

In comparison to research investigating efficacy of group interventions for carers, published studies into groups for pwd are more theoretically driven, and rarely psychoeducational in nature.

Theoretical models emerging from neuropsychological investigations provide a strong rationale for developing interventions for people with early-stage dementia that help people build on relatively preserved aspects of cognitive functioning or make the most of residual abilities in impaired domains (Clare, 2006, cited in Attix & Welsh-Bohmer, 2006). Experimental studies have also provided evidence that suggest that pwd can modify behaviour in response to changed environments (Burgess, Weardon, Cox, & Rae, 1992); and learn new skills (Salmon, Heindel, &

Butters, 1992) with the appropriate conditions and right support (Little, Volans, Hemsley, & Levy, 1986). These studies indicate a strong basis for the development of group interventions based on cognitive and behavioural frameworks.

There has also been an emphasis on the importance of optimising functioning in multiple domains, including affective and interpersonal functioning (Kitwood, 1997). This holistic perspective promotes a person-centred approach that should be an important consideration for all types of interventions (Kitwood, 1997).

A holistic approach to pwd suggests that aspects of Pfeiffer's (1999) model may also apply to the experiences of people in the early stages of dementia. For example, earlier detection and diagnosis of dementia would suggest that many would have an increased awareness of their condition and prognosis, and seek out relevant information, resources, treatment and support.

2.3 Parallel Groups for pwd and their carers

The research literature reviewed includes little information about parallel groups for carers and pwd, i.e. groups that run separately but concurrently with the same topics covered for all participants (Scott, Clare, Charlesworth & Luckie (2002). The limited research that is available appears to suggest this model of working may be useful.

Moniz-Cook *et al.*, (1998) developed an intervention that included crisis prevention, coping strategies and memory management techniques for pwd and their carers. Results at follow-up suggested that there was a significant improvement in pwd's memory scores and carers' well-being had remained stable in comparison to a deterioration found in the control group. Quayhagen & Quayhagen (1989) ran a cognitive stimulation programme for pwd and their relatives. They obtained similar findings; the cognitive functioning of pwd and level of burden demonstrated by

carers' were maintained in comparison to those in the control group, where carer burden increased and pwd's cognitive functioning declined..

More recently, Scott *et al.*, (2002) have reflected on the process and practicalities of running a parallel group for pwd and their partners, rather than reporting quantitative findings. They described the course development, and manualisation of the course content. They report on the importance of encouraging other professions to co-facilitate the course to maximise the range of skills offered. They described the importance of timing and formatting of exercises in the group for pwd and relating this to the emotional impact that the group can have for pwd. Scott *et al.*, (2002) recommended the parallel approach as a way forward in providing services for pwd and their carers, as it facilitates support for both pwd and carers, yet also acknowledges and works with the pwd and their carer as one system.

2.4 Background to the development of the audit project.

In response to government initiatives to promote community-based resources for carers and pwd (NSF Older People, 2001) and NHS Trust objectives, the Older Peoples Psychology Service and the Alzheimer's Society developed a joint-working strategy. This aimed to provide improved support for people recently diagnosed with dementia and their carers, in a psychoeducational format.

A psychoeducational group for carers only was piloted and evaluated. Recommendations from this project included the development and delivery of a parallel group to include pwd, providing both sets of people with the opportunity to spend time with others in a similar situation and to hear, think and talk about dementia and ways of moving forward.

The group format was closed, structured, and the intervention was over seven sessions. The content of the parallel psychoeducational group (PPG) was broadly based on the first stages of Pfeiffer's model; factors known to influence the stress process among carers of pwd (Pearlin *et al.*, 1990) and elements from other

psychoeducational groups reported in the research literature. Table 1 outlines the broad content of both groups.

2.5 Audit objectives:

In line with the available clinical and research literature, the audit objectives on completion of the seven-week PPG were to assess:

1. a) Factors associated with psychological adjustment among carers of pwd; Including: self-efficacy, depression, anxiety, strain, self efficacy; and dementia related knowledge (biomedical, coping and service related).
- b) Effectiveness of the PPG for pwd with regard to their acceptance of their illness and strategies for managing memory loss.
2. To assess the carers and pwd's general level of satisfaction with the PPG.

3. METHODOLOGY

3.1 Design

To evaluate the effectiveness of the PPG a pre-test–post-test design was used. Self-efficacy, anxiety, depression, strain, and knowledge of dementia were measured pre and post intervention for each carer. Acceptance of illness and strategies for managing memory loss were measured at pre and post intervention for pwd

3.2 Participants

Participants were identified from the local NHS Trust Memory Clinic or by a member of the Alzheimer's Society. They were then referred to a Clinical Psychologist working in the Older Peoples Psychology Service. People who had received a diagnosis of dementia within the last twelve months, and fulfilled the inclusion criteria (Appendix 3) were considered for the group. Carers of pwd had to live in the local area; be able to commit to the seven sessions; and be supporting an individual who was aware of their diagnosis of dementia.

The numbers who opted to participate in the groups (n=10), were in line with Yalom's (1995) recommendation for optimal group participation. The carers (n=5) were all spouses of pwd, four were female. All participants were over 65 years of age and were white British; reflecting the ethnic diversity of the local region.

3.3 Procedure

Potential participants who met the inclusion criteria were given an information leaflet about the PPG and then contacted by the Clinical Psychologist or member of the Alzheimer's Society to discuss the group. All potential participants were informed of their rights to decline or withdraw from the PPG at any time and that this would not affect other services received.

Potential participants who displayed interest in the PPG were then visited by the Trainee Clinical Psychologist to complete pre-evaluation questionnaires (Appendix 5-6) and were given a further opportunity to discuss the group. Informed written consent (Appendix 2) was obtained from all participants before completing measures to fulfil the audit objectives.

3.3.1 Group content and format.

Table 1: Programme outline

Week	Session Topic:	Target/Discussion:
1	Hello and welcome	-Introduction & norms setting -discussion of dementia generally; including the importance of 'individual differences'.
2	What is dementia?	-Understanding and managing the signs, symptoms and difficulties caused by different dementias.
3	Making the most of your memory (1) (Joint session-couple work)	-Different types of memory, how memory works, why we forget and external memory strategies to reduce forgetting
4	Making the most of your memory (2) (Joint session-couple work)	- Further practical and internal memory strategies to assist cognitive abilities -develop and assist use of strategies designed specifically for each couple.
5	Managing stressful situations	- Identifying, preventing and managing experiences of stress.
6	How has life changed?	-Adjusting to new situations, moving forward and being positive.
7	- Evaluating & reflecting on the group and moving on.	Talks from local professionals and services.

A Clinical Psychologist, a Trainee Clinical Psychologist and two members of the Alzheimer's Society, facilitated the groups. Sessions were ninety minutes in length and ran on a weekly basis. Sessions were delivered through discussion exercises, didactic and dynamic teaching and information handouts.

Upon completion of the PPG participants were visited in their homes to complete the post-evaluation questionnaires and a qualitative questionnaire regarding consumer satisfaction with the psychoeducational group (Appendix 7).

3.3.2 Measures

The limited research published on PPG's for pwd and their carers provides little guidance for the measures that would best evaluate this PPG. The following measures therefore relate to key elements of Pearlin *et al.*'s (1990) Stress Process Model and Pfiesser's (1999) stage model. All have been used in previous clinical and research work with pwd and their carers. Please see Appendix 4 for a brief description of each measure and the qualitative satisfaction questionnaire.

Carers completed the following quantitative questionnaires to fulfil audit objective 1a (Appendix 5):

- The Dementia Quiz (DQ) (Gilleard & Groom, 1994)
- Generalised Self Efficacy Scale (GSES) (Schwarzer & Jerusalem, 1993)
- Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)
- The Machin Strain Scale-modified version (MSS) (Gilleard, 1987).

People with dementia completed the following questionnaires (Appendix 6):

- Index for Managing Memory Loss - adapted version (IMMEL) (Keady & Nolan, 1995).
- Acceptance of Illness Scale (AIS) (Felton, Revenson, & Hinrichsen, 1984).

All pwd and carers completed the satisfaction questionnaire (Appendix 7).

3.4 Data Analysis

Descriptive statistics will be presented to address the audit objectives 1a and 1b. Qualitative data will be summarised to address audit objective 2.

All information gathered was filed and locked securely in the Clinical Psychology department. All participants were allocated an anonymised participant number to ensure confidentiality.

3.5 Ethical consideration

The NHS Trust Research and Development office considered this project to be an audit of routine practise. Therefore ethics committee approval was not sought. The NHS Trusts Clinical Audit Committee accepted the audit proposal in June 2006 (Appendix 1).

The facilitators agreed that any participant who required additional support as a result of the PPG would be referred to the Older Adults' CMHT .

4. RESULTS

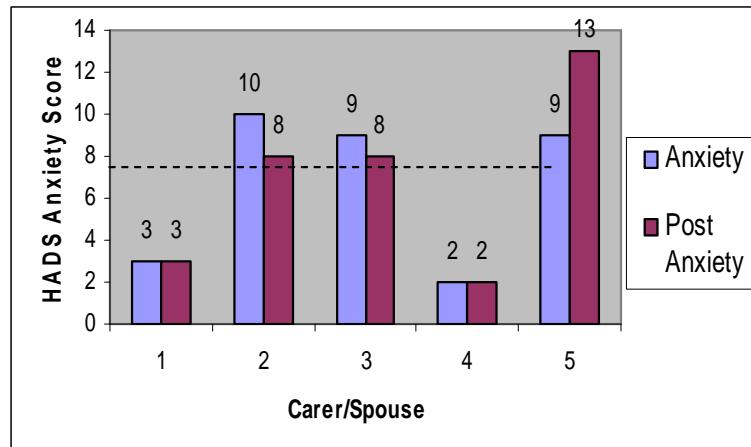
4.1 OBJECTIVE 1a:

Table 2 shows results on pre/post group measures associated with psychological adjustment in carers of pwd. Findings on each measure indicate a trend towards positive change, with the exception of participants' levels of anxiety. No significant differences were observed between pre/post scores on any measure as assessed by the HADS, Strain Scale, Generalised Self-efficacy Scale and the Dementia Quiz.

Table 2. Factors associated with psychological adjustment among carers of pwd: pre/post PPG results.

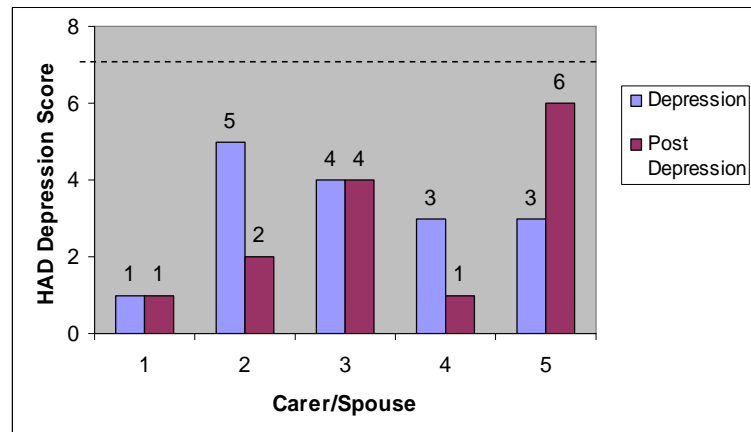
Questionnaire		Pre carer group mean	Pre carer group range	Post carer group mean	Post carer group range
HADS	Anxiety	6.6	3-10	6.8	3-13
	Depression	3.2	1-5	2.8	1-6
Strain Scale		9.8	6-14	9.2	5-17
Self-efficacy		32	28-36	32.6	27-36
Dementia Quiz (Knowledge)	Biomedical	4	2-6	4.8	3-6
	Coping	6	3-7	6.2	4-7
	Services	5.2	2-8	8.2	5-8
	DQ Mean Total	15.2		19.2	

Figure 1: Graph illustrating individual carer pre/post group HADS Anxiety scores.



----- Clinical cut off

Figure 2: Graph illustrating individual carer pre/post group HADS Depression scores.



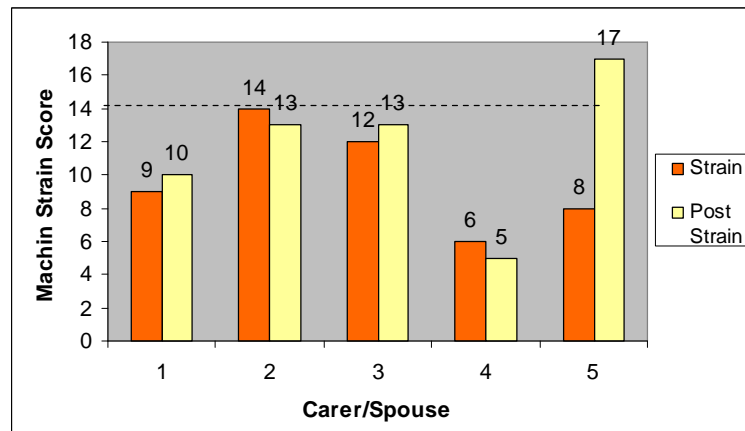
----- Clinical cut off

The mean pre/post group ratings for anxiety and depression (HADS) were all below the clinical cut off for caseness. Ratings assigned to measures of anxiety were distributed over a wider range compared to those for depression. In Figure 1 scores for carers 2, 3 and 5 suggest clinical caseness for anxiety prior to the group. Post group scores for carers 2 and 3 depict a reduction in anxiety, falling within the mild range. However, carer 5 reported an increase in anxiety. It would appear that

carers 1 and 4 at the outset of the group were already experiencing low levels of anxiety.

Figure 2 shows that regard to symptoms of depression carers 1 and 3 remain stable; carers 2 and 4 reported a reduction in symptoms, and carer 5 reported an increase in depressive symptomatology. All scores remained below clinical caseness for depression.

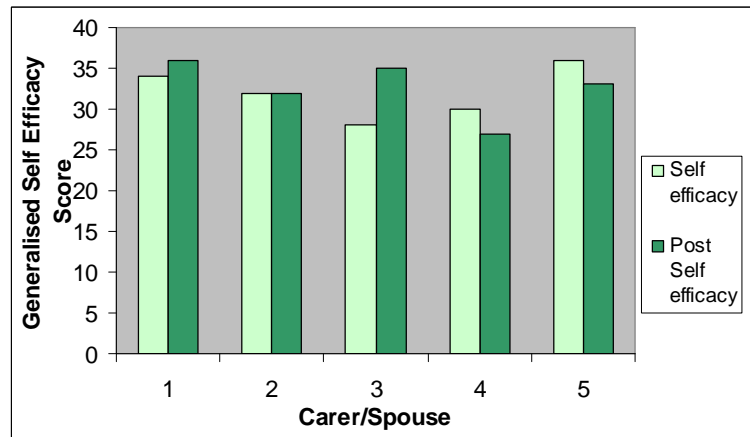
Fig 3: Graph illustrating individual carer pre/post group Strain Scale scores



----- Clinical cut off

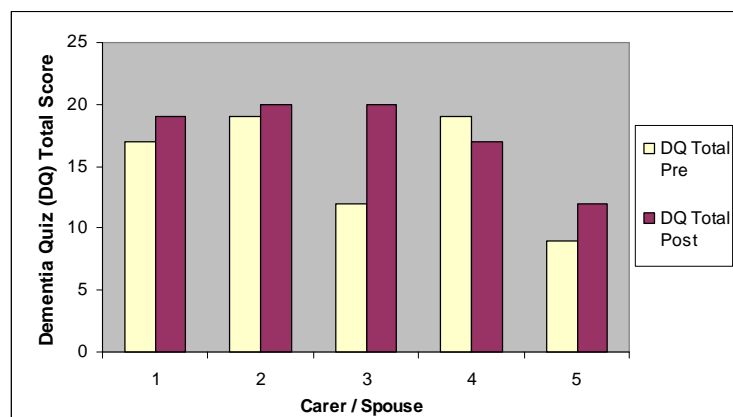
The mean pre/post group ratings for strain slightly decreased following the PPG, but this was not significant. Strain score ranges depicted in Figure 3 show that carer 2 falls on the cusp of significant experiences of strain. Carer 5 reported a marked increase in perceived levels of strain post group, which may have skewed overall scores given the small numbers in the group.

Figure 4: Graph illustrating individual carer pre/post group Self-efficacy scores.



The group mean for self-efficacy shows a minor increase post group. High scores at baseline suggest that carers were already reasonably confident and optimistic in their abilities to cope with the different demands presented in their day-to-day life. Figure 4 indicates this view was generally held post group with the exception of carer 3 whose level of self-efficacy considerably improved.

Figure 5: Graph illustrating individual carer pre/post group Dementia Quiz (DQ) total scores.



The group means for the DQ total score suggests that the PPG has slightly increased the carers overall knowledge about dementia, with carers 3 and 5 demonstrating the greatest increase in knowledge.

Figure 6: Graph illustrating carer pre/post group DQ (Biomedical Knowledge) scores.

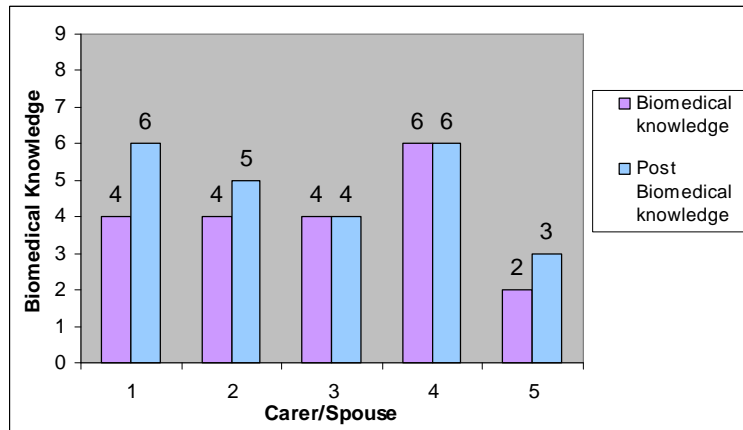


Figure 7: Graph illustrating carer pre/post group DQ (Coping Knowledge) scores.

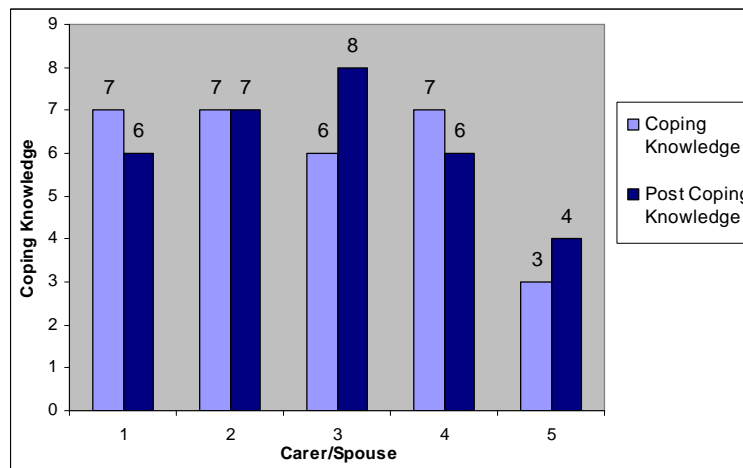
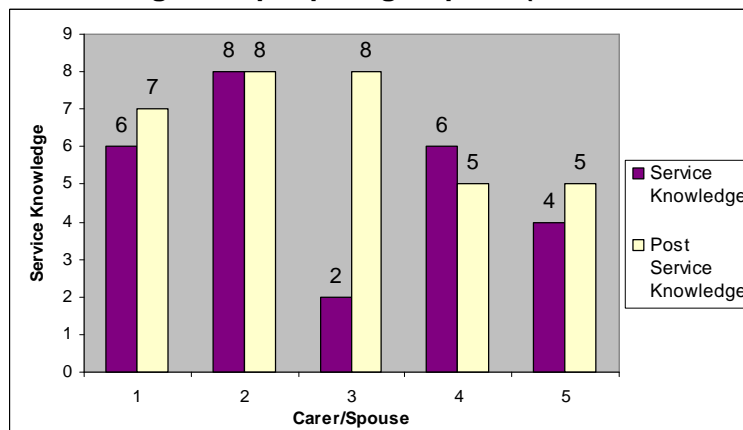


Figure 8: Graph illustrating carer pre/post group DQ (Service Knowledge) scores.



Figures 6, 7 and 8 illustrate pre/post group levels of knowledge across biomedical, coping and service-related issues for each carer. For each of these elements, the majority of carers obtained similar ratings pre/post group. Carer 3 however, demonstrated a trend towards increased coping and services knowledge post group.

4.2 OBJECTIVE 1b:

Table 3 shows results on pre/post group measures for ways of managing memory loss and acceptance of illness among pwd. Findings suggest almost no change in acceptance of illness among pwd. Approach coping showed the highest increase for managing memory loss at post group.

Table 3. Pwd: pre/post PPG results.

Questionnaire	Pre pwd group mean	Pre pwd group range	Post pwd group mean	Post pwd group range
Acceptance of Illness Scale	23.2	20-27	23.4	18-28
Index for Managing Memory Loss (IMMEL) (methods of coping)				
Approach coping	9.6	6-13	16.6	12-21
Avoidant coping	10.8	6-13	12.8	10-16
Creating Alternative perceptions	15	11-22	17.6	14-21
Managing symptoms of stress	8.8	8-11	11.8	9-14

Figure 9: Graph illustrating individual pwd pre/post group IMMEL Approach Coping scores.

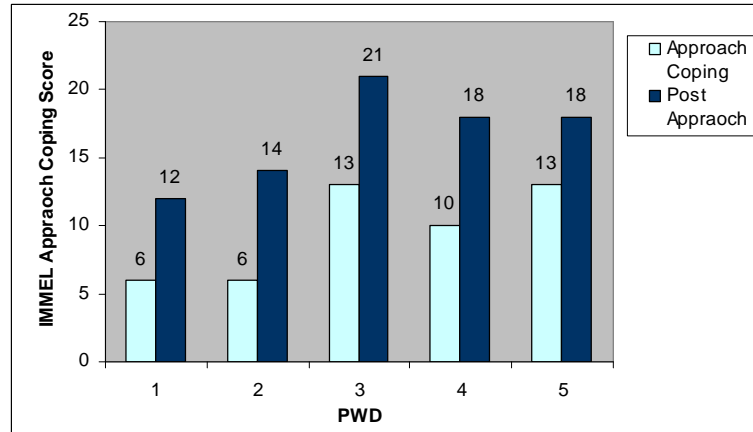


Figure 10: Graph illustrating individual pwd pre/post group IMMEL Avoidant Coping scores

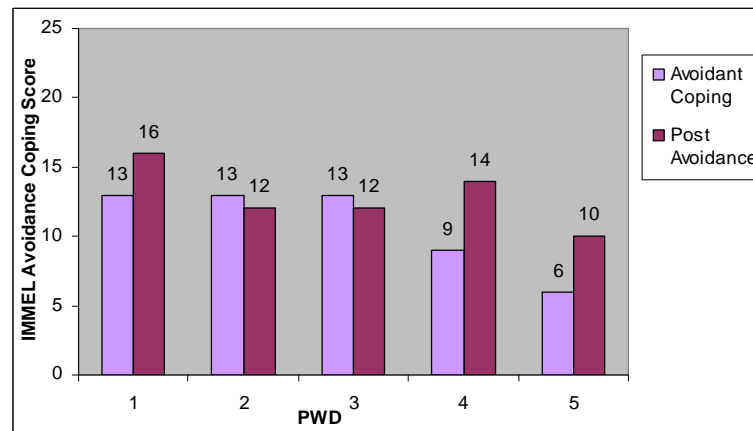


Figure 11: Graph illustrating individual pwd pre/post group IMMEL Alternative Perception of Events Coping scores.

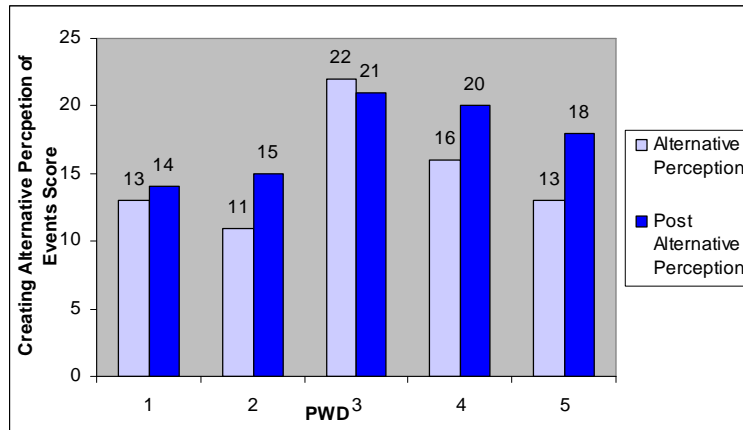
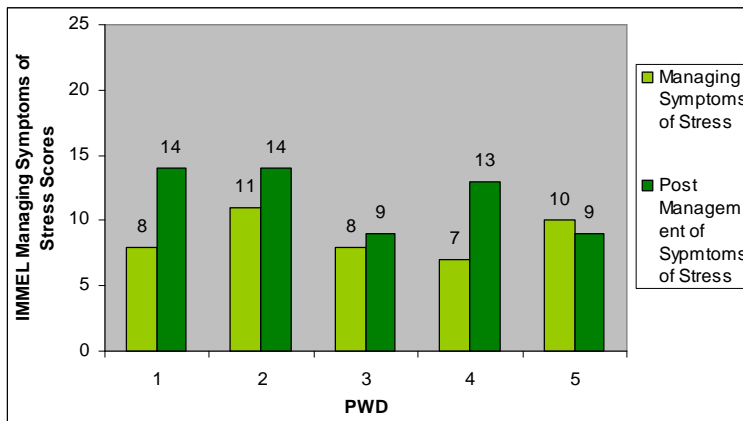
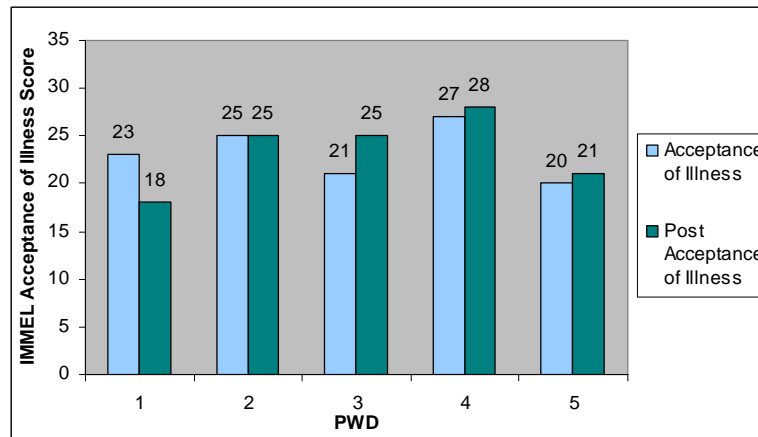


Figure 12: Graph illustrating individual pwd pre/post group IMMEL Management of the Symptoms of Stress score.



Group mean scores for each of the IMMEL subscales indicate that at pre group, the most commonly used method for managing memory loss was creating alternative perceptions of events. The least used involved managing the symptoms of stress. Post PPG indicates that this pattern was maintained, although pwd's scores on all subscales increased, particularly generally for approach coping. Few observable differences were seen on individual pwd pre/post scores with the exception of pwd 4 and 5 who indicated increased use of avoidant coping and creating alternative perceptions of events post PPG - additionally, perhaps also for pwd 1 and 4 on increased management of symptoms.

Figure 13: Graph illustrating individual pwd pre/post group Acceptance of Illness (AIS) scores.



Mean ratings on the AIS questionnaire showed marginal change for participants following the PPG with the exception of pwd 1 who indicated a trend towards reduced acceptance post PPG.

4.3 OBJECT 2:

The carer's and pwd's general satisfaction with the PPG appeared to be good and positive feedback was provided. Both parties found joining with others in a similar situation was most helpful. Responses supporting this theme include:

PWD said:

- *“We were all in the same boat, sharing experiences. I’m not the odd one out”.*
- *“meeting with others has restored my interest in going out and going places, rather than avoiding places..... I thoroughly enjoyed it. It gave me the initiative to get up and go out again it restored my confidence....”*

Carers said:

- *Talking with other relatives about our problems and being able to relate to them.*
- *To meet with others in a similar situation*

Feedback about the parallel format was also generally positive. Responses reflecting this theme included:

PWD said:

- *"I think it was the best thing to have your partner to discuss things together and separately. It was good to have time alone to discuss things".*

Carers said:

- *"Very helpful, as our partners are (generally) always with us, we (usually) cannot discuss our fears and concerns"*
- *"[the format was useful) because that gave us freedom to express ourselves without hurting the feelings of our partners"*

Feedback about changes made following the group was varied. Responses suggested changes in attitude towards the nature of dementia and increased use of memory strategies by some carers and pwd. Other general comments included:

PWD said:

- *"I enjoyed it one hundred percent; my problems seemed to diminish a bit. I just know that when I came away I was happy and enjoyed the experience".*

Carers said:

- *"I no longer feel alone and I have a reference point"*

5. DISCUSSION

5.1 Summary & discussion of findings

Quantitative findings measured by objectives 1a and 1b provide little evidence to suggest that the PPG was effective in producing significant, positive changes for carers psychological adjustment or pwd's acceptance of illness, or management of memory loss. However, it must be borne in mind that group numbers were low for quantitative analyses.

With regard to objective 1a, a slight increase was observed on the post group ratings for anxiety; carer 5's heightened score in part affected this. Pusey & Richards (2001) suggest increased knowledge about dementia, its challenges and prognosis can have such an effect on the carer's well-being and that this may be a short-term negative effect of education about the disease.

By contrast, mean levels of strain appear to have reduced slightly; perhaps due to the support offered through sharing of experiences, or developing techniques to manage stress. Overall, self-efficacy findings remained relatively high at pre and post intervention. Pearlin *et al.*, (1990) and Gilliam & Steffen (2006) would suggest that this would mediate the effects of depression, which may support the current findings obtained in this evaluation. The efficacy of the PPG for carers appears greater when considering the above alongside dementia knowledge, where mean group scores suggested that some learning had occurred during the intervention.

In relation to objective 1b, pre-group mean scores indicated high levels of acceptance of illness which Clare (2002, In Attix *et al.*, (2006) associated with enhanced learning outcomes. However, learning outcomes were not formally evaluated in this audit. Rather, use of coping styles were evaluated and results indicated that overall, participants increased their application of all types of strategies, particularly approach coping. This type of coping reflected the strategies disseminated during the group. Furthermore, volunteering to attend and participate in the PPG was indicative of an approach style of coping. Given voluntary participation, it is likely that this group were bias in this in this direction.

Qualitative data gathered to evaluate objective 2 indicated that all carers and pwd found the PPG to be a positive experience. The combination of psychoeducational material, social and emotional support and parallel format were most helpful, alongside the opportunity for pwd and carers to share experiences with others in a similar situation. Such experiences are thought to allow people to: empathise and learn from others; use social comparison to re-evaluate their difficulties; feel less isolated; facilitate hope and regain confidence (Lavoie, *et al.*, 2005, Depp, *et al.*, 1993, Pearlin *et al.*, 1990). The qualitative information from both pwd and their carers were varied but accentuated overlapping themes. This finding offers some support for the relevance of the early stages of Pfeiffer's (1999) stage model for experiences of carers and pwd alike.

5.2 Methodological limitations

The insignificant quantitative findings of this audit reflect those obtained in much of the research reviewed to date (Cooke *et al* 2001, Pusey & Richards, 2001). The lack of valid, reliable and sensitive measures to assess such interventions is believed to be an integral reason for such findings (Peacock & Forbes, 2003; Thompson & Briggs, 2000).

It is generally agreed that using self-report measures for anxiety, depression and strain to evaluate time limited carer groups is far from ideal (Thompson & Briggs, 2000). It is important to emphasize that these measures do not consider individual contextual factors, e.g.: the physical health of the carer, which Pearlin *et al.*'s (1990) Stress Process model would regard as imperative when considering outcomes in this population. Developing or adapting existing tools to consider more complex biopsychosocial issues would be a step forward in evaluating interventions for pwd and their carers and could better reflect the most up-to-date theoretical knowledge.

The qualitative findings yielded insightful results, however, some questions were biased towards eliciting positive gains from the group members e.g.: 'What did you find most helpful?' and 'How helpful did you find the handouts?' These questions also tap into overlapping concepts, which Nathanwi (2006) acknowledges as a common difficulty with satisfaction questionnaires.

5.3 Project limitations and Improvements

The intervention was restricted by the limited resources available and the inclusion criterion may have reflected this, targeting those already accessing services. Ultimately this produced a sampling bias of highly motivated individuals. By adopting this type of recruitment strategy, the service potentially missed a large proportion of carers who may have benefited from the PPG.

To help improve the efficacy of the intervention, it may have been worthwhile to consider case heterogeneity. Using the pre PPG evaluation results as a screen would have revealed that two of the carers were already experiencing minimal distress as measured on the HADS scale. Using results obtained on the Dementia Quiz would have also highlighted the varying levels of knowledge within the group which had implications for the material covered in the sessions.

The PPG format meant that both carers and pwd were required to attend. Scott *et al.*, (2002) acknowledged that the motivation of carers' might influence the decision of the pwd to participate. Interviewing the pwd and their carer both jointly and separately at the initial meeting about participation would have been ideal. However, this would have required two professionals and resources did not permit this.

5.4 Service Implications

With further investigation and continued auditing, the PPG aims to become an integral part of the standard pathway of care for pwd and their carer. A long-term

aim for the PPG includes delivering a rolling programme across the West of the County for all people in the early stages of dementia and their carers. This will of course have resource implications and it will be necessary to encourage other professional and branches of the Alzheimer's Society to co-facilitate these groups.

The provision of a PPG service for pwd and their carers is designed for those who have recently received a diagnosis. However, it is important to consider that people adjust to this diagnosis at different rates (Scott *et al.*, 2002). Therefore, contacting people at various stages after diagnosis and checking whether they are ready to access this type of service, is a positive step towards providing ongoing individualised support after a diagnosis of dementia.

5.5 Direction for future research

The ongoing implementation of the PPG will make it possible to obtain sufficient numbers of people to investigate any statistically significant changes in the quantitative measures. However, any future quantitative findings will be subject to the measurement limitations discussed. It is thus important to develop sensitive and appropriate measures. The next stage would then be to introduce a waiting-list or social support group as a comparative control to examine the efficacy of the PPG.

As mentioned in the introduction, many of the research and audit papers disregard a theoretical underpinning for their interventions for pwd and/or their carers (Lavoie *et al.*, 2005). This leaves both the clinician and researchers with a 'black box' phenomenon, because there is a lack of knowledge about how and why an intervention is effective.

Finally, the material presented in the PPG was considered in relation to Pearlin *et al.*'s (1990) and Pfeiffer's (1999) theoretical models and concepts. Continued research into these models and integration of research investigating PPG's may help to reveal more about which aspect(s) of the groups are most effective (Lavoie

et al. 2005) and which elements are involved in the process of positive change experienced by carers and pwd. This may help to further develop and refine theoretical models that attempt to understand and assist with the support and management of dementia.

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7. Appendix Content:

Appendix 1: Audit committee application

Appendix 2: Consent form

Appendix 3: Referral form with Inclusion criteria

Appendix 4: Description of measures

Appendix 5: Carer - Questionnaires

Appendix 6: People with dementia - Questionnaires

Appendix 7: Consumer Satisfaction Questionnaire



APPENDIX 1

Clinical Audit and Effectiveness Project Application Form

Project Title

AN EVALUATION OF A SEVEN WEEK PARALELL COURSE FOR PEOPLE IN THE EARLY STAGES OF DEMENTIA AND THEIR CLOSE RELATIVES.

Which Category best fits the work you wish to undertake? Please

Audit (i.e. measuring a known standard)	
Service Evaluation	<input type="checkbox"/>
User Evaluation Survey	

Your Name			
Job Title/Profession	CLINICAL PSYCHOLOGIST		
Address			
Telephone Number			
Email Address			
Line Manager's Name			
Other Participants and Job Titles	TRAINEE CLINICAL PSYCHOLOGIST CONSULTANT CLINICAL PSYCHOLOGIST MANAGER FOR THE ALZHEIMER'S SOCIETY, AND CO-FACILITATOR FOR THE COURSE		
Is this Project Multidisciplinary?	Yes		No <input type="checkbox"/>

Please give a brief description of your proposal.

Background	<p>THE ABOVE SEVEN WEEK COURSE WAS DEVELOPED IN ORDER TO PROVIDE A TIME-LIMITED, PSYCHOEDUCATIONAL SERVICE TO BOTH PEOPLE WHO HAVE RECENTLY BEEN DIAGNOSED AND ARE IN THE EARLY STAGES OF DEMENTIA AND THEIR CLOSE RELATIVES WITH IN THE AREA OF *****. NO SUCH SERVICE IS CURRENTLY PROVIDED FOR PEOPLE WITH DEMENTIA AND THEIR CLOSE RELATIVES IN THIS AREA OF *****.</p> <p>IT IS INTENDED THAT IN THE LONGER TERM, THIS PARALELL COURSE WILL BE ADAPTED ACCORDING TO FINDINGS FROM THE PROPOSED EVALUATION, AND GRADUALLY BE EXTENDED ACROSS ***** IN ORDER THAT ALL PEOPLE WITH DEMENTIA WHO HAVE RECEIVED A DIAGNOSIS VIA THE ***** MEMORY CLINIC HAVE THE OPPORTUNITY TO ATTEND THE COURSES AS WELL AS THEIR CLOSE RELATIVE.</p>
Objective	<p>THE OBJECTIVES OF THIS EVALUATION ARE TWOFOLD: -</p> <p>1. TO MEASURE THE EFFECTIVENESS OF THE COURSE ALONGSIDE FACTORS ASSOCIATED WITH PSYCHOLOGICAL ADJUSTMENT IN CLOSE RELATIVES OF PEOPLE WITH DEMENTIA IN THE CLINICAL / RESEARCH LITERATURE INCLUDING ANXIETY, DEPRESSION, STRAIN, SELF-EFFICACY</p>

- AND KNOWLEDGE OF DEMENTIA.
2. TO MEASURE THE EFFECTIVENESS OF THE COURSE ALONGSIDE FACTORS ASSOCIATED WITH PSYCHOLOGICAL ADJUSTMENT IN THE PERSON DIAGNOSED WITH DEMENTIA IN THE CLINICAL / RESEARCH LITERATURE INCLUDING: ACCEPTANCE OF ILLNESS AND INDEX FOR MANAGING MEMORY LOSS
 3. TO ESTABLISH WHETHER PARTICIPANTS VALUED THE PSYCHO-EDUCATIONAL COURSE AS INDICATED BY THEIR GENERAL SATISFACTION WITH THE SERVICE RECEIVED.

<p>Methodology <i>(please include what kind of data collection you are using and why, attach copies where applicable)</i></p>	<p>DESIGN</p> <ul style="list-style-type: none"> • A PRE-TEST – POST-TEST DESIGN WITH TWO GROUPS OF PARTICIPANTS' GROUP 1 ARE THE RELATIVES OF PEOPLE WITH DEMENTIA - ANXIETY, DEPRESSION, STRAIN, SELF-EFFICACY, KNOWLEDGE OF DEMENTIA, AND GENERAL SATISFACTION BEING THE DEPENDANT VARIABLE. GROUP 2 ARE THOSE DIAGNOSED WITH DEMENTIA – ACCEPTANCE OF ILLNESS AND THE INDEX FOR MANAGING MEMORY LOSS BEING THE DEPENDANT VARIABLE AND THE SEVEN WEEK COURSE THE INDEPENDENT VARIABLE <p>PARTICIPANTS</p> <ul style="list-style-type: none"> • POTENTIAL PARTICIPANTS FOR THE COURSE HAVE BEEN IDENTIFIED BY *** AND **** FROM THE SERVICES INTO WHICH THEY WORK • PARTICIPANTS (N=14) ARE SPLIT INTO TWO GROUPS. N=6 ARE PEOPLE WHO HAVE RECENTLY BEEN DIAGNOSED WITH DEMENTIA AND N=6 ARE CLOSE RELATIVES OF PEOPLE WHO HAVE BEEN RECENTLY DIAGNOSED WITH DEMENTIA. ALL PEOPLE LIVE IN THE ***** AREA • ALL PARTICIPANTS ARE COMMITTED TO ATTENDING ALL OR THE MAJORITY OF THE SEVEN SESSIONS OF THE COURSE <p>PROCEDURE</p> <ul style="list-style-type: none"> • POTENTIAL PARTICIPANTS FOR THE COURSE WERE SOUGHT, ACCORDING TO THE ABOVE CRITERIA, AND INVITED TO ATTEND THE COURSE BY **** AND ***** • POTENTIAL PARTICIPANTS WERE GIVEN THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE COURSE, A LEAFLET SUMMARISING THE CONTENT OF THE COURSE AND WERE ASSURED THAT A DECISION NOT TO ATTEND THE COURSE OR TO WITHDRAW FROM THE COURSE WOULD NOT AFFECT THE SERVICES THEY RECEIVED NOW OR IN THE FUTURE • POTENTIAL PARTICIPANTS WERE GIVEN AT LEAST TWO WEEKS TO CONSIDER WHETHER THEY WOULD LIKE TO ATTEND THE COURSE AND ASKED TO CONTACT **** OR ***** IF THEY WISHED TO ATTEND • EACH OF THE PEOPLE WHO AGREED TO PARTICIPATE WILL BE CONTACTED BY **** WHO WILL ARRANGE TO MEET THEM AT A MUTUALLY CONVENIENT LOCATION TO COMPLETE THE PRE-COURSE EVALUATION. THIS MEETING IS ANTICIPATED TO TAKE NO LONGER THAN 45 MINUTES IN TOTAL. • DURING THIS MEETING, ***** WILL REMIND PARTICIPANTS THAT A DECISION NOT TO ATTEND THE COURSE OR TO WITHDRAW FROM THE COURSE WILL NOT AFFECT THE SERVICES THEY RECEIVE NOW OR IN THE FUTURE • PARTICIPANTS WILL BE ASKED TO SIGN A CONSENT FORM BEFORE COMPLETING THE QUESTIONNAIRES FOR THE PRE-COURSE EVALUATION • ***** WILL BE PRESENT TO ANSWER ANY QUESTIONS PARTICIPANTS MAY HAVE ABOUT THE GROUP AND TO CHECK THAT QUESTIONNAIRES ARE
--	--

COMPLETED IN FULL. SHE WILL NOT ASSIST PARTICIPANTS IN CHOOSING ANSWERS TO QUESTIONS ON MEASURES USED

- THE COURSE WILL TAKE PLACE OVER SEVEN WEEKS COVERING ISSUES SUCH AS: UNDERSTANDING DEMENTIA, MAKING SENSE OF THE DIFFICULTIES CAUSED BY MEMORY PROBLEMS, MANAGING STRESSFUL SITUATIONS, AND ADJUSTING TO NEW CHALLENGES.

- IN THE FINAL SESSION OF THE GROUP, PARTICIPANTS WILL BE ASKED TO COMPLETE A GENERAL SATISFACTION QUESTIONNAIRE
- **** WILL MEET WITH THE PARTICIPANTS IN THE WEEK FOLLOWING THE FINAL SESSION OF THE GROUP IN ORDER FOR PARTICIPANTS TO COMPLETE THE REMAINDER OF THE POST-COURSE EVALUATION. THIS MEETING IS ANTICIPATED TO TAKE NO LONGER THAN 40 MINUTES IN TOTAL.
- INFORMATION GATHERED FROM QUESTIONNAIRES WILL BE SCORED AND CODED BY *****. ALL INFORMATION GATHERED WILL REMAIN CONFIDENTIAL, ANONYMOUS AND SECURELY PROTECTED. NO PERSONAL DETAILS WILL BE DISCLOSED AT ANY POINT DURING OR AFTER THE SERVICE EVALUATION.
- A WRITE UP OF THE EVALUATION WILL BE PRODUCED AND DISTRIBUTED AS INDICATED BELOW

MEASURES (ATTACHED)

- THIS SERVICE EVALUATION WILL BE QUESTIONNAIRE-BASED AND WILL INVOLVE THE COMPLETION OF A QUESTIONNAIRE PACKAGE BY THE PERSON WITH DEMENTIA AND CLOSE RELATIVE OF THE PERSON WITH DEMENTIA
- ALL MEASURES TO BE USED ARE FREQUENTLY USED WITH PEOPLE FOR CLINICAL AND RESEARCH PURPOSES AND ARE NOT KNOWN TO CAUSE DISCOMFORT OR DISTRESS. THEY ARE AS FOLLOWS: -

QUESTIONNAIRES FOR RELATIVES:

- HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS, SNAITH & ZIGMOND, 1983).
- THE MACHIN STRAIN SCALE- MODIFIED VERSION (GILLEARD, 1987).
- GENERALIZED SELF-EFFICACY SCALE (SCHWARZER & JERUSALEM, 1993).
- THE DEMENTIA QUIZ (GILLEARD & GROOM, 1994)

QUESTIONNAIRES FOR PEOPLE WITH DEMENTIA:

- INDEX FOR MANAGING MEMORY LOSS –ADAPTED VERSION (KEADY & NOLAN, 1995)
- ACCEPTANCE OF ILLNESS SCALE (FELTON ETAL, 1984)

ALL PARTICIPANTS WILL COMPLETE:

- GENERAL SATISFACTION QUESTIONNAIRE (CONSTRUCTED FOR THE PURPOSE OF THIS SERVICE EVALUATION)

MATERIALS

- THE COURSE WILL RUN FOR SEVEN WEEKS BETWEEN 3RD AUGUST AND 14TH SEPTEMBER 2006 FROM 10.30 A.M. TO 12 NOON
- THE COURSE WILL BE HELD AT THE **** CENTRE, *****.
- THE COURSE WILL HAVE FOUR FACILITATORS (TRAINEE CLINICAL PSYCHOLOGIST ****, CLINICAL PSYCHOLOGIST, **** WILL BE FACILITATING THE CARERS GROUP). ****, MANAGER OF THE ALZIEHMER'S SOCIETY HARLOW BRANCH AND **** OUTREACH WORKER

	<p>FOR THE ALZIEHMER'S SOCIETY WILL BE FACILITATING THE PEOPLE WITH DEMENTIA GROUP)</p> <ul style="list-style-type: none"> • VISUAL AIDS INCLUDING FLIP CHARTS, OVERHEAD PROJECTORS AND VIDEOS WILL BE USED • QUESTIONNAIRES WILL FORM THE BASIS OF THIS SERVICE EVALUATION AND ARE LISTED ABOVE • ALL INFORMATION GATHERED VIA THESE QUESTIONNAIRES WILL BE RECORDED ON A DATABASE. A CODING SYSTEM WILL BE USED AND THE NAMES OF PARTICIPANTS WILL BE CODED ONCE CONSENT TO PARTICIPATE IN THE COURSE HAS BEEN OBTAINED. • DETAILS RELATING THE CODES TO INDIVIDUAL PARTICIPANTS AND COMPLETED QUESTIONNAIRES WILL BE KEPT WITHIN A SECURE AND LOCKED CABINET AT THE PSYCHOLOGY AND PSYCHOTHERAPY SERVICE, ***** HOSPITAL AND WILL BE DESTROYED ON COMPLETION OF THE EVALUATION.
--	--

What action plan does this work fulfil?	SERVICE DEVELOPMENT
---	---------------------

Start date	03.08.2006
Length of project	7 WEEKS

How will you collect the information you need to provide the evidence of change? **Please attach a copy of all questionnaires, interview schedules, or data collection tool you will be using. Please**

Service user questionnaire	<input type="checkbox"/>
Staff Questionnaire	
Case Note review	
Electronic record review	
Staff interview	
Service user interview	
Other (please state)	

How do you intend to share the information that you collect from your study?

Please

Presentation at local audit group/peer group	<input type="checkbox"/>
IT IS INTENDED THAT THIS EVALUATION WILL BE WRITTEN UP BY **** PART FULFILMENT OF THE DOCTORATE IN CLINICAL PSYCHOLOGY COURSE AT THE UNIVERSITY OF HERTFORDSHIRE	<input type="checkbox"/>
Report in Journal or professional publication (state which)	
Presentation at or conference paper	
Other (please specify)	

**Is your Area Director and Service Manager aware of this project? Please
☐ and indicate names**

Area Director ****	Yes	<input type="checkbox"/>	No	
Service Manager ****	Yes	<input type="checkbox"/>	No	

Thank you for completing this form. Please forward this to your local Service Governance Facilitator you will arrange for it to be considered at the next Clinical Audit and Effectiveness Group Meeting.

Please note that details of your project and your contact details will be made available on the Trust's intranet site. This is to enable staff who are interested in your project to contact you directly.

APPENDIX 2

CONSENT FORM FOR PEOPLE WITH MEMORY PROBLEMS

Participants Copy

- Please read this consent form carefully.

If there is anything that you do not understand about the information sheet or consent form, or if you want to ask any further questions please speak to (Trainee Clinical Psychologist) on ()

- If you understand the information provided please tick the boxes below ✓ and sign this form.

-
- I have had the opportunity to ask questions and discuss the evaluation of the group.
 - I have received enough information about the group and it's evaluation.
 - I understand that I am free to withdraw from attending the group at any time, without giving a reason and without it affecting the future care of either my close relative or myself.
 - I understand that I am free to withdraw from completing the evaluation for the group at any time, without giving a reason and without it affecting the future care of either my close relative or myself.
 - I have had enough time to consider taking part in the group, and to think about the evaluation of the group and to decide, without pressure, if I want to take part.
 - I agree to take part in the evaluation of the group.
-

Name of close relative (BLOCK CAPITALS please) _____

Signature _____

Date: _____

Name of witness (BLOCK CAPITALS please) _____

Signature _____

Date: _____

CONSENT FORM FOR CLOSE RELATIVES

Participants Copy

- Please read this consent form carefully.

If there is anything that you do not understand about the information sheet or consent form, or if you want to ask any further questions please speak to (Trainee Clinical Psychologist) on ()

- If you understand the information provided please tick the boxes below and sign this form.

-
- I have had the opportunity to ask questions and discuss the evaluation of The group.
 - I have received enough information about the group and it's evaluation.
 - I understand that I am free to withdraw from attending the group at any time, without giving a reason and without it affecting the future care of either my close relative or myself.
 - I understand that I am free to withdraw from completing the evaluation for the group at any time, without giving a reason and without it affecting the future care of either my close relative or myself.
 - I have had enough time to consider taking part in the group, and to think about the evaluation of the group and to decide, without pressure, if I want to take part.
 - I agree to take part in the evaluation of the group.

Name of close relative (BLOCK CAPITALS please) _____

Signature _____

Date: _____

Name of witness (BLOCK CAPITALS please) _____

Signature _____

Date: _____

APPENDIX 3

REFERRAL FORM WITH INCLUSION CRITERIA

REFERRAL FORM Parallel Psycho-educational Group

The group is a seven-week course for people in the early stages of dementia and their close relative/friends. There are no age restrictions. Over seven sessions, the group will look at:-

- How people with a diagnosis of dementia first notice they had some problems with remembering
- Questions and concerns about memory problems
- Making the most of memory: exploring and practising practical strategies
- Exploring how life has changed: worries and concerns about the future, adjusting to new situations
- Moving forward and being positive.

There are a number of criteria that should be considered when thinking through who would benefit most from attending the group. Please run through the checklist of criteria below, before discussing this group with the person with dementia and their close relative/friend.

Checklist of criteria (Please tick box)

- Does the person with dementia and their close relative/friend live in the _____ area?
(This group is restricted to those living in _____. We are looking to develop the group so it will cover a wider area of West _____)
- Is the person with dementia in the earliest stage of the illness? I.e. do they have an MMSE score of no less than 20
OR minor changes in their abilities, behaviour and cognitive functioning, an interest in engaging in daily activities and making the most of their memory? (People in the earliest stages of dementia are likely to benefit most from attending the group).
- Are the person with dementia and their close relative/friend able to get from their home(s) to the location of the group?
(We are able to book taxis to assist people in accessing the group). Does this person require taxi (circle): **Yes / No**
- Are the person with dementia and their close relative/friend committed to attending all, or the majority of, the seven group sessions?
- If the person with dementia and their close relative/friend satisfy all of the above criteria, are they aware of this referral?
Have they been given a leaflet and had the opportunity to ask questions about the group?
- Does the person with dementia or their close relative/friend have any physical difficulties e.g. mobility, eyesight, hearing, diabetes, epilepsy, cardiac, other? If yes, please list:

(We will not exclude people from attending the group on the basis of this information).

Details of the person with dementia and their close relative /friend

• Name of the person with dementia: _____ Date
of Birth: __ __/ __ __/ __ __

Address: _____ Tel
No.: _____

• Name of the close relative/friend (carer): _____
Date of Birth: __ __/ __ __/ __ __

Address: _____ Tel
No.: _____

• Referrer (name of person completing this form) _____ Contact Tel
No. _____

• What do the person with dementia and their close relative/friend hope to gain from attending this group?

Person with dementia:

Close relative/friend:

• Do the person with dementia or their close relative/friend have any further queries about this group/ Please state below.

APPENDIX 4

CARER QUESTIONNAIRES: Brief description of measures

The Dementia Quiz (DQ) (Gilleard & Groom, 1994): A 25 item questionnaire designed to assess knowledge of biomedical aspects of dementia, knowledge concerning health and welfare issues, and knowledge about caring for and coping with a person diagnosed with dementia. A score of ** is the maximum score for each subscale, a total score of ** on the quiz indicates good all round knowledge.

Generalised Self Efficacy Scale (GSES) (Schwarzer & Jerusalem, 1993): A 10 item questionnaire designed to assess optimistic self-beliefs to cope with a variety of demands in life and is adjusted to relate directly to the demands associated to the dementia. A score of 40 is the maximum, the higher the score the greater the level of self-efficacy.

Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983): A 14-item questionnaire designed to screen for anxiety and depression. Scores of 0-7 for anxiety indicate a normal symptom range; scores of 7 and above on the scale for depression indicate caseness; a score of 9 and above on the anxiety component is indicative of caseness. Caseness warrants further investigation.

The Machin Strain Scale-modified version (MSS) (Gilleard, 1987): A 13-item questionnaire designed to assess the level of strain involved in caring for an older person who is frail or disabled (including people with dementia). This scale assesses restrictions placed on the carer and their emotional responses in relation to their role as primary caregiver. 26 is the maximum score; the higher the score the greater the experience of strain. The literature suggests 14 as a cut off for significant experiences of strain.

PWD QUESTIONNAIRES: Brief description of measures

Index for Managing Memory Loss- adapted version (IMMEL) (Keady & Nolan, 1995): The IMMEL gives an account of the methods used to manage memory loss. These methods are separated into four types: Approach coping, Avoidance coping, creating an alternative perception of events and managing symptoms of stress. The index has 32 items for which respondent's rate whether each is used as a coping strategy, and if so how useful each strategy is on a scale of 0-3. There are eight items for each type of coping and the maximum score for each type of coping is 24. A higher score indicates greater use of a particular coping method.

Acceptance of Illness Scale (AIS) (Felton et al, 1984): This measure focuses on the extent to which respondents are able to accept their illness (dementia) without experiencing negative feelings or responses. It is an 8 item scale which respondents rate the extent to which they agree or disagree with statements about their acceptance/adjustment.

APPENDIX 5
CARER QUESTIONNAIRES

APPENDIX 6

QUESTIONNAIRES FOR PEOPLE WITH DEMENTIA

APPENDIX 7

FEEDBACK QUESTIONNAIRE

It is important for us to know whether you found this group to be helpful or not. This will help us to improve the way in which we run groups in the future.

Please take some time to fill in this questionnaire. We would like you to feel free to be honest about which aspects of the group were helpful and which aspects could be improved. You do not have to put your name on this form.

1. Overall how helpful did you find the group? (please circle)

Not helpful Somewhat helpful Helpful Very helpful

2. What did you find most helpful about the group?

3. Is there anything that we did not cover that you would like to be included?

4. How helpful did you find the handouts that were given out?

5. Have you made any changes as a result of attending the group? (please circle) YES NO

5a. What changes have you made?

6. Was it useful to have the group running for yourselves and a parallel group for your partners? Is there any other format for the group that you would prefer?

7. Do you have any other comments?

Thank you for taking the time to come to the group and to complete this questionnaire.

CHAPTER FOUR: LITERATURE REVIEW
Psychological trauma and road traffic accidents

Doctorate of Clinical Psychology
University of Hertfordshire

Sara B Rassool
Student Number: 05108127

Submitted: 9th November 2007

Word count: 5047

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SECTION 1:

Introduction

This review provides a summary of the literature concerning the psychological impact of road traffic accidents (RTAs). In section one; I shall give a brief description of what is meant by psychological trauma and accidental killing. I will then set the context of RTAs and consider the social back-drop of this everyday trauma. In section two, I will introduce posttraumatic stress disorder (PTSD), locate RTA trauma within this literature base, present some epidemiological findings and review the literature relating to mental health consequences associated with RTAs. In section three, I will describe some of the mainstream trauma models, including information processing, neurocognitive models and psychodynamic understandings. This will be followed by alternative models/theories including Personal Construct Theory and narrative approaches. In section four, I will consider the limited literature regarding the perpetrator's perspective after causing accidental death. The final section of this review will make recommendations for future research.

1.1 Key constructs:

1.1.2. Psychological trauma: The term 'trauma' stems from the Greek word meaning 'a piercing of the skin, a wound'. Freud (1920) used the word metaphorically to illustrate how the mind, being a protective shield akin to the skin, could also be pierced and wounded by experiences. The word trauma has become frequently used in modern western societies to mean a highly stressful 'event/situation' that overwhelms an individual's ability to cope (Horowitz, 1986; Janoff-Bulman, 1992; McNally, 2005). From this perspective, the traumatised individual feels emotionally, cognitively and physically overwhelmed. However, I wish to emphasise that, in my view, it is an individual's *subjective experience* that determines whether an event is traumatic, or not.

Pearlman & Saakvitne (1995, p.60) suggest that psychological trauma is the unique individual experience of an event or enduring conditions, in which:

1. The individual's ability to integrate his/her emotional experience is overwhelmed,
- or
2. The individual experiences (subjectively) a threat to life, bodily integrity, or sanity.

1.1.3 Accidental killing: For the purposes of this review, accidental killing or causing an accidental death is defined as a disastrous event that occurs suddenly, unexpectedly, without planning or intention and results in the death of a person (Kastenbaum & Aisenberg, 1979).

1.1.4 Road traffic injury: The World Health Organisation's (WHO) *World Report on Road Traffic Injury Prevention* (2004) defines a road traffic injury as fatal or non-fatal injuries incurred as a result of a road traffic crash. A road traffic crash is defined as a collision or incident that may or may not lead to injury, occurring on a public road and involving at least one moving vehicle.

1.1.5 Setting the context: RTAs

Britain's first motorised vehicle appeared on our streets in January 1896. In August 1896, a pedestrian was killed by a car travelling at four miles an hour, becoming the first of Britain's 430,000 road accident fatalities (Mitchell, 1997). In 2002, nearly 1.2 million people worldwide died as a result of a road traffic crash. This represents an average of 3,242 persons dying each day around the world (WHO, 2004). In Britain, the latest Government Statistics (2002) show that over three and a half thousand people die each year on our roads.

1. 2 The social back-drop to everyday trauma

Given the high numbers of deaths that are caused on our roads, these accidents and deaths are treated in a surprising manner. Whilst driving into work each morning I have become increasingly aware of the road traffic bulletins which provide us with information about accidents on the main roads, alongside road repair information and other difficulties on the road. The information is delivered in a fairly cheerful manner; often a woman and often with some pleasant music in the background. The aim of these bulletins seems to be to advise drivers to avoid certain areas, especially where there has been an accident, and emergency services are blocking the roads. These bulletins endeavour to keep the flow of traffic moving and prevent congestion. Whilst necessary, these bulletins strike me as being an odd way to present information which may represent that a person, or people, may have been killed or injured. In the delivery of this information, we seem to be disconnected from the aftermath of such events for those involved.

It would appear that accidents and deaths on the road have become part of our everyday lives. We are so bound up by the use of our vehicles that it seems as though we are expectant that such accidents and deaths will occur on our roads. As illustrated by my reflections on the road traffic bulletin, we seem to treat road accidents and deaths very differently to other potentially destructive events. This unusual social context provides a backdrop to the aftermath of fatal road accidents.

SECTION 2:

2.1. Posttraumatic Stress Disorder (PTSD): locating RTA trauma in the literature.

Research around trauma in the 1980's and 1990's reflected a dominant interest in what was then a new disorder: PTSD. The PTSD diagnosis first became officially recognised in the Diagnostic Statistics Manual of Mental Disorders, third edition (DSM-III; American Psychiatric Association, 1980) in 1980. According to the DSM-IV (1994), trauma involves witnessing or experiencing actual or threatened death or serious injury, or a threat to the physical integrity of oneself or others. The

experience of trauma constitutes the primary criterion for PTSD and the identification of a threatening event is thought necessary in the onset of the disorder (Kinzie and Goetz, 1996; Yule, 1999). The cardinal triad of symptoms recognised as PTSD include: re-experiencing, numbing and avoidance and hyperarousal. The International Classification of Mental and Behavioural Disorders (ICD-10) shares very similar criteria to the DSM-IV (1994). There appeared to be a shift in later editions of the DSM (DSM-IV, APA, 1994) whereby the nature of the PTSD stressor criteria had changed considerably. The earlier version (DSM-III, 1980) excluded road accident injuries; whereas the later criteria were much broader (McNally, 2003).

It is apparent that there are considerable differences in the long-term and short-term effects of different types of trauma. Attempting to distinguish between normative responses to trauma and pathological responses is an area of contention. Again, these apparent differences found in the empirical literature (Blank, 1993; Harvey and Bryant, 1995; Bryant & Harvey, 1998; McFarlane, Atchison and Yehuda, 1997; Pincus, Frances, Davis, First and Widiger, 1992) reflected a change in diagnostic categories outlined in the DSM-IV (APA, 1994). The addition to PTSD of a second trauma-related diagnosis, 'Acute Stress Disorder' (ASD) was included in the DSM-IV (APA, 1994) to describe 'pathological' responses to trauma occurring within the first 30 days of an event. Prior to this new category, the only other stress-related diagnosis available in the first month was the non-specific diagnosis of adjustment disorder.

PTSD appears to be the most investigated psychological 'disorder' resulting from trauma (Blanchard, Hickling, Taylor, Loos and Gerdi, 1994; Breslau, Kessler, Chilcoat, Schultz, Davis, Andeski, 1998; Fisher and Reason, 1988; Gerson, 2005; Giller, 2006; Green, 1994; Jeavons, Greenwood and Horne, 2000; Keane, Marshall and Taft 2006; Kuhn, et al. 2006; McNally, 2005; Ozer, Best, Lipsey, Weiss, 2003; Shalev, Freedman, Peri, Brandes, et al. 1998). However, despite the everyday occurrence of RTAs, my literature search has revealed a massively

disproportionate amount of research paid to the psychological consequences of large-scale man-made and natural disasters (Galea, Nandi and Vlahov, 2005; Koopman, Classen and Spiegel, 1994; Mellman, Randolph, Brawman-Mintzer, Flores and Milanese, 1992; North, Nixon, Shariat, Mallonee, McMillen, Spitznagel, and Smith, 1999; Whalley, and Brewin, 2007; Wilkinson, 1983) in comparison to everyday traumatic events such as road accidents. There are a number of well known edited books that are devoted to traumatic events and PTSD, such as 'The International Handbook of Traumatic Stress Syndrome' (Wilson and Raphael, 1993), conceptual and theoretical approaches to the sequelae of life events (Fisher and Reason, 1988), and issues of bereavement (Dickenson and Johnson, 1993, Stroebe et al 1993). Others offer practical advice for treatment and management following various personal crises (Parry, 1990), or following disasters (Scott and Stradling, 1992). McCann and Pearlman (1990), in their volume on adult survivors of trauma, discuss genocide, armed conflict, torture and crime. Yet, none of these writers seem to consider the trauma associated to RTAs. Thus, reflecting a lack of investigation and published work in this area. Fienstien (1993) suggests that the trauma associated with more commonplace events such as RTAs may be dismissed in the literature for no other reason other than that they are relatively frequent and the interest is dwarfed by the drama of major disasters.

Whilst diagnostic labels such as PTSD and ASD are useful tools to aid discussion and research amongst professionals in western psychiatry and psychology, this dominant medical model understanding and discourse is constantly critiqued (Johnstone, 2000; Slife, Wiggins, and Graham, 2005; Summerfield, 2001; Keane, et al., 2006). It is important to bear in mind that the etiology of most mental 'disorders' is largely unknown and psychiatric and mainstream psychological research remains particularly dependent on the principles and process of syndrome identification, thus centring on the diagnosis of psychological 'disorders'. Furthermore, there are considerable uncertainties about the validity of conditions like PTSD and ASD (Bowman, 1999; Marshall et al, 1999; McNally, 2003; Summerfield, 2001). This is perhaps due to their controversial beginnings. PTSD

was one of the few diagnoses that seemed to have been socially and politically constructed; it was a legacy of the American war in Vietnam (Summerfield, 2001). PTSD was therefore an invented, rather than a discovered, phenomenon.

2.2 Epidemiology:

Large-scale epidemiological surveys, such as the Australian National Survey of Mental Health and Well-Being (Creamer, Burgess and McFarlane, 2001), suggest that the risk of developing PTSD after trauma is 8-13% for men and 20-30% for women (Kessler, Sonnega, Bromet, Hughes and Nelson, 1995) with a 12 month prevalence of 1.3% to 3.9%. In the UK, NICE guidelines suggest that 25-30% of people who have experienced a traumatic event go on to develop PTSD, thus creating a huge burden on society.

Serious RTAs, industrial accidents and domestic household accidents are very frequent events that are regarded as traumatic because they can be associated with loss, threat and fear of dying. Further, epidemiological studies in the USA (Breslau, Kessler, Chilcoat, Schultz, Davis, Andreski, 1998; Kessler, Sonnega, Bromet, Hughes and Nelson, 1995) suggest that lifetime prevalence of exposure to an accident is estimated to be 25% for men and 13% for women. These studies have revealed that PTSD is one of the most prevalent categories of mental illness in the community, with RTAs emerging as the single leading civilian cause of PTSD (Blanchard and Hickling, 1993). For the majority of RTA survivors, acute stress symptoms resolve within a few weeks post-accident. However, there appears to be a considerable number of people (10% to 30%) that display PTSD symptoms at 6 to 18 months post-accident (Ehler, Mayou, Bryant, 1998; Koran, Arnon, Klien, 1999; Silove et al., 2003).

2.3 Mental health consequences associated to RTAs

Research in the field of trauma has shown that accidents can lead to the onset of an array of psychiatric disorders, not only PTSD and acute stress disorder (ASD).

Depression, anxiety and specific phobias, substance misuse, and insomnia have all been implicated in the psychological aftermath of RTAs, (Blaszczynski, 1998; Kuhn, Ehler, Rumpf, Backhaus et al. 2006; Marshall, Spitzer, Liebowitz, 1999; Mayou, Bryant and Ehlers, 2001; Parker, 1977; Schnyder, Moergeli, Trentz, Klaghofer and Buddeberg, 2001; Shalev, Freedman, Peri, Brandes, et al. 1998).

Many have attempted to identify predictor's of psychiatric morbidity following RTAs. Variables examined have included: psychiatric history (Blanchard et al., 1996; Koran et al. 1999); demographic factors (Blanchard et al, 1996; Ehler, et al., 1998; Green, 1994); fear of dying (Blanchard et al, 1995); cognitive factors such as perceived threat (Schnyder et al, 2001); and the presence of ASD and/or depression and anxiety (Koopman, Classen, Cardena, Spiegel, 1995; Silove, Blaszczynski, Manicavasager, Tyndall, Petridis & Hillman, 2003). However, none of these factors seem to have emerged as a consistent predictor of later psychiatric morbidity (Blanchard et al., 1996; Ehlers at al., 1998; Jeavons, Greenwood and Horne, 2000).

Despite the knowledge and research that suggests a high prevalence of mental health consequences after serious accidents, the knowledge base is still limited and inconsistent (Blaszczynski, et al., 1998; Kuhn et al. 2006). Blaszczynski, et al's, (1998) methodological review of twenty seven studies examining psychiatric morbidity following RTAs found high variations in outcome, particularly in studies specifically investigating PTSD; ranging from 100% prevalence (Kuch, 1985) to 1% prevalence (Malt, 1988). Blaszczynski et al., (1998) suggested that many of the larger scale studies have relatively small sample sizes, short follow-up periods, high attrition rates and poor quality psychometric measures. Most importantly a significant proportion of the studies reviewed used participants who were seeking medicolegal assessment. The influence of medicolegal factors and compensation claims may affect the reporting of PTSD and other mental health symptoms.

Throughout my review of the literature, I have observed an important limitation: the predominant use of clinical populations, who are largely recruited from hospital A&E Departments. Whilst this may limit a self selection bias, we are presented with a distorted picture made up of only those that are admitted to A&E due to physical injuries. This creates a huge sampling bias.

Furthermore, there appears to be a lack of sample information. There were very few articles that distinguished between non-fatal RTAs and those RTAs where a fatality had occurred. Almost all identified participants as victims. It is possible that the reason for the lack of recruitment of perpetrators is due to the popular time of recruitment, i.e: immediately following the accident at A&E. Perhaps those perceived as causing accidents are dealt with immediately after the accident by other agencies such as the police, as is often the case in paedestrian fatalities and so may not be represented in samples unless they sustained physical injuries requiring hospital treatment. I found only three articles where there had been fatalities and where the drivers were explicitly reported to have been included in the research (Chesser, 1981; Foeckler, 1978; Harvey and Byrant, 1998). I will discuss these papers in more detail in the perpetrator's perspective section below.

Overall, most of the literature reviewed considering mental health difficulties in the aftermath of RTAs has been written from the perspective of survivors and/or victims and their families and friends. The vast majority is collected through quantitative methods. Despite such methods being essential for documenting the scale of death and injury, these methods tell us very little about the emotional and psychological toll of road traffic crashes.

There appears to be a resounding absence of literature concerning the perpetrator's perspective in research studies. This inevitably contributes further to a distorted picture of experiences in the aftermath of RTAs. The absence of this perspective is worrying when we consider how clinical models are derived. It appears that clinical models are often derived from clinical samples (those who

seek treatment) rather than from those exposed to a similar event (Bowman, 1999). This raises the question about the experience of those who do not attend hospitals? Nonetheless, these models provide conceptual frameworks to help us to understand psychological trauma and guide treatment.

SECTION 3:

3.1 Mainstream models and adjustment after traumatic experiences

The experience of trauma raises a number of issues for theorists. Yule (1999) curiously points out that following a content analysis of psychiatric diagnostic manuals, PTSD was one of the few so-called 'disorders' that had a specific 'external' aetiology, and thus, could happen to anyone of us at any given time. Furthermore, there appears to be a huge spectrum of different reactions which people experience and report following a traumatic event. Some people seem to endure the most horrendous experiences psychologically unscathed, whereas others have long-term posttraumatic responses that last years, even decades and may experience profound changes in their personality (Adshead and Ferris, 2007; Epstein, 1990). Others appear to cope well after a trauma but may experience late onset or delayed PTSD (Byrant & Harvey, 2002; Neria, Nandi and Galea 2007; Van Dyke, Zilberg & McKinnon, 1985).

The sheer indiscriminate nature of traumatic events and the large variation of individual differences in relation to the response to such events has lead traumatologists to invest a whole host of variables to try and explain and define the nature of posttraumatic reactions. For example: elements of the event, such as whether individuals were bereaved and the nature of that bereavement, such as sudden deaths through unnatural causes, accidents or suicide (Joseph, Yule, Williams and Hodgkinson, 1994; McNeil, Hatcher and Reubin, 1998, Zisook, Chentsova-Dutton, Shuchter, 1998); or the person's ability to express emotions in relation to the event (Joseph, Dalgleish, Williams, Yule & Hodgkinson, 1995). Others have examined comorbid or predisposing factors as discussed

earlier in relation to road accidents (Blanchard et al., 1996; Green, 1994); Kuhn, et al. 2006; Silove, et al., 2003).

The combination of intra-individual, social and event variables has led to the development of numerous psychosocial frameworks within which PTSD can be understood (Green, Wilson and Lindy, 1985; Joseph, William and Yule, 1997). Whilst these models help to bring order to the high volume of literature and research, they remain very descriptive. Yule (1999) and Brewin and Holmes (2003) provide extensive reviews and critiques describing how a parallel strand of research has been necessary which seeks to explain an explanatory model of *how* the various factors interact with each other and *how* the different reactions to trauma become manifested.

3.1.1 Information processing theories:

Yule (1999) and Brewin and Holmes (2003) review a number of theories, beginning with Horowitz's (1975, 1979) formulation of the stress response system, a model that was influential in the development of the DSM-III (APA, 1980) PTSD classification. Whilst Horowitz (1975) drew upon psychodynamic and information-processing concepts, cognitive information processing models have since dominated the literature. Cognitive theories that have focused mainly on the traumatic event itself, rather than on its wider personal and social context, have been termed "information-processing" theories (Chemtob, Roitblat, Hamada, Carlson, and Twentyman, 1988; Creamer, Burgess, and Pattison, 1992; Foa, Steketee, and Rothbaum, 1989; Litz and Keane, 1989).

The central idea is that there is something special about the way the traumatic event is represented in memory and that if it is not processed in an appropriate way, psychopathology will result. Some of these models include: Foa's Fear Network (Foa and Kozak, 1986; Foa, Steketee and Rothbaum, 1989; Foa, Zinbarg and Rothbaum, 1992); Janoff-Bulman's (1992) Theory of Shattered Assumptions; Chemtob, Roitblat, Hamada, Carlson, and Twentyman's (1988) Cognitive Action

Theory; Creamer, Burgess and Pattison's (1992) Information-Processing Theory; Brewin, Dalgleish and Joseph's (1995) Dual Representation Theory; and Dalgleish and Power's (1995) Schematic, Propositional, Associative and Analogical Representational System (SPAARS) .

These models collectively, have produced a vast amount of empirical evidence which underpins the current NICE PTSD treatment guidelines that inform current clinical practice (Gerson, 2005). The NICE guidelines suggest trauma-focused cognitive behavioural therapy as the treatment of choice (DoH, 2005).

3.1.2 Neurocognitive model:

Born out of the informational processing theories, Shapiro (1989) proposed a further development in the processing of trauma. Eye movement desensitisation and reprocessing (EMDR) is based on the notion that disturbing material can be directly facilitated at a neurophysiological level involving a variety of dual attentional tasks. Yule, (1999) suggests that a by-product of bilateral re-processing at a neurophysiological level is cognitive and emotional well-being. It is worth noting that, despite the growing evidence base, this is still a relatively new area of research. Nonetheless, the NICE PTSD treatment guidelines support the use of EMDR, but not as strongly as CBT.

3.1.3 Psychodynamic understanding:

The concept of psychological trauma has evolved over the 20th century. From a psychodynamic perspective, a traumatic event is one that breaks through, or overrides the mind's filtering process and floods the mind with a degree of stimulation that it cannot manage. There is a colossal disruption in functioning, amounting to a kind of breakdown of the defence organisation, leaving individuals vulnerable to intense overwhelming anxieties from internal sources which have been provoked by an external event (Garland, 2000).

The associated treatment guided by this conceptual model is long term psychotherapy. The aim of which is to make the unconscious conscious and resolve conflicts that the current trauma may have unearthed.

3.2 Alternative models relating to adjustment after traumatic experiences

Social constructionist and social constructivist approaches offer an alternative to mainstream empirically based models. The thrust to both of these approaches is to emphasise the notion that we are not merely passive recipients; we are active agents who seek and create meaning (Bowman, 1999).

3.2.1 Personal Construct Theory (PCT):

This theory examines how people make sense of the world and how they predict the future based on their previous experience. One individual's constructs will therefore always be different to the next and will be based upon their particular interpretation of an event. Therefore, the concept of construing parallels with the appraisal processes ie: 'causal attributions' as described by the cognitive theorists (Janoff-Bulman, 1992).

The theory postulates that psychological difficulties can arise both in terms of the structure of an individual's construct system and the content of their constructs. For example, if an individual's constructs are 'tight' or impermeable they are unlikely to be able to re-construe in the face of a life-changing event such as causing an accidental death. According to PCT, psychological disorder such as depression or anxiety is considered to be '*a failure to revise constructions in response to invalidation*'. (Winter, 1992).

3.2.2 Narrative approaches and trauma

Narrative theorists and practitioners take an alternative view of trauma. They place great emphasis on the stories that people tell that represent their lives. Narrative approaches are interested in how individuals construct their sense of self and meaning (Crossley, 2000). After experiencing a traumatic event, it is not solely the internal explanations of trauma as characterised by most mainstream theorists (i.e.: the information processing theories), but also the wider cultural and community discourses that are considered as important. These discourses help to create our internalised views of society which are drawn upon to shape our sense of self (Crossley, 2000; Parker, 1990). White (2004) writes about his work with traumatised individuals and describes a 'single story' phenomena from which often emerge themes of loss and tragedy. Following trauma, it is as if people feel totally trapped in a single dimension of their life, one that predominantly features futility, a sense of hopelessness, emptiness, shame, depression and despair. He goes on to describe how these stories are quite thin and disjointed and often exclude any awareness of the valued themes that are reflected in the 'preferred self' (White, 2004).

According to this approach traumatic events and mental health problems can lead to a radical sense of disorientation and the breakdown of a coherent life story or an inadequate narrative account of oneself or a life story that has gone awry (Howard, 1991; Polkinghorne, 1988; Showalter, 1997). In line with this view, some psychotherapists using narrative approaches would characterise the practice of psychotherapy as an 'exercise in story repair' (Dwivedi, 1997; McAdams 1993; Mair, 1989; Schaffer 1992; Spence, 1982; White and Epston, 1990). Together, the client and the therapist enter a process of re-authoring a life through co-authoring it. They create 'a dialogue' through which the person's (problematic) life story is transformed (Gergen, 1996; McLeod, 1997; McNamee, 1996a; Polkinghorne, 1988; White, 2004). It seems that within this approach there is a place for posttraumatic growth (Tedeschi, Park, and Calhoun, 1998).

SECTION 4:

4.1 Causing accidental death: the perpetrator's perspective

4.1.1 A note on terminology:

Despite the seldom mention of those that cause accidental death, the terms perpetrators and, in some cases, killers seem the most frequent to emerge from the road accident literature. I will use the term perpetrator to describe the perspective of those who have caused an accidental death.

4.1.2. Review of the literature from the perpetrator's perspective

The academic literature concerning the perspective or indeed the inclusion of perpetrators of RTAs appears very limited. As mentioned previously in the mental health consequences section, only three papers explicitly identified drivers involved in RTAs where deaths occurred (Chesser, 1981; Foeckler, 1978; Harvey and Byrant, 1998). Due to the word constraints of this review i will only give a brief summary of each paper. Foeckler's (1978) study, 33 drivers were recruited through police records at 6 months to 11years after they were in an RTA that involved a fatality. Their findings suggest that 33% exhibited disturbed thinking, depression and nightmares; 36% reported that they had difficulty talking about the accident; 12% reported being fearful of having another RTA, whilst 48% were fearful that someone they loved might be hurt or killed in an accident.

In the second study, Harvey and Byrant (1998) recruited 92 participants from a possible 222 successive RTA admissions to a major trauma hospital. Individuals who were excluded from the study included: 8 non-English speakers; 11 individuals who had been prescribed narcotic analgesia for the first 4 weeks posttrauma; 98 individuals who had sustained traumatic brain injury; and 13 individuals who were discharged before the assessment could take place and could not be contacted post trauma. From the 92 remaining participants, only 3 were identified as having been involved in RTAs in which fatalities occurred. The findings suggested that all

three of these people were diagnosed with ASD. Unfortunately, at the 6 month follow-up two of the individuals who had been involved in a fatality declined to participate. The remaining participant involved in a fatal RTA was diagnosed with PTSD. I was left feeling very curious about why drivers were so under represented in the study, and why even those who began the study later declined?

Although limited, these quantitative studies suggest that perpetrators do experience PTSD and ASD. However, they tell us very little about the experience of psychological distress of drivers who have caused deaths. This lack of depth is largely a product of the studies' empirical methodological approach. These papers contrast with the third paper (Chesser, 1981), which tries to convey a richer account of the experiences of people who caused an accidental death. Chesser (1981) drew upon a semi-structured interview and postal questionnaire methodology over a two year period (n=10, only 4 of which related to RTAs). The results, obtained through content analysis, identify a number of themes, including: the role of supportive persons; changes in personal happiness and family organisation; effects on religion; and family relations. Chesser (1981) concludes that the study's results reinforce the important role that family members, friends and the community play in helping traumatised people manage stress. Despite the poor methodological explanations and lack of data analysis procedure the paper reveals important qualitative experiences of people that have killed another person.

4.1.3 Review of non-academic literature

Given the lack of academic research into the experiences of accidentally killing, I have turned my attention to sources of relevant information found in the literary world and media. Writers, such as Kelly Connor (2004) and the poet Gregory Orr (2002) tell the story of their personal experiences of accidental killing. Orr (2000) described violent trauma as shredding the web of meaning and destroying a sense of connectedness to others and the world. He describes the task of the trauma victim as making life worth living by re-weaving the web of meaning in life and

reconnect to the world. Orr's (2000) insight lays bear the importance of such experiences for psychological investigation and knowledge:

Connor's (2004) book, 'The Aftermath of Accidental Killing' was published at the same time as the WHO and the World Bank launched their *World Report on Road Traffic Injury Prevention* (WHO, 2004). This document reflected solely the perspective of the victims of RTAs. It included a moving publication called 'faces behind the figures' which described personal accounts of the aftermath for family members of fatal RTAs. However, Conner's (2004) publication offered a story relating the other side of the coin: 'the perpetrators perspective' and thus, provoked some media interest. I have revisited several radio interviews with Kelly from national shows (BBC Radio Two, 2006; BBC Radio Five, 2006) where the public were encouraged to phone in and share their stories. A brief thematic analysis of the phone-in stories revealed a number of common themes. These included: deep feelings of shame and guilt, carrying a dark secret, grief, panic attacks, depression, nightmares, alcohol abuse, responsibility, needing to be punished and having little support.

Collating the themes that have emerged from the work of Chesser (1981), Connor (2004), Orr (2002) and those voiced in the radio phone-ins, would suggest that exploring peoples' experiences of accidentally killing another person is of interest to clinical psychology. Extrapolating from the research looking at victims and survivors experiences following RTAs, it seems plausible that perpetrators of such accidents have similar, if not worse, experiences. Yet, there remains a huge silence amongst this group of people, who are likely to be suffering psychological distress.

SECTION 5:

5.1 Recommendations for future research

As discussed, there has been a vast amount of research done in the wider area of PTSD. However, there has been substantially less relating to trauma experiences

and RTAs. From this small amount of literature there appears to be a one-sided story emerging, ie: that of victims, families and friends. As health care professionals, we are beginning to understand this group of people and thus, provide the appropriate care and support they need. However, this review and my informal enquiries amongst fellow health care professionals revealed little contact, knowledge or understanding of those who have accidentally killed. The scarcity of literature is surprising if one estimates that the number of people involved in accidentally killing another person may be almost as great as the number of people who have died as the result of an accident. Since Chesser's (1981) publication in which she identifies a lack of research in this area of trauma, there still appears to be a significant gap in the literature that explores the perspective of those that have accidentally killed.

Furthermore, the vast majority of studies concerning families, friends and survivors use quantitative methods. These methods lack the informative richness and depth of alternative qualitative approaches such as interpretative phenomenological analysis (Smith, 2004). First-hand accounts deepen awareness of the impact and repercussions of road traffic crashes and provide a powerful understanding of people's lived experiences following a fatal RTA. Giving a voice to this group of people (perpetrators) will contribute and begin to address this identified gap in the trauma and RTA literature and ultimately stimulate interest for further research.

6. References

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APPENDIX 1: LITERATURE REVIEW STRATEGY

1. A preliminary search for review papers using Annual Review Database and Cochrane database was undertaken using the following search terms:

- Posttraumatic stress disorder
- PTSD
- Trauma
- road traffic accidents
- motor vehicle accidents
- victim
- survivor
- perpetrator
- accidental death
- accidental killing

2. From relevant papers, an initial set of search terms and MeSH terms were developed. MeSH terminology ensures that relevant information which may use different terminology for the same concept is retrieved. The search terms have been grouped below to make viewing easier, they include:

- posttraumatic stress disorder, PTSD, acute stress disorder, trauma, psychological trauma, traumatisation, traumatic events, mental health, mental illness.
- Theories, models, conceptual frameworks
- Road traffic accidents, motor vehicle accidents, RTA, MVA, car crashes, vehicle crashes, pedestrian accidents,
- Victim, survivors, perpetrator, drivers

- accidental death, accidental killing, unintentional killing, fatalities, serious accidents, pedestrian fatalities
3. Boolean operators (AND, OR, NOT) were used to manage inclusion and exclusion of the search terms for each search engine.
 4. The initial literature search was targeted at publications between 1997-and 2007. However, due to the limited number of relevant articles retrieved, those written prior to this and those that had been cited within the acquired literature were also sourced.
 5. The search terms that seemed to identify the most relevant papers were used as the main search terms for the systematic review of the literature.

4. Systematic Search:

The final set of search terms were ordered in different combinations using Boolean terms and applied to each database.

- Posttraumatic stress disorder, PTSD
- Theories, models
- Road traffic accidents, motor vehicle accidents, RTA, MVA, car crashes, vehicle crashes, pedestrian accidents,
- Victim, survivors, perpetrator, drivers
- accidental death, accidental killing, unintentional killing, fatalities, serious accidents, pedestrian fatalities

The databases used in the review include:

- Annual reviews
- Cochrane Library
- HMIC (contains three health management bibliographic databases)
- IBSS (International Bibliography of the Social Sciences)
- National research Register (lists current NHS research)

- PsycINFO (psychological literature data base)
- Scopus (contains articles relevant to psychology, social sciences and life sciences)
- Web of Science (Science Citation Index (SCI and Social Sciences Citation Index (SSCI))

5. Reference list searches:

Reference list searches were conducted from those papers obtained and deemed most relevant. Emerging relevant papers were sourced to ensure a thorough review of the literature.

6. Citation alerts:

Alerts were set up on the above databases to detect new relevant publications.

7. World Wide Web searchers:

- Internet search engines such as 'Google' and 'Google Scholar' were used to search for additional relevant material. These helped to source media and reveal non-academic literature
- The Department of Health and World Health Organisation websites were visited for relevant information and linking publications.
- Known sites such as kellyconnor.com (developed to bring awareness to the experiences of people who accidentally kill) were visited to access any relevant information.

CHAPTER FIVE: DOCTORATE THESIS

Experiences of Causing an Accidental Death: An Interpretative Phenomenological Analysis Study

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

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1. ABSTRACT

Accidentally killing or feeling responsible for another person's death constitutes a traumatic event that is unique from any other traumatic stressor. Considering the frequency of incidents such as deaths resulting from road traffic accidents (RTAs), it is surprising that the academic literature regarding those who have accidentally killed is almost none existent. This study therefore aimed to gain an insight into the lived experiences of drivers who have caused an accidental death.

Five participants were recruited through an on-line advertisement; all were drivers directly involved in a RTA that occurred suddenly, unexpectedly, without planning or intention and resulted in the death of a person. An interpretative phenomenological approach was used to analyse data collected through semi-structured interviews.

Three main themes emerged from the participants' accounts: trying to make sense of a life changing moment; struggling to cope with the trauma of causing a death and a changed sense of self. These findings are discussed in relation to the relevant literature. Clinical implications, methodological limitations and directions for future research are presented. The study provides a valuable insight for any professional working with people who have caused, or feel responsible for, an accidental death. It is hoped that this study will be a catalyst for discussion and future research.

2. INTRODUCTION

...it's sort of like being stuck in a trap....a bear trap, or stuck in a pit, and really finding ways to live there.....stuck in a dark, smelly, difficult pitforaging around for anything that will keep you alive, but not really being able to get out of it,...and sort of finding that there might actually be a way to get out, is sort of the journey I've taken over the last twelve years in very simple terms. And that last realisation has only been in the last few months really, on the basis of over a decade. Ben

I came to this research with the view that the experience of accidentally killing is perhaps one of the most difficult circumstances that anyone could experience. It was important for me to find a way of allowing this often unspoken experience to be expressed. This thesis therefore opens with the words of one of the participants, Ben. This verbatim extract shows how he managed to find the words that describe *his* experience of accidentally killing another person.

In the apparent scarcity of more formal psychological accounts of this type of experience, I have turned my attention to those who have expressed such experiences through other genres such as autobiographical literature. George Orr (2002), author and poet, describes his experiences of accidentally causing the death of his sibling as follows:

Violent trauma shreds the web of meaning. It destroys all the threads of relationship that link the hurt self to the world to other people and objects, or to nature, or even to the inner world of its own feelings. The real task of a trauma victim - the task that makes life worth living again - is to re-connect the self to the world. To do that, you need to re-weave the web, to risk the spinning of new threads until they form a sustaining pattern that the self can inhabit (Orr, 2002, 'The Blessing: A Memoir'. pp.135).

Through this extract, Orr vividly describes how one's assumptions about the world, relationships and sense of self are affected and thus demonstrates the potential

devastation caused to the individual who has accidentally killed. Both extracts depict insights, which highlight the importance of such experiences for psychological investigation and knowledge.

In this opening chapter, I will discuss how I as the researcher, became interested in the experiences of people who have caused or feel responsible for accidentally killing another. My epistemological position, situated within a social constructionist paradigm, will be declared before a definition and discussion of some key constructs such as 'accidental killing' and road traffic fatality in relation to history, statistics and law. Next, psychological trauma, including epidemiological studies relating to road traffic accidents (RTA), will be reviewed. Academic and non-academic literature specific to drivers who cause accidental deaths (AD) will be considered, concluding with the study's rationale and aims.

2.1 My position as researcher

My interest in the experiences of accidental killing has emerged from an interest in what I have termed 'silent stories'. Through history personal accounts of sexual abuse, incest and torture have become more researched and have received increased social acknowledgement through media coverage. This process facilitates a sense of permission to speak out and share stories of this nature. It is through the sharing of stories that we re-author ourselves and integrate our life experiences (White, 2004; Sarbin, 1986). This raised my interest into other 'silent stories' in society, why they remain silent, and how they move from a silent arena to one in which they can be talked about.

Speaking openly about this type of experience became apparent when Kelly Connor presented a workshop describing her experiences of causing an accidental death as part of the DClinPsy Programme at Hertfordshire. Her story resonated with my experience many years ago, where a friend had caused an AD whilst

driving. I recall this being an incredibly distressing time and thinking that such a tragedy can happen to any of us.

Despite the distressing nature of such an experience, our natural curiosity often leads to questions of culpability; that is, who deserves blame. This prevailing social attitude is shaped by the growing litigation culture and our culture's construction of morality and/or what constitutes 'the good' (Taylor, 1989). Taylor (1989) suggests that our sense of morality and our sense of self are inextricably linked and that one of our basic aspirations is to feel connected to what we see as 'good'. By identifying those deemed blameworthy, we create a divide, a distance from what society constructs as 'bad', in turn providing a continuum on which to judge our own sense of self in relation to 'the good' and 'the bad'.

The visions of 'good' and 'bad' are culturally bound and made available to us in various forms, such as the media and/or governing institutions like the judicial system. We are often confronted with media reports that deliver notions of good and bad packaged in stories of trauma, loss and litigation. Yet, the needs of those that find themselves at the very centre of distressing experiences such as a fatal RTA are often not considered. In their judgements of what is good and bad, Taylor's argument suggests that people have possibly lost the notion of 'tragedy' and 'empathy'. Instead, the terms, 'marginalised' and 'stigmatised' come to mind; concepts all too familiar within mental health. Driven by the lack of academic understanding and compassion for people who have caused or feel responsible for an AD, I believe that this is a valuable project that has the potential to help develop a better understanding of this complex area of human distress. I hope that this research will begin to bring this silent story into an arena in which it can be told.

As described, I came to this project with my own history, values and beliefs, which has led me to write in the first person rather than 'the researcher' (Webb, 1992). My own experiences will inevitably colour the construction of this research. Although aiming to demonstrate a transparent process through reflection (Sword, 1997), the

researcher's active role is supported within a qualitative epistemology and social constructionist/constructivist theoretical framework (Smith, 2008, Burr, 2003).

Research from a social constructionist approach centres around the social construction of realities; the importance of the social meaning of accounts and discourses. Constructivist approaches are also interested in how human experiences are informed and shaped by social processes. Both of these theoretical orientations lend themselves to qualitative methodologies (Burr, 2003; Augustinus and Walker, 1995) and provide a good fit for investigating the experiences of people who have accidentally killed.

The following section outlines some key constructs such as accidental killing and how RTA fatalities sit within a historical, social and legal context.

2.2 Key constructs

2.2.1 Accidental killing

For the purposes of this study, accidental killing or causing an accidental death (AD) is defined as a disastrous event that occurs suddenly, unexpectedly, without planning or intention and results in the death of a person (Kastenbaum & Aisenberg, 1979).

2.2.2 Road traffic fatalities: History, statistics and law

Britain's first motorised vehicle appeared in January 1896. In August 1896, a car travelling at four mph killed a pedestrian, becoming the first of Britain's RTA fatalities (Mitchell, 1997). The Department for Transport (DfT) (2005) suggest that human fatalities, or those killed, are casualties who sustained injuries causing death less than 30 days after the accident. In 2002, nearly 1.2 million people worldwide died as a result of RTAs, representing an average of 3,242 persons dying each day around the world (WHO, 2004). Since 1951 when RTA statistics first became formally recorded in Britain, through to 2004, 302,771 people were killed in accidents on Britain's roads (DfT, 2006). The latest Government Statistics

(2006) suggest that 3,172 people died in 2006 on our roads, equating to nine deaths everyday (DfT, 2006).

Undoubtedly a number of these deaths are caused by 'dangerous driving' (DfT, 2008), or negligence such as drink driving and speeding, while others are simply due to misfortune. Some result from momentary lapses of concentration, or circumstances such as a child running out into the road. Under British Law, these instances may be considered as 'driving without due care and attention' or 'driving without reasonable consideration of other road users' (DfT, 2008). Such road traffic charges may be issued alongside a coroner's court verdict of AD.

Given the proportion of fatalities on British roads, it is conceivable that for a large number of these deaths there are drivers who found themselves in a disastrous situation that occurred suddenly, unexpectedly, without planning or intention, resulting in the death of a person for which they may feel responsible. Despite extensive recording of Government statistics, they tell us very little about the psychological sequelae and consequences for quality of life for those drivers that survive RTAs, particularly those viewed as 'perpetrators' of such deaths. To shed some light on this topic, I will next discuss our understandings of psychological trauma and the mental health consequences associated with RTAs.

2.3 Psychological trauma and the mental health consequences of road traffic accidents

There have been a number of significant developments in the diagnosis of posttraumatic stress disorder (PTSD), including the recognition of RTAs as a causal factor for the onset of PTSD. (See Rassool, 2007 for an overview of PTSD and related theoretical conceptualisations of adjustment following trauma). Despite the inclusion of RTAs in the diagnosis criteria, it seems that large-scale traumatic events continue to be widely researched and documented. Numerous texts are devoted to diagnostic classifications such as PTSD (eg: Wilson and Raphael, 1993; Fisher and Reason, 1988; Dickenson and Johnson, 1993; Scott and Stradling,

1992). However, there is a paucity of research which considers the traumatic responses and bereavement associated with smaller-scale disasters such as RTAs. This perhaps demonstrates the lack of investigation and published work in this area. Fienstien (1993) suggests the trauma and distress associated with more everyday events such as RTAs may be overlooked in the literature because they are relatively frequent and overshadowed by the drama of major disasters.

Whilst large-scale disasters appear to dominate academic writing, epidemiological studies suggest a different picture. For example, Breslau, Kessler, Chilcoat, Schultz, Davis, Andreski (1998); Kessler, Sonnerga, Bromet, Hughes and Nelson (1995) propose that PTSD is one of the most prevalent mental diagnoses in the community, with RTAs emerging as the single leading civilian cause of PTSD (Norris, 1992).

There is a small body of evidence that has investigated an array of psychological disorders, which are implicated in the psychological aftermath of RTAs, including: PTSD; Acute Stress Disorder, anxiety, depression, specific phobias, insomnia and substance misuse (Kuhn, Ehler, Rumpf, Backhaus *et al.* 2006; Mayou, Bryant and Ehlers, 2001; Schnyder, Moergeli, Trentz, Klaghofer and Buddeberg, 2001; Shalev, Freedman, Peri, Brandes, *et al.* 1998; Parker, 1977). (See Rassool, 2007 unpublished, for a literature review). Much of the research has a quantitative orientation, which supports these more formal classifications of psychological distress. In turn the evidence base appears to have led to the production of manualised cognitive behavioural treatment programs such as 'How to overcome your Motor Vehicle Accident' (Hickling and Blanchard, 2006).

However, the literature and research on which such evidence based treatments are derived appear biased towards those considered as surviving 'victims' and the 'victims' families, rather than those drivers causing an AD. The possible reasons for this are discussed later. Nonetheless, the absence of knowledge and evidence from the driver's perspective inevitably contributes to a distorted experiential picture

of the aftermath of RTAs. The absence of this perspective is concerning in light of how clinical models are derived. (See Rassool, 2007 for a more detailed critical review of RTA studies). Regardless of the dearth of research considering the experiences of drivers having caused an AD, I shall next consider those few studies that have acknowledged this perspective.

2.4 Drivers who cause an AD: A literature review

An extensive literature review has revealed only three papers explicitly examining the perspective of those causing or feeling responsible for an AD (Foeckler, Garrard, Williams, Thomas, Jones, 1978; Chesser, 1981; Lowinger and Zoloman, 2004). A fourth study conducted by Harvey and Byrant (1992) also identified three drivers (from ninety-two participants) who had been involved in fatal RTAs. However, two of the three drivers later withdrew from the study (see Rassool, 2007 for a detailed review of Harvey and Byrant's, 1998 study), thus making their findings limited in relation to drivers who have accidentally killed.

Lowinger and Zoloman (2004) investigated the constructs of guilt and shame in relation to drivers having caused death and subsequently charged with 'reckless driving'. In their study of 38 drivers who had caused RTA fatalities and 37 matched controls, they suggested that drivers who accidentally cause the death of another person are a high-risk group for PTSD and accident-related guilt. Their findings also indicate that PTSD and guilt are associated with the severity of the punishment, degree of responsibility the driver assumes for the accident and the driver's sense that he/she could have prevented the accident.

Based on Lowinger and Zoloman's (2004) findings, it could be hypothesised that shame/guilt experiences may cause cognitive dissonance, that is, if two or more opinions, attitudes, pieces of knowledge or values within an individual differ (Festinger, 1957). As identified by Taylor (1989) most of us believe that we are fairly good people. However, the responsibility for the death of another has a high propensity for one to consider oneself as 'bad'. Resuming an internal harmony towards consonance would mean believing that we were not responsible for a

death, a difficult and in some cases impossible feat, thus resulting in the presence of dissonance, which is psychologically uncomfortable.

Foeckler, Garrard, Williams, Thomas and Jones' (1978) study appeared to be particularly relevant to the current study. Consequently, their findings will be described in detail. A commentary of thematic similarities and differences with Harvey and Byrant's (1998) study and Chessser's (1981) study will also be provided. In the latter study, Chessser (1981) described the experiences of four drivers (from ten participants) who had caused an AD.

Foeckler *et al.* (1978) investigated 33 American drivers at 6 months to 11 years after they were involved in a RTA involving a fatality. The study explored drivers' experiences of causing a RTA death, regardless of whether they were at fault. The purpose of the study was to determine what, if any, crisis intervention was needed for such drivers. It is notable that this paper was written in the context of clinical change regarding the treatment of PTSD. At that time, an empirical evidence base was beginning to emerge in support of early debriefing practices. In contrast, the recent evidence base for the treatment of PTSD does not support such practices (NICE, PTSD 2005).

Regardless of the study's aims and agenda, it reported some interesting findings. They suggested that for most drivers, the accident had long lasting 'impressions' and 'strong emotional responses' evident six months to eleven years after the accident. Chessser (1981) reported similar findings. Foeckler *et al.* (1978) reported that the predominant affective response immediately following the accident was upset and sadness (76%). Others included feeling afraid, fearful, confused, depressed and anxious. The reported long-term responses included sadness, depression, upset and confusion. However, 13 of the 33 drivers reported no long-term affective responses. They also suggest that 33% exhibited disturbed thinking, depression and nightmares, persisting one month to several years after the accident; 36% reported having difficulty talking about the accident; 12% reported

being fearful of having another RTA, whilst 48% were fearful that someone they loved might be hurt or killed in an accident.

The study also reported on some unintended findings regarding the effects on family members of drivers who had accidentally killed. These included: five families feeling 'closer together'; two families feeling that they had 'grown further apart'; other families reporting 'closed communication' and the accident becoming 'the family skeleton'. They suggested that support from family, friends and significant others was the most important help received by drivers (97%). Similar findings were reported in Chessser's (1981) study, which reinforced the important role that family members, friends and the community play in helping traumatised people manage stress. Foeckler *et al.*, (1978) reported a constellation of variables found to hinder the drivers' attempts to resolve their crisis. Variables described as hindering adjustment were being blamed by the driver's family, the victim's family and significant others. This lack of understanding and support was reported as the single most important variable (42%) hindering crisis resolution.

Foeckler *et al.* (1978) reported unintentional findings on positive effects following the accident such as the drivers' attempts to cope and becoming more religious - a theme found in Chessser's (1981) study. However, Chessser (1981) also described ambivalence experienced by one participant regarding confusion about his religious beliefs following the accident. Other positive changes included changes in unhealthy lifestyles; becoming more determined to help others and expressing gratefulness to be alive (Chessser, 1981; Foeckler *et al.*, 1978). Despite the reported high degree of distress experienced by the participants, none sought professional help from social agencies or mental health services (Chessser, 1981, Foeckler *et al.*, 1978). This appears to be a recurrent theme, found also in Lowinger and Zoloman's (2004) study.

The literature base in this area of research is incredibly limited. However, Chessser (1981) and Foeckler *et al.*, (1978) have begun to report the experiences of people

who accidentally cause the death of another. Whilst they generate useful hypotheses about such experiences, both studies have methodological limitations. Foeckler *et al.*, (1978) acknowledge a number of problems, for example using changeable interview schedules and attempting to quantify information against a scoring system to depict those 'high effect drivers', that is, those who 'appeared to suffer a crisis following the accident' from 'low effect drivers'. They commented on the scoring system as 'rather gross'. However, conclusions from Foeckler *et al.*'s (1978) study suggest a high propensity for Acute Stress Disorder and PTSD, similar to the conclusion of Harvey and Byrant (1998). Foeckler *et al.* (1978) propose that drivers causing AD would benefit from some type of intervention allowing the person to discuss their experiences, providing support around the trauma and grief, and helping in overcoming specific fears such as driving again.

In contrast to these largely quantitative studies, Chesser's (1981) qualitative method provides a richer experiential account of causing an AD, drawing upon semi-structured interviews and postal questionnaires. However, the lack of methodological explanation and transparency limits credibility.

In spite of their methodological limitations, these studies are valuable in the absence of more quality research in this area.

2.5 The non-academic literature related to accidentally killing

Given the paucity of more formal research literature, I have decided to also consider the wider literature. In so doing, I have consulted Kelly Conner's (2004) autobiographical account of her experience of accidentally killing a pedestrian, and phone-in broadcasts discussing causing AD such as BBC 5 Live (April, 2006) and BBC Radio Two, (June, 2006).

In conducting a brief thematic analysis of the phone-in stories a number of common themes emerged, including: deep feelings of shame and guilt, feeling responsible,

carrying a dark secret, grief, panic attacks, depression, nightmares, alcohol misuse, needing to be punished and feeling unsupported. A more recent BBC 5 Live broadcast (February 2008), originating from interest around this research, revealed similar emerging themes. The show was joined by Dr Pearlman-Curr (a practising trauma specialist) speaking from the position of a clinician working with a number of clients who had accidentally killed another person. She suggested this group of people experience trauma responses in the same way as other RTA victims. However, she described how additional factors like guilt and shame made the response and recovery from the trauma more complex.

In view of the growing evidence base regarding RTAs, it is surprising to find that almost all of the literature examining the pathogenic effects of such accidents focuses on those physically injured, and neglects the drivers who caused an AD. Mitchell (1997) suggests there are two possible factors overwhelming such consideration. Firstly, she suggests medical factors ie: “often drivers are not physically injured” (p.13). It appears commonplace that participants in RTA literature are recruited at A & E; uninjured drivers may be dealt with by other agencies such as the police and are therefore not recruited into studies. Secondly, she proposes that in a legal context, “often they are construed as blameworthy” (p13). This reasoning may suggest that we are entering a complex ethical area of making moral judgements and decisions about who is and is not worthy of clinical exploration and intervention.

The potential devastating nature of causing an accidental death may render this group of people vulnerable to mental health problems. Considering the high frequency of RTA fatalities, it is surprising that the needs of those who feel responsible for such deaths appear too have been overlooked. Why is there a pervasive silence in both social and academic arenas around this topic? The term ‘experiential avoidance’ comes to mind (Foa, Steketree, and Young, 1984, Hayes, Strosahl and Wilson, 2003). From this perspective, it is possible that a pervasive silence may be an attempt to escape and avoid the unpleasant emotions that

causing a death evokes for us individually and as a society. In this study I hope to address this challenging issue by giving a voice to people who have caused an AD and to open a forum to discuss and understand this topic.

2.6 Rationale and aims of the study

In the small amount of existing academic literature there appears to be a one-sided story: that of surviving 'victims' and their families. As health care professionals, we are beginning to understand this group of people and provide appropriate trauma and bereavement care. However, the formal research literature and informal enquiries amongst fellow healthcare professionals revealed little contact, knowledge or understanding of those who have accidentally killed. The scarcity of literature from the perspective of drivers who have caused an accidental death is surprising when one considers how common RTA fatalities occur. It is plausible to consider that this group of people also have needs that are as equally important and worthy of investigation. Congruent with Chesser (1981) and Mitchell's (1997) attempts to highlight the paucity of research from this perspective, there still appears to be a significant gap in the literature that explores the perspective of those that have accidentally killed.

Furthermore, the vast majority of studies concerning perpetrators, families, friends and survivors use quantitative methods and like those studies described they generally lend themselves to more formal diagnostic categorisation. These methods tend to lack the informative richness and depth found in alternative qualitative approaches such as interpretative phenomenological analysis (Smith, 2004). First-hand accounts deepen awareness of the impact and repercussions of causing an AD, providing a powerful understanding of people's lived experiences following a fatal RTA. Giving a voice to drivers who have caused and feel responsible for another person's death will begin to address this apparent gap in the trauma and RTA literature and ultimately stimulate interest for further research.

The primary aim of this study is therefore to develop an in-depth exploratory account of people's experiences of causing an AD for which they feel responsible.

2.7 Research questions

This study aims to explore:

- How those who had accidentally killed experienced their mental well-being following the accident.
- What meaning individuals were able to find in their experiences
- What helped or hindered their experiences of coping with causing an AD
- How the experience of causing an AD impacted on their sense of self and identity

3. METHOD

This research aimed to explore the experiences of people who caused or felt responsible for a disastrous road accident, occurring suddenly, unexpectedly, without planning or intention and resulted in the death of another person. The exploratory nature of the study and aims dictated the epistemological perspective and research design.

3.1 A qualitative epistemology

To create an in-depth, rich account of lived experience of drivers who accidentally killed, and to develop an understanding of how such drivers process these personal experiences, an idiographic, phenomenological and person-centred research design was adopted. Phenomenological investigations are concerned with attempting to record the individual's subjective account of reality rather than an objective 'reality' itself (Giorgi, 1986). The idiographic approach to this study, attempts to build its claims on findings from individual case studies and only cautiously moves to generalisations for a wider group (Smith, 2008).

This research was concerned with capturing and retaining the diverse and complex accounts of individuals' understandings and experiences of causing an AD. To facilitate this process participants' were interviewed using a semi-structured

interview schedule. This approach generates greater flexibility and opportunity to produce richer information than traditional structured methods (Smith, 2008). It also allows the interview to be 'person centred' (Frosh, Phoenix, and Pattman, 2002) and participants to be the 'experiential experts' and guide the interview into new emerging areas not previously considered, thus demonstrating its utility when exploring a phenomena yet to be investigated extensively.

3.2 Analytical tool: Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) (Smith, 1995; Smith, Flowers and Osborn, 1997; Smith and Osborn, 2008) was chosen as the most appropriate analytical tool for a number of reasons. Firstly, Smith *et al* (1997: p.68) suggest that "IPA is a method which attempts to tap into a natural propensity for self reflection on the part of the participant". Thus, IPA aims to explore the participant's subjective view of the world, their lived experience and as far as possible attempts to gain an 'insider's perspective' (Conrad, 1987). IPA can therefore be described as an existential phenomenological perspective (van Manen, 1997). This framework seemed congruent with the exploratory aims of the research, offering an approach capable of exploring and capturing the lived experience of drivers having caused AD and ways they make sense, or give meaning in their life-world to this experience.

Secondly, the aim of IPA research is to say something in detail about the perceptions and understanding of a small group of people, rather than make larger generalisations about a specific population (Smith, 1996). Again, this fits with the intention of this project.

Thirdly, as a relatively novice qualitative researcher, the structure and practical guidance available on how to conduct IPA research (Smith and Osborn, 2008) was considered valuable. This was further supported by supervision by an experienced IPA researcher.

3.2.1 IPA: Theoretical philosophy

IPA is phenomenological insofar as it is concerned with individuals' subjective personal perception (Smith and Osborn, 2008). However, IPA acknowledges that it is not possible to access an individual's world directly. Due to no clear unmediated window into the participant's life (Eatough and Smith, 2006) the researcher's interpretative activity is required. Smith and Osborn (2008) describe this as a dual process where "the participant is trying to make sense of their world and the researcher is trying to make sense of the participant trying to make sense of their world" (Smith and Osborn, 2008, p 51). This double hermeneutic has its theoretical foundations in symbolic interactionism (Denzin and Lincoln, 1994). The process of co-construction and interpretation will inevitably be coloured by the researcher's own values, background, beliefs and ideas. Whilst subjectivity is supported and accepted within IPA, Sword (1999) suggests that subjectivity must be reflected upon and made explicit: keeping a reflective diary facilitates this process.

The literature appears unclear about whether to place IPA within a constructionist or constructivist approach; rather it seems to have one foot in either camp. However, Eatough and Smith (2006) suggest that IPA can be described as a 'light constructionist' stance, opposed to the 'strong constructionism' of discourse analysis. IPA can be described as 'experiential' research as opposed to 'discursive' research (Crossley, 2000; Reicher, 2000). It seems that both the phenomenological and interpretative qualities of IPA fit well with the social constructionist philosophy on which this study is based.

3.2.2. Contrasting IPA with other qualitative methods: strengths and limitations

IPA shares with discourse analysis a commitment to the importance of language. However, the two approaches differ distinctly in terms of the status they afford to the 'chain of connection' between cognition, and the experience of self and body (Crossley, 2000; Smith, *et al.* 1997). IPA is based on 'realist' epistemological assumptions. The chain of connection between language and the experiencing

'self' is questioned and 'bracketed out' in discursive approaches, thus telling us little about how the person subjectively thinks or feels about the phenomena being discussed (Abraham and Hampson, 1996). IPA suggests that lived life with its vicissitudes is much more than historically situated linguistic interactions (Eatough and Smith, 2006).

Despite this positive conceptualisation, Willig (2001) suggests that IPA may not adequately capture participants' views or experience, as it is dependant on language to sufficiently communicate those views and experience. She proposes that many participants may find it difficult to find the right words to express themselves, which questions the validity of an IPA analysis. However, this critique would also apply to other qualitative and quantitative methods, whereby peoples' experiences are categorised to fit with pre-existing conceptualisations of experience (e.g. tick boxes).

Crossley (2000) has further criticised postmodernist constructivist approaches, suggesting they tend to 'lose' the experience of the subject by operating at a more theoretical level, driven by a methodological focus. This position lies contrary to IPA and Narrative approaches, which attempt to 'retrieve the subjectivity' by specifically focusing on the lived experience of the individual (Crossley, 2000). An alternative analytical tool might have been a narrative approach. However, its application to psychological studies is relatively new. Consequently, few texts outline a dominant structured narrative approach. The structure offered by IPA (Smith and Osborn, 2008) was appealing when conducting research in an area where little is known.

The analytical structure and theoretical underpinnings of IPA are similar to those found in Grounded Theory (Strauss and Corbin, 1990). However, Willig (2001) suggests that IPA represents a more psychological, rather than sociological approach. IPA was therefore deemed better suited to accessing participants 'lifeworlds' (Smith and Osborn, 2008) rather than building a 'theoretically saturated'

account (Strauss and Corbin, 1990) of the social processes that partly explain the phenomenon under investigation.

3.3 Participants

3.3.1 Recruitment

A purposive sampling strategy was used to illicit a closely defined group for whom the research question would be significant (Smith and Osborn, 2008). The author of the autobiographical book 'To cause a death, the aftermath of accidental killing' kindly agreed to place an advertisement on her website (see appendix J). This strategy aimed to access a resource that people of interest to this study, may use. The location of the recruitment advert would suggest that participants were already on a journey to find and connect to others with a similar experience of causing an AD. This will be discussed later in relation to the research findings.

The inclusion criteria aimed to recruit people who shared a central experience i.e.: drivers who caused or felt responsible for a road accident occurring suddenly, unexpectedly, without planning or intention and resulting in the death of another person. Participants were required to be over the age of 18 years and fluent English speaking. The target recruitment number was between five and six participants as recommended by Smith & Osborn (2008).

Eight potential participants contacted me via e-mail and/or telephone. Three were deemed unsuitable as they were relatives of the person who had caused an AD. The remaining five participants were sent a letter providing information about the study (see Appendix A) and were asked to respond via e-mail or telephone if they wished to pursue participation. They were all sent a consent form (see Appendix B) and a personal background information form (see Appendix C). The information form aimed to gather demographic information regarding the participant's life circumstances and histories, thus helping to 'situate the sample' (Elliot *et.al.*, 1999) and facilitate the reader in making a judgement about the degree to which findings

can be transferred to other contexts or settings. All five participants returned both forms.

3.3.2 The sample

The sample consisted of five volunteers who responded to an online advertisement describing the proposed research: two men, aged 36 years and 39 years and three women, aged 45, 47 and 57 years. All were drivers who had caused or felt responsible for an AD. None were charged with dangerous driving or imprisoned because of the accident. Participant demographic information and some background information can be found in Table one.

3.4 The setting of the study

The frequency and volume of road fatalities currently stands at nine fatalities daily in Britain (DfT, 2008). This statistic led me to hypothesise that for many of these deaths there may potentially be a driver who feels responsible for its cause. Due to the specialist nature of the experience of interest, and the lack of specialist services available for those who have caused an AD, I was interested in independently recruiting a non-clinical sample from the general population. The internet provided an innovative recruitment strategy to access such a population from across Britain. Two participants were interviewed in the North of England, one in Wales, and two in the South of England.

Table 1: Participant demographics reference table

Participant *Pseudonym	<u>Ben*</u>	<u>Sandra*</u>	<u>Amy*</u>	<u>Jane*</u>	<u>Daniel*</u>
Age	36	57	45	47	39
Ethnicity	White/European	White/Irish	White/British	White/British	White/British
Educational level	Degree	Degree	Degree	Degree	Professional training
Current Occupation	Business professional	Health Care Professional	Health Care Professional	Voluntary sector Administrator	Business professional

Member of a religious affiliation	No	Roman Catholic	No	Christian	Brought up as Church of England, but unsure.
Described self as a spiritual person	Unsure	Yes – No	Yes	No	Yes
Age at time of accident	23	39	38	27	33
Years since accident	13	18	7	20	6
Country of accident	Australia	UK	UK	UK	UK
Marital status at the time of the accident	Single	Married	Married	Married	Married
Current marital status	Partner	Married	Married	Married	Divorced
Relationship to the person killed	Acquaintance	Acquaintance	Stranger	Stranger	Stranger

3.5 Ethical considerations

Ethical approval was sought from the University of Hertfordshire Research Ethics Committee Board. The ethics approval certificate can be found in Appendix E. Informed consent was ensured through the provision of a written information sheet (see Appendix A). The information sheet detailed issues of confidentiality and related risk limits; anonymity procedures; participants right to withdraw at any time and potential advantages and difficulties that participants may experience as a result of participating. Participants were also given the opportunity to ask questions arising from the information sheet. The nature of the subject was likely to be emotive, causing some discomfort and distress. Participants were made aware that they did not have to answer questions and that they could withdraw or break at

any time. Participants were also given debriefing information including a number of contact details for voluntary support agencies (see Appendix D).

All information gathered was held securely, consistent with the data protection act. Consent to audiotape interviews was obtained and participants were informed that recordings would later be destroyed.

3.6 Data collection

One participant opted to be interviewed at the Psychology Department at the University of Hertfordshire, three were interviewed in their own homes and arrangements were made for one interview to be conducted at a university in the north of England. Each interview lasted between 60 to 70 minutes. All interviews were digitally recorded and later transcribed.

An interview schedule was formulated prior to the interview stage (see Appendix F). It was created with consideration of the limited literature base and related non-academic sources found in popular culture. The structure and content of the interview was adapted following feedback and discussion from a pilot interview with Kelly Connor, author of 'To cause a death. The aftermath of accidental killing'.

The interview schedule was used as a guide to monitor the coverage of topics during the interview (Smith and Osborn, 2008). This process allowed the participant to take the position of 'experiential expert' on the subject, and therefore have maximum opportunity to tell his/her own story. This strategy created rapport and empathy, ultimately allowing greater flexibility, and detailed reflexive exploration into interesting and new areas. The process was facilitated by using open and nondirective questions to begin with and 'funneling techniques' to probe and generate curiosity in specific areas of interest (Smith and Osborn, 2008). The iterative nature of IPA meant the interview schedule was revised between interviews in response to unexpected and interesting areas that had emerged.

Following the interview, participants were debriefed. Personal reflections in relation to the process and content of the interview were noted to facilitate the analysis (see Appendix G).

3.7 Analysis of interview data

Analysis followed the IPA procedural steps outlined by Smith and Osborn, (2008). The process is detailed below.

1. Each interview transcript was analysed individually, case by case. Each was read several times and initial notes were made in the left hand margin. These notes aimed to paraphrase; summarise; indicate interesting/significant aspects of the text; note any association or connections that came to mind; comment on language used and emphasise the contradictions, similarities and differences found in the transcript.
2. The next stage entailed noting inferences concerning the nature, meaning and context of the participant's experiences, in the right-hand margin. Critical questions of the data, such as "what is the participant trying to achieve here?, is something leaking out here that was not intended to and do I have a sense of something going on here that maybe the participants themselves are less aware?" (Smith and Osborn, 2008:p.51). At this stage, the analysis was more interpretative. The emerging theme titles reflected a slightly higher level of abstraction which evoked more psychological terminology. The practice of constant checking between interpretations, sense making and the text ensured that the themes remained grounded in the text.
3. The third stage involved seeking connections between themes. The iterative process of moving between the transcript and the list of themes facilitated clustering and merging themes in accordance to their shared meanings. Clusters of themes were given superordinate titles, aimed at capturing the essential quality of the meaning derived from the cluster. The superordinate concepts, together with the associated sub-themes and supporting text

extracts were gathered in an ordered and coherent manner (see Appendix H for an example section of the complete analytic process as applied to one interview transcript).

4. The above analytic process was conducted for the second interview. Themes identified in the first interview helped to orientate the analysis. Noticing any replication of themes whilst remaining open to new emerging themes, I was respectful of convergences and divergences in the data. This process was applied to transcripts, three, four and five.
5. After all the interviews had been analysed, the superordinate concepts and related theme clusters for all interviews were examined and were clustered together. Supervision was used to refine the consolidated list and consider alternative groupings. This process helped to produce a master list of themes and their constituent subordinate themes for the group as a whole. The superordinate theme titles indicated organising principles that enabled understanding and an effective communication of the views and lived experiences of the participants who had caused an AD.

3.8 Presentation of results

Figure 1 illustrates the master list of superordinate themes and constituent subordinate themes that emerged from the group as a whole. This produced the framework for the findings and supporting extracts. Each theme is also discussed in relation to relevant academic and non-academic literature.

3.9 Quality and validity in qualitative research

The construction of several evaluation frameworks to assess the quality of qualitative research have been useful in considering issues of quality and rigour (Yardley, 2000, 2008; Spencer *et al.*, 2003); publication guidelines (Elliot *et al.*, 1999) and establishing 'trustworthiness' (Lincoln and Guba, 1985). Appendix I outlines the steps taken to demonstrate validity in relation to guidelines suggested

by Yardley (2008). Peer review and supervision were further means of establishing credibility and validity in the analysis process. An IPA group was formed consisting of my research supervisor, a Consultant Clinical Psychologist who is experienced in using IPA, and four colleagues who were conducting IPA studies. Two colleagues simultaneously audited one of the transcripts and the related audit documentation. Both auditors agreed that the themes produced could be justified and appeared to be grounded in the text, thus demonstrating triangulation and sound trustworthiness of the data. Emerging themes were also discussed in supervision as the analytic process developed. Thus the overall process of analysis was reviewed and the coherence and comprehensibility of the analysis commented upon.

Finally, throughout the research process a reflective journal was kept (Smith, 1996) in which, ideas, influences, interests, personal learnings, worries and feelings that the research evoked were documented. Supervision created a space to discuss issues and reflections and how they may have impacted upon the analysis. These issues are considered in the Discussion section.

3.10 The researcher: self-reflexivity

I discussed at the outset of the introduction chapter how I came to be personally interested in this project and my position in relation to theoretical and philosophical orientations ie: I affiliate to social constructivist/constructionist approaches. However, further background information including assumptions, beliefs and clinical experiences are presented below so that their interaction with the data and analysis can be fully considered (Elliott *et al.*, 1999).

I am a 30 year old female of mixed race (White British and Indian South African), from a working class background. I am a final year clinical psychologist in training and am undertaking this research as part of a Doctorate programme. I have been working in the area of psychology and related mental health professions for the past 10 years. In recent years, I have developed an interest in working clinically using systemic and narrative approaches.

I have had a keen interest in trauma related clinical work and research for a number of years. I am particularly interested in trauma and links to broader existential questions about the line between life and death and how people then construct, re-author and make sense of such experiences. The combination of my interests and my own life experiences will inevitably have shaped my contribution to co-constructing meaning with the participants in this study. However, practises such as keeping a journal and personal reflections throughout the research process have increased my awareness and reflexivity.

As part of the reflective process, I became aware of the dilemma of moving between a research position and a clinical position. Furthermore, my awareness that most had not had the opportunity to speak confidentially and in-depth about their experiences prior to the interview, created further challenges. I will discuss these issues more in the reflective section of the discussion.

4. FINDINGS

The central concern of this phenomenological investigation is to present an account of how the world *appears* to the individuals interviewed. This is adhered to in the analysis that follows which privileges the five participants' own accounts of their experiences of causing an AD. This account should be viewed as socially constructed, partial and incomplete in line with the study's underlying theoretical orientation (Smith & Osborn, 2008). The participants' accounts clustered around three superordinate themes:

- trying to make sense of a life changing moment
- struggling to cope with the trauma of causing a death
- a changed sense of self.

The emergent superordinate themes and sub-themes are outlined in Figure 1. Each Superordinate theme and its constituent themes are described, paying attention to the convergences and divergences within and between experiences. Whilst I have attempted to extrapolate and present distinct themes, it is important to acknowledge the overlap between the themes. The superordinate theme and sub-themes are discussed in light of the relevant literature and related theoretical concepts (Smith and Osborn, 2008). However, in consideration of the limited academic literature in this novel field of study, I have drawn upon both academic and anecdotal evidence. The findings and discussion follows with a summary of findings relating to the research questions, clinical implications and methodological limitations.

Figure 1: Superordinate and sub-themes derived from an IPA methodology

<p><u>SUPERORDINATE THEME 1:</u> TRYING TO MAKE SENSE OF A LIFE CHANGING MOMENT a) Making sense in the context of shock and confusion b) Making sense in the absence of memory c) Making sense over time ('living with it')</p>
<p><u>SUPERORDINATE THEME 2:</u> THE STRUGGLE TO COPE WITH THE TRAUMA OF CAUSING A DEATH a) Processes that helped and hindered coping with causing a death b) Disenfranchised trauma and grief c) Experiences of seeking and accepting professional support d) The process and struggle of recovery</p>
<p><u>SUPERORDINATE THEME 3:</u> A CHANGED SENSE OF SELF</p>

- a) The initial adjustment in their self view
- b) An unwanted self
- c) Challenges to personal roles and identities

4.1 Trying to make sense of a life changing moment.

This theme depicts the experiences of how participants tried to make sense of a catastrophic, life-changing moment. Attempts to make sense occur within a context of shock and confusion as the events of the accident unfolded, ultimately leading to the knowledge that another person had died. The uncertainty of not knowing and the fragmented nature of memories from the accident render sense-making almost unobtainable for most participants. Conversely, trying to make sense with a complete absence of memory (as described by two participants) further challenges and complicates the process of creating sense and making meaning. A part of the trauma reaction, shock and confusion remain dominant features for all participants, particularly during the first year following the accident, regardless of the quality of memories. It is during this time that police investigation and court proceedings are undertaken and, for all but one participant, these procedures were described as “*traumatic*”.

4.1.1 Making sense in the context of shock and confusion

This sub-theme is dominated by early psychological trauma reactions. For those who could recall the moments of the accident, the physicality of the accident was described alongside their internal world experiences. Personal experiences included, feeling “*shocked*” and “*confused*”, which were characterised by sensory distortions such as experiencing the world in “*slow motion*” or their “*brain going double time*” or at “*a million miles an hour*”, depicting a sense that cognitive processing was working intensely to accommodate and make sense of this “*strange*” experience. The disoriented experiences occur alongside feeling vocally inhibited and cognitively impaired, such as not absorbing information and

experiencing a loss of recall for key moments such as not remembering “*the windscreen smashing or getting out of the car*”.

From the descriptions, a picture of immense uncertainty emerges. Sandra’s extract below illustrates how her fragmented and “*disjointed*” memories created considerable uncertainty, thus making it difficult for her to organise the pieces of this experience into a coherent narrative.

...everything was in slow motion...you want to call for help but you can’t seem to. It’s really a strange feeling. [I] never realised all the windscreen was shattered...I think the more you tried – of course initially you try to put it together. (Sandra)

The fragmented or disjointed nature of the memories was mirrored during the process of the interview. Participants’ recall of events was tangential and lacked coherence in places. However, participants demonstrated an awareness of this by statements such as “*I’m getting a bit disjointed here as well*” and “*it’s a bit jumbled.*” This fragmentation may be indicative of dissociative experiences at the time of the accident, which is thought to result in the fragmented encoding of the event, as suggested by Brewin, Dalgleish and Joseph’s (1995) Dual Representation Theory. Moreover, dissociative experiences can impede subsequent emotional processing of the experience and purportedly lead to longer-term psychopathology, (American Psychiatric Association, 2000).

Sandra also described a “*great imbalance of emotions*” in the weeks that followed the accident, characterised by emotional dysregulation, moving between hysteria, laughing and quietness. She described feeling in touch with reality on one hand, yet disconnected with it on the other hand: “*you are devoid - you’re here but you’re not here.*” Jane also described a similar feeling indicative of a dissociative experience at the time of the accident; she also described this as a recurrent feeling, despite the accident occurring twenty years ago. These unfamiliar

emotional experiences contribute to the difficulties of trying to make sense of this life changing moment.

...there was a buzzing in my ears that came up and this peculiar feeling of almost being weightless. It was a floating feeling as if you're going to faint, perhaps that feeling before you get anaesthetised...that's what I had immediately around the accident.... And describing it to you when I wrote it down, I was getting that feeling. (Jane)

The feeling of loss of control and powerlessness in the days, months, and years that followed the accident seems evident in participants' cognitive and emotional experiences. Daniel described the invasive ruminative nature of his thoughts and feelings following the accident. He captures these relentless feelings aptly in the metaphor below.

...there was always that moment first thing in the morning when you woke up and thought "Was that a bad dream?".... it would have been in your mind and it was churning over and over...it was like it was switched on all the time... So you couldn't just think about ordinary things.....it's a bit like being a bit of driftwood in a storm....when it's really stormy you don't really know which way is up and which way is down, you just hope that your head's going to pop up often enough to get a breath...you just hope that, however long the storm lasts that eventually it will calm, and eventually you'll... reach...dry land. But it's...not knowing how long it's going to last for or...how choppy the waters are going to be. (Daniel)

Descriptions such as those above (Daniel, Jane and Sandra's extracts) represent participants accounts that fit to some extent to more formal descriptions of traumatic responses, such as Acute Stress Disorder and PTSD (American Psychiatric Association, 2000). For some, in my clinical judgment, their experiences extended into more chronic trauma responses or PTSD (American Psychiatric Association, 2000). However, I remain cautious with the use of diagnoses based

upon the retrospective descriptions of participants' experiences. Nonetheless, such observations are not surprising given prospective research by Byrant and Harvey (1996) who suggest that approximately 80% of RTA victims who initially display Acute Stress Disorder still suffer PTSD six months later. Lowinger and Soloman (2004) also indicate high prevalence rates of PTSD (45%) in drivers who had caused fatalities.

For all participants the accident represented a life-changing moment personified by a loss of control and powerlessness. Daniel's narrative below demonstrates a clear punctuation in his life, or distinct change, distinguishing life before and after the incident. Sandra's description of the time of day at which the accident occurred, "*it turned from light to dark quite suddenly*" may also be suggestive of how her life changed in that moment. Similarly, Amy described learning about the death as a "*huge blow*" and how the landscape of her life changed, her "*world came tumbling down.*"

I can remember thinking... "My life's changed now and it's, it's not changed for the better. It's never going to be the same again."... Yeah you just knew that there was going to be a before this and after this sort of aspect to me life.
(Daniel)

I mean that was just like a huge a huge blow, and you just felt awful, just your world comes tumbling down.(Amy)

These extracts demonstrate how being confronted with a catastrophic situation that occurred suddenly without planning or intention and resulting in another person's death, is experienced as incomprehensible. The extracts correspond to Janoff-Bulman's (1992) theory of shattered assumptions. According to Janoff-Bulman (1992) we hold personal assumptions about the world as being a safe and predictable place, and in the face of a traumatic experience these assumptions become obliterated. In that single moment, the world becomes a very uncertain and an unsafe place, violating one's assumptions of personal vulnerability ("it won't

happen to me”) (Burgess and Holmstrom, 1974). Personal agency is replaced by fear, powerlessness and loss of control. These experiences are similar to those discussed by Hendin and Haas (1984) in relation to soldiers’ experiences in Vietnam. Whilst it is important to extrapolate from related research, it is essential to acknowledge that the circumstances and meaning might be very different, particularly given the social legitimacy for killing and the emotional readiness to cause and be exposed to death for which soldiers are trained.

The participants’ experiences of trauma and distress extended beyond their accident narratives. The accident appears to trigger a concurrent process of difficult experience predominantly over the year that follows. The police investigations and court proceedings are described as “*hard... really traumatised*”; “*horrible....awful*”; “*traumatic.....horrendous*”; and “*harrowing*”. For most participants these experiences are characterised by uncertainty about the process, a lack of knowledge, and a lack of communication about likely outcomes. The legal processes seemed to worsen the severity of the crisis for participants. Chesser (1981) supports this finding. For Jane this process of “*not knowing*” was particularly distressing to the extent that she rejected her children (including a newborn baby), believing that she was destined for prison.

I really thought I would go to prison...so unfortunately, my new baby I didn't bond with him at all (sniffs)...I deliberately didn't bond with him.....Because I thought, "Well I'm going to go to prison and this poor baby is going to be left not knowing his mother." (Jane)

In summary, the extracts presented in this sub-theme illustrate the complexity of sense-making in the context of shock and confusion. Participants’ internal experiences seem overwhelming and unfamiliar. The extracts demonstrate how difficult feelings tend to persist, and how they can become re-ignited during the legal process. The level of uncertainty surrounding personal recollections and feelings represents a great challenge for participants who are uninformed about the

legal process to make sense and meaning from their experiences. Furthermore, their experiences seem to extend beyond normative responses to stress into symptoms possibly synonymous with Acute Stress Disorder and PTSD. It is possible that these intense emotional and cognitive experiences inhibit the early sense-making process (Charney, Deutch, Krystal, Southwick and Davis, 1993).

4.1.2 Making sense in the absence of memory

All participants talked about living with an uncertainty and sense of incomprehensibility regarding the accident, repeating phrases such as, “*I don’t know, I will never know*”, “*I don’t remember*” and “*I don’t understand*”. This was perhaps most notable for Amy and Ben who had no recollection of the accident. Amy’s last memory of the accident was being cut from her car, followed by receiving the news of the death of the other driver whilst in hospital.

....it was almost like...somebody hitting me in the stomach....at that point thinking, “My God,” but still not knowing what had happened, and still sort of thinking, “Oh God, I’ve just got no idea her”....the weeks afterwards were...a bit of a daze really....still not knowing what had happened, I still had no...well I had no memory of it, and it hasn’t actually ever come back. (Amy)

Ben’s extract below illustrates how he learnt about the accident and death of the passenger in his car.

I don’t remember anything else that happened that day...I couldn’t remember what had happened...that caused some memory loss, caused some amnesia and I woke up in the hospital...“Where am I?...What happened to the guy in the car next to me?”... Because I remembered what had happened yesterday up to a point... “What happened to the guy next to me?” He said I’m sorry but he didn’t make it. (Ben)

Following the news, Ben had a physical examination and was subsequently discharged from hospital. At this time, Ben described an external calm, contrasting with his private world, which he described as “*inner turmoil*.”

I suppose quite calm and collected myself, but there was a lot of inner turmoil going on I think. [Sara: Can you say a little bit more about that?] Yeah I mean – I think the implications of it really...I wasn't able – they weren't able to sink in...at that point, I also because I had no memory of the accident, it was difficult for me to interpret how it had happened, what had happened, whether or not I was responsible you know, had the car had a mechanical failure? All those things were all possibilities so I didn't know much. (Ben)

Due to the absence of personal memories, Ben's narrative had a particularly unique essence. His learning about the accident and sense-making of the experience occurred through the context of multiple systems including medical, police, and legal systems. The legal explanation or rationalisation of the accident seemed to have become internalised by Ben in the absence of having his own memories to access. During the research interview process, it appeared that Ben, whose accident occurred 12 years ago, had constructed a well-formed narrative about the accident, which he repeated at several points. The extract below illustrates how Ben seems to have internalised the voice of the prosecution, i.e. critical and intellectualised. He uses the terms “*legal logic*” to help him understand or fill the gaps in his memory. Following the court procedures, Ben's thoughts and feelings over the following ten years had culminated in alcohol misuse and depression.

...it was difficult, it was difficult, because I was then learning about what had happened...somebody had died, there had been an accident, and if you've had an accident and there was no other vehicle involved and it wasn't an act of God, and there wasn't an animal across the road, and there wasn't mechanical failure to the vehicle then by law, under traffic law, you must have been careless, otherwise you wouldn't have had the accident. That's pretty much how the logic of it works...it's almost that simple. So therefore I must have been careless because I'd had the accident and X died, so the accident caused X's death, so therefore I caused X's death. That was the legal logic of it that was at work...it took months and months and months for this to come to court...six or eight months afterwards. (Ben)

I asked Ben about his thoughts and feelings during this six to eight month period and his experiences during the court process.

...I had been told all this and...I initially went through a long period of denial where I was sort of going, "Well no, I can't be responsible for this, and I can't remember it, so how can I take responsibility for it? It's just crazy."....Well highly traumatised. I mean.....here I was under a form of...potential judgement or assessment a critique of you going, you know, "What have you done?"it wasn't really until after the trial, where it went through the legal process and I then understood with a bit of hindsight. (Ben).

In the absence of memory, it seemed that Ben's sense-making had been borne out of and moulded by the legal narrative. The coherent nature of his narrative suggests that this was the story presented as 'truth' within the court of law. Whilst Ben initially rejected the story, he now seemed more accepting of this understanding of what had happened to him. The conflicting and rejecting nature of what he later described as a "*conclusion enforced upon me by law*" (Ben) will be discussed later in the superordinate theme relating to self and identity.

For Ben, whose loss of memory was caused by a traumatic brain injury, the process of making sense is more difficult. Ben did not have a clear mental picture of how he came to be in that situation. The natural propensity to make sense of experiences becomes severed when memories are not available. His learning occurs through the narratives that were available to him, in his case, the legal narratives.

Similar reconstructions of fragmented or absent memories are reconstructed by intensive care patients, where memories for events are created through the narratives of nurses and family members (Rassool, 2005; Jones, Griffiths, and Humphris, 2000). When we consider the process of learning about such events in the context of the legal system, the agenda of social justice and attributing blame

negates any experiences of empathy and understanding. It is possible to infer how detrimental such critical and judgemental narratives could be to the individual who is in the process of trying to make sense of giving meaning to causing an AD.

In summary, the absence of memory for the accident makes sense-making a struggle, and appears to create deeper challenges for the integration of a reconstructed self narrative, particularly when the narrative is constructed within a highly critical legal context.

4.1.3 Making sense over time: ‘living with it’

The RTA alone constitutes a major trauma. However, there is the additional matter of a violent death that participants themselves had caused. Such an experience can undermine and violate their fundamental beliefs about themselves and their larger world, thus shattering their assumptive worlds (Janoff-Bulman, 1992). Janoff-Bulman, (1992) suggests that we hold three core inner world assumptions: people are personally invulnerable to negative events (“it won’t happen to me”), that the world is meaningful and just (i.e. that people get what they deserve) and that they themselves are good, worthy people.

The desire to assimilate their sudden traumatic experiences, feel understood and make sense of causing an AD was important for all participants. Amy demonstrated this need early on, when she attempted to connect with others in the media who had shared her sense of tragedy, trauma, loss and pain. Amy’s assumptions about personal vulnerability and the meaningfulness of the world, as identified by Janoff-Bulman (1992) clearly become shattered. In the extract below, Amy’s actions demonstrate how she tried to cope with this experience by generating a new set of beliefs that helped disprove her sense of isolation and helped validate her inner world experiences.

In the weeks, months after that, I was always trying to make sense of it... I found myself....reading the paper and listening to the news and [crying] it was almost like homing in on things that were difficult, like tragedies. Only to sort

of tell myself, "Look this does happen to other people, it does happen, Amy you're not the only one."....knowing that somebody else is going through what you're going through. (Amy)

Both researchers and clinical theorists emphasise the central role of 'sense-making', or the formation of a subjective understanding of the trauma and loss in the restoration process following the shattering of assumptions (Currier, Holland and Neimeyer, 2006; Davis, Nolen-Heoksema and Larson, 1998; Niemeyer and Anderson, 2002). Whilst this process of assimilation or accommodation has been written about in relation to violent loss and bereavement, it does not go as far as to consider those that have actually contributed unintentionally to a violent death. One could hypothesise that such populations face greater challenges in the process of making sense in a personally meaningful way.

Similar to the findings of Chesser (1981) and Foeckler *et al.*, (1978), some participants found meaning and sense-making through spiritual development, deepening their religious or spiritual beliefs as they struggled with questions of responsibility, control, meaning, and distress.

Faith, yes...I've seen different...ministers who've been very....supportive and shown me from the Bible that there's a scripture..."Time and unforeseen occurrence befalls all men." Meaning that things aren't foreordained....it's not fate. It's just being in the wrong place at the wrong time where imperfect things happen. (Jane)

In the process of trying to make sense of accidentally killing, participants reflected on their own mortality and spent time soul searching for meaning. Some found new meaning and beliefs about the essence of life, death and the soul, providing some solace and meaning in death.

...I must believe in a God because I think when you die that's not the end....yeah dead is not the end and there's more to people than just skin. We

are not – I believe you have a body and you have a soul and that your soul goes on somewhere. (Daniel)

For Ben religious beliefs did not provide meaning or comfort. The accident caused a shattering of his core value system, causing “a *change*” in his “*world view*.” Thus, Ben was unique in that his experiences appeared to create an existential crisis.

...I spent about a year after the accident sort of agonising over...what kind of help the Christian faith and a Christian God could be in a world where this had happened, and I couldn't get any relief from it. I couldn't undo him, I couldn't bring him back, I couldn't fix anything and I ended up leaving Christianity. So, I made a fairly significant life shift and said “Well this just isn't working for me. I can't believe in a God that has a relationship with people and then lets this kind of stuff happen to them.” So I'd left my Christian world view.....all the things that were supposed to be available through Christianity in the form of absolution and forgiveness.....never seemed to make any difference or help me resolve any of the feelings of guilt or responsibility for X dying in any meaningful way. (Ben)

Ben's “*disembarking*” from his former religious identity, was prompted by a host of existential questions for which he found no meaningful understanding. A weakening in religious faith is one of the most common and pervasive difficulties experienced in the face of trauma (Calhoun and Tedeschi, 1999; Decker; 1993; Fontana and Rosenheck, 2004). Existential questioning was common to all participants.

I suppose I was left with this thing that mainly it was, “Why did it happen? And why did it happen to me?” (Sandra)

“What's it all about, and why did that happen?”....“If only I hadn't left at that time.” (Amy)

The “*why me?*” question (spoken by all participants) supports the literature which suggests that when extreme misfortunes or bad things happen to careful and good

people, the assumption that the world is meaningful is shattered. Their beliefs about how they think the world operates are incongruent with their experience, thus causing great distress (Jannoff-Bulman, 1998, Kushner, 1981).

Over time, it appears possible to reflect and develop new meanings. Consistent with constructivist theorists, literal truths and facts are not important, but rather seeking a truth that can be lived with; thus, the narrative meaning is important (Neimeyer, 2008). Sandra demonstrates meaning-making in construing the person's life as perhaps "*better*" than it might have been. Amy, demonstrates her current meaning of the accident and death as illuminating her role in helping others, yet she also draws attention to pain and discomfort of this meaning.

I feel that he's in a better place. And I hope he's got many cigarettes because that's all that interested him...(Sandra)

....maybe I'm here because there is a reason why I should be here, you know, maybe if it is about helping other people... then...that feels like a very difficult thing to say, because it feels very selfish...it feels like I'm making a judgement about my life over and above her life...(Amy)

In summary, searching for meaning and sense-making is attempted, but it seems an incredibly difficult, challenging task, one which is ongoing and continually reflected upon: "*we have to go through experiences of life....you have to live with it, deal with it*" (Sandra). All participants talked about their experiences of accidentally killing and the pain associated to this as being part of their life experience, a part that has to be lived with and acknowledged rather than avoided.

4.2 The struggle to cope with the trauma of causing a death

This theme is concerned with the processes that were helpful and/or hindered participants coping with their experiences of causing an AD. This theme captures

similarities in the experiences of coping, but also demonstrates diversity of experiences. I have separated out participants' experiences of seeking and accepting professional support into a distinct theme due to the clinical relevance that such experiences reveal in light of therapeutic treatment for this client group. The final sub-theme 'the process and struggle of recovery', encapsulates how participants reflect upon and view their journeys since causing an AD. For some their journey has been over twenty years, for others, their understandings and reflections reflect a six-year period since causing an AD.

4.2.1 Processes that helped and hindered coping with causing a death

This theme is characterised by coping that involved connecting and disconnecting with others, their social worlds and unwanted aspects of self (the latter is discussed in detail in relation to self and identity in the next superordinate theme). Relational processes feature heavily in this theme: as participants talked about their sources of support, some were experienced as helpful and, others as unhelpful.

Amy, like several others spoke about the invasiveness of the media. Most participants kept a distance from the media coverage surrounding the accident, possibly to protect them from further distress.

....It was huge, it was huge. I mean I am a very private person anyway, and that was awful. I made the point of not reading the papers during that period...(Amy)

Dr Perman-Kurr, a chartered psychologist and trauma specialist supported this type of proactive coping in a radio interview regarding accidental killings (BBC 5 Live, 2008). She suggested that media coverage in such cases is generally presented in a biased and unbalanced manner, and thus could be construed as potentially damaging for those people who have caused an AD. Thus, the intentional disconnection from the media seemed helpful.

Participants spoke about a pervasive sense that those around them no longer understood them; a feeling akin to alienation. This interpersonal detachment or social distancing is characteristic of post-traumatic states (American Psychiatric Association, 2000). RTA survivors recruited in Byrant's (1997) large-scale A&E study have also reported such findings. Daniel's experience of accidentally killing was described as like no other "stressor" and for this reason he spoke about how nobody could understand the immense psychological scar and emotional pain that this experience had left behind. The following extract illustrates Daniel's sense of isolation and disconnection from those around him.

...it felt like nobody really understood how hurting it made me....just how all-consuming it was.....on a scale of 1 to 10, separation [divorce] was like 2, and the accident was 22.....people couldn't understand that....they're almost treating it the same as...."it's just a bad day".....It's not a bad day, it's a tragedy.... I wasn't physically injured, I think that's the hardest thing in the whole world, is if it's physical injuries people can see the cast on your leg or they can see the scars or whatever, when it's sort of emotional or psychological damage nobody can see it, nobody can measure it.(Daniel)

The notion of feeling disconnected and the desire to feel understood may have motivated participants to seek connections with others who had experienced similar distressing events. This process was reflected in how all of the participants came to be a part of this study. They had all accessed Kelly Connor's (2004) website, which led to their participation in the study. Thus, all participants had initiated a process of connecting with another (Kelly) who had shared in their experience. The desire to want to connect, compare, and contrast experiences was further evident during the process of the interview. All of the participants were curious about others who I had met and were keen to know about similarities in their experiences.

I don't know whether everybody that has this experience experiences the same. That's why I was so interested in what you were doing. (Sandra)

The idea of connecting and sharing experiences as a means to learn, validate, and support is common in our therapeutic practice of group work. There are a number of voluntary sector organisations specific to road trauma survivors, such as 'Road Peace' and 'Brake'. They recognise the benefits of communality, normality, solidarity, reciprocity and control that these types of groups can provide (Hopmeyer and Werk, 1994). However, these groups are all targeted at 'victims and their families', rather than those who have caused an AD.

In the absence of others who had shared such experiences, support and comfort was sought from their immediate family and friends, and from religious systems. There is an abundance of literature, including an extensive meta-analysis review by Brewin, Andrews and Valentine's (2000), alongside several psychological models, such as the stress-buffering model (Cohen and Willis, 1985) and the social support and coping model (Thoits, 1986) which suggests that social support is a protective factor and buffers the impact of trauma. For most adults their marital or long-term relationship is perhaps the most significant of any relationships, and thus one can intuitively hypothesise that this relationship should be a particularly potent resource for individuals coping with trauma of causing an AD. For some participants in this study their marital attachment was supportive and positively strengthened and maintained over time. Similar findings were evident in Chesser's (1981) study.

...it's brought my husband and I closer together, because he has supported me through it all...without him I wouldn't be here. (Jane)

I mean my husband was just brilliant....he's just known what to say and when not to say something...he's just been great. (Amy)

The above extracts support Johnson and William-Keeler's (1998) theory that a marital/long term relationship can offer a "recovery environment" in the wake of trauma. Such observations are also supported by a number of qualitative studies investigating marital relationships in adults who have suffered a variety of traumas. These include childhood sexual abuse (Valentine and Fienhauer, 1993), workers

who had handled human remains after large-scale disasters (McCarroll, Ursano, Wright and Fullerton,1993) and Cagnetta and Cicognani's (1999) study involving individuals who had sustained serious permanent injuries following an RTA. However, it is difficult to extrapolate from many studies in the RTA literature as researchers rarely specify whether fatalities had occurred, or whether their sample included drivers who had caused the accidents. More often than not, the term 'victim' is used, leaving the reader to make the assumption about the sample. Nevertheless, to demonstrate the mediating and/or moderating effects of a marital/long term relationship following an experience of trauma is very difficult (Whiffen and Oliver, 2004). Such research is fraught with challenges, such as establishing the pre-existing quality of the relationship prior to the trauma. Such factors are important because they can become amplified during the aftermath of trauma (Dyregrov, 2001; Oliver,1999).

Two participants described their marital relationship in a way reminiscent of a 'recovery environment'. However, for both Sandra and Daniel, there appeared to be a detachment within the marital relationship. Johnson and Williams-Keeler (1998) describe how avoidance and immersion in trauma can leave spouses feeling alone and abandoned in their relationships. Furthermore, an inability to regulate negative emotions may exasperate or create marital conflicts (Cassidy and Mohr, 2001). Whilst Sandra remained in her relationship despite difficulties, Daniel felt unable to maintain his marital relationship, causing their relationships to break down.

Home should be your sanctuary, you then start to get, "Well listen, when are you going to be yourself?"...there didn't seem to be any escape. So when I said before about the marriage breakdown being a 2 on the scale of stress, it actually took me stress levels down. Because, there's a certain overhead to being in any relationship....you need to give a bit of your time and energy to the other person and they – you expect things of them and they expect things of you. I just couldn't be bothered with it, either with me wife or other people....you always withdraw. (Daniel)

Some participants experienced support from outside of the marital relationship, such as from parents.

...initially me Dad was great...and like me Dad would just sit and listen for hours on end on the phone. (Daniel)

Other participants found that their parental relationships were un-supportive. Ben experienced his parents' attempts to support him as invasive, rather than protective. At the time of the accident Ben was living away from home at university, thus representing a time of separating and establishing himself as an adult. This time of independence may have in part influenced how he interpreted and received the support offered by his family.

...it felt like I was being boxed in and sort of tried to be wrapped up in cotton wool...It wasn't helping. (Ben)

Sandra's description below illustrates how her efforts to seek closeness and support from her father were rebuffed. This extract illustrates a distinct communication that talking about causing an AD was not acceptable.

...when I saw my father, who I was always able to talk to....But when I was trying to tell him about this....It was a bit like end of conversation. (Sandra)

The experience of being silenced, characterised by closed communication is common in Connor's (2004) autobiography. She struggled with her mother's avoidant response to the accident: 'pretend it didn't happen'. One participant in the Foeckler (1978) study also experienced this and they similarly reported the detrimental effects of silence in the family system. These experiences correspond with McGoldrick's (1987) family therapy theory, which suggests that secrets or unspoken events can create isolating positions within a family system. The concept

of 'silencing' is discussed in the next sub-theme in relation to disenfranchised grief and trauma.

Four of the five participants had children at the time of the accident. They experienced their relationships with their children as both supportive and un-supportive. In both Daniel and Sandra's extracts below, they illustrate how their children responded to them "*as if nothing had changed*", thus demonstrating a lack of awareness or perhaps using denial as a functional means of coping. However, Sandra's interpretation and attribution of meaning concerning her daughter's response lead her to experience feelings of rejection, whilst Daniel's attribution of meaning meant that he found his children's responses refreshing and hugely beneficial to his recovery.

I was going through a lot of trauma with the husband, I felt my daughter should have been more supportive. But, now when I look back or when I used to mention it, it was as if she pretended it wasn't going on....it was a dreadful feeling. (Sandra)

The only people I could have done with were me children... because as far as they were concerned, I was no different....Children - what you see is what you get, and they just have the enthusiasm for life.....one of the reasons I feel a lot better about things now is that you almost need to learn to have that enthusiasm about life again. It's almost like it got sucked out of me and, seeing their enthusiasm is almost like rekindling my enthusiasm for life. (Daniel)

The relational processors in coping may be influenced by gender difference. Cathrell (2004) and Crossley (2000) suggest that women tend to want to talk extensively about their distress, thus connecting, whereas men tend to prefer solitary coping strategies, depicting separation and autonomy. This was evident in participants' descriptions. Both Ben and Daniel initially talked about their thoughts and feelings as "*a problem to be solved alone*", something "*to be fixed*", suggesting

a sense of needing restoration, as if something had been broken or fractured. In the absence of personal or relational resources alcohol featured as a means of coping, most predominantly for Ben. Daniel initially avoided alcohol because he knew he was “vulnerable”; however, he progressively used alcohol to facilitate sleep, ultimately suppressing his thoughts.

...I stayed well clear of any alcohol because I knew I was vulnerable,....the only way you could get to sleep [and] relax...was to have a couple of drinks.....I wouldn't go to bed until late because I wouldn't want to go to bed not knowing that – that I wouldn't fall asleep immediately. (Daniel)

For Ben self-medicating was used more extensively to avoid the uncomfortable thoughts and feelings of guilt and anxiety, ultimately affecting his ability to work. Mayou and Byrant (1995) reported similar findings that suggested that increases in alcohol use following RTAs were more likely to be associated with emotional distress.

I started to drink fairly heavily in the year after the accident...But alcohol has subsequently become a problem for me...[but] it wasn't until last year that I was formally diagnosed with severe depression. (Ben)

Over time (three and a half years for Daniel and ten years for Ben) both recognised their need for support from professional health care services.

I can solve problems on my own if I just give it enough time...“I'll resolve it myself.” The reality was I couldn't resolve it myself. (Daniel)

In summary, participants described a range of helpful and unhelpful coping experiences. Relational factors featured in this sub-theme. Participants voiced a lack of understanding resulting in feeling detached and socially distanced. However, all of the participants sought connection with others (by visiting a website and reading Connor's (2004) autobiography), thus, seeking social support. In

relation to systemic factors, marital relationships were reported as fundamentally important in the coping process for some, but detrimental for others, one resulting in separation. Parental relationships were also experienced as supportive for some, but for others, their parents silenced their attempts to seek support. Participants' perceptions of support from their children were determined by the attribution of meaning to their child's possible lack of awareness or use of denial mechanisms. One participant found this distressing; another embraced the feeling of normality experienced with his children.

4.2.2 Disenfranchised trauma and grief

Perhaps one of the most complex barriers to recovery is the dilemma between wanting to talk about their experiences of accidentally killing, but feeling a strong sense from others that talking about it is not acceptable. Thus, their experiences of trauma and grief seem to be socially negated or socially unspeakable. The strong message of silence appears to have been made explicit early on in their interactions with the legal system. Most were advised not to talk about the accidents, and especially not to apologise, possibly because that could be construed as an admission of liability. These initial experiences are likely to mould the development of beliefs that one should not talk about their experiences of causing an AD.

Sandra spoke at length about the detrimental effects that not talking could have for people's mental health. She was very insightful about the concepts of psychological suppression and her beliefs that such strategies lead to mental health problems, requiring extensive support and resources in later years. In this context, Sandra talks about 'others/they', yet there is a sense that this reflects her own experiences, as she described herself as not receiving support, not being listened to, and how, in later years she saw herself as being "*prone to depression*".

...in some ways I envy people that they appear to put everything to the back of their mind. But then probably that's why they end up in a psychiatric hospital,

because they try to suppress these things...Why do we have to wait until somebody is diagnosed as being mentally ill, and suddenly we're all listening to them? There should be lots of support out there... (Sandra)

Daniel also spoke about the difficulties of being confronted with people who avoided or ignored his pain.

At the time there was three groups of people....those that would pretend it never happened and....felt awkward to talk to you, those that wanted to know every detail and....were intrusive, and then a very, very small number who were just, "Are you OK? I know you're having a bad time...Do you want to talk? I'm here." I always make the effort to say to somebody, "I know you're having a bad time." Because I think there's nothing worse than people ignoring it as if it hasn't happened. It makes you feel absolutely alone, "Oh pretend it didn't happen." How can you take that view? (Daniel)

Similarly, Amy spoke about the difficulties that people had in relation to talking about the accident.

Others just couldn't mention it....Again that was quite hard... the idea of blame, I think that made it even more difficult for people to talk about. (Amy)

The conspiracy of silence seems to be a social condition that hinders the process of adjusting and recovery (Worden, 2002). This phenomena is often found in the suicide literature where there is a tendency for friends and family to remain quiet about the circumstances surrounding a death (Worden, 2002). Furthermore, Doka's (2002) work regarding disenfranchised grief also resonates with this finding; a term that refers to the grief that is not socially acknowledged or publicly sanctioned. However, I think the concept for these individuals, drivers that have caused an AD, extends beyond grief to include disenfranchised trauma.

Whilst some literature acknowledges the concept of perpetration-induced traumatic stress (MacNair, 2002; Nader, Pynos, and Fairbanks, et al, 1993), most of this

research concerns police officers (Mann and Neece, 1990; Manolias and Hyatt-Williams, 1993) and soldiers (Grossman, 2005). These types of killings are generally socially sanctioned (McNair, 2007). They occur within and are contained to some degree within an organisational structure that ultimately holds some degree of responsibility for a death whilst 'on duty'. Terms such as blue on blue or friendly fire have been used by the military to describe such killings, thus facilitating a social acknowledgement of such deaths. Drivers who have caused an AD are considered unlawful, despite the accidental nature of the killing and as a result, their distress potentially remains disenfranchised.

Nonetheless, in the available grief literature Doka (2002) identifies three situations whereby grief can be considered as disenfranchised. The first, in my view, is highly relevant to those who have accidentally caused a death. In this situation, the relationship of the disenfranchised griever to the person that has died may not be recognised. Doka (2002) suggests that, within western society, unspoken rules have been created and exist about recognised relationships. If a given relationship does not meet these implied criteria for the right to grieve, the surviving member of the relationship may experience the disenfranchisement of his/her grief. Doka (2002) suggested that past lovers, roommates, and teachers/students, to name but a few are not recognised relationships. It is likely that a relationship with a 'stranger' or a brief acquaintance would sit within the realms of an unrecognised relationship. In the circumstance of causing an AD on the road, it seems that the relationship begins at the scene of an accident, and continues for the person who had caused the death. One participant told me how she was "*here [participating in the research] remembering him*" and how each year she remembers his death, as if he were a friend or family member, thus demonstrating the quality of the relationship, despite not really knowing this man in the traditional sense.

I still was having mass said for him, because it's something I do anyway for friends, family, and at the anniversary of his – his death...I've often thought to myself, probably in a weird sense, yes I caused him pain...or maybe he didn't

feel a lot, I shall never know that, but the fact was that it happened, and I have to live with it. He died and I think it's my duty to remember him in some specific way. (Sandra)

Kelly Connor (2004) also spoke about the importance and significance of the ongoing relationship with the deceased, which she described as unrecognised.

The notion of feeling disenfranchised, appears to be evident in the context of participants' trauma and grief. Socially negated grief and trauma is consistent with the work of Lazare (1979), who suggests that such social processors can cause great harm to the surviving person, who may need to communicate with others to resolve his/her grief. The idea of communicating with others as a means of processing difficult experiences and re-constructing our stories to make sense of traumatic experiences, can be found in the work of White and Epston (1990) and Crossley, (2000). However, when the social milieu negates such experiences, the social process of trauma and grief cannot be dealt with within the social arena, thus restricting potential support, comfort and reinforcement of such an adaptive coping process. In the extract below, Sandra describes her observations and understanding of the silencing effect at large within British culture.

....living in England people don't discuss things, that's the sad thing....there must be a lot of people suffering. [Sara: What do you think stops people from being more open or talking about these kinds of things?]: Well I think, as I think I've pointed out without even realising, I mean culturally being [] you were able to, communication is one of our – we talk too much I suppose...but I suppose it's how other people are going to react. And also people, they say about the English becoming more insular....there is a lot of loneliness in this country. You're surrounded by people but er. (Sandra)

Contrasting with the external social message that speaking out about such experiences is not permissible, there are the internal beliefs and prediction about

how others would react. This was eluded to in Sandra's extract above "*it's how people are going to react*". When asked about this, Sandra responded:

Well initially I thought, if you talked about it too much, they'd probably say "Oh maybe it was your fault," or "Did you do this, or did you do that?" (Sandra)

Sandra's extract shows how her beliefs about what others might think influence her not to talk about her accident. In this way, she might be trying to avoid the predicated experiences of judgement, blame and criticism and the related negative emotions are avoided. Jane also spoke about her feelings of shame and guilt as being the main reason why she has kept the death a secret from members of her family. Again, this might be construed as an attempt or strategy to avoid these negative emotions. Both Sandra and Jane's accounts are representative of the experiences of all participants. They seem to resemble aspects of internal experiential avoidance (Hayes, Strosahl and Wilson, 2003), alongside avoidance initiated from society.

In summary, it seems that mechanisms such as disenfranchised grief, trauma and experiential avoidance help society to negate the experiences of drivers who have accidentally killed. Participants spoke about the lack of opportunity to talk and the social taboo around their experiences. Furthermore, internal processes and defence mechanisms seem to protect against the predicted criticism and judgement, this may ultimately perpetuate the cycle of disenfranchised grief and trauma.

4.2.3 Experiences of seeking and accepting professional support

This sub-theme is concerned with the processes of seeking professional support. These include factors such as feeling suicidal; problems accessing support due to the difficulties of disclosing the accidental killing, and problematic referral procedures. The second part of this sub-theme illustrates the types of therapeutic

input offered and whether these were construed as helpful or unhelpful interventions.

Four of the five participants had sought help from professional mental health services in order to help cope with the emotional and psychological impact of causing an AD. Sandra was unique in the sense that she did not seek any therapeutic input from professional services due to a belief that counselling was not available (20 years ago). She described how people, even now are “*just left*” to cope.

I don't think counselling was available then...one person covering the whole area....that's what I think is the sad thing, is there's people out there that will try and cope no matter what....say an accident, something like this, they're just left to – I did (Sandra)

For three of the four that sought professional support, they did so at a point of despair. Ben spoke about returning feelings of suicide and his escalating alcohol use, both presented as solutions to find relief from his feelings of guilt. He also acknowledged the detrimental effect on his working life.

I got really to rock bottom probably about two years ago really. Where I was really going, “Well you know, why me?”...and I'd felt suicidal in the year after the accident, but had never done anything about it. Contemplated it at one point and made a plan, but then decided well actually I want to live, and grit my teeth and got on with it, even though I really wanted to check out as well, and felt very conflicted about that at the time...and then felt, I think, more recently, perhaps two years ago, suicidal to some degree again, and not able to er – to do anything that was going to fix anything or really resolve the problem for me, which was that I felt responsible for X dying. And ended up...having difficulties coping at work, drinking more and more and more because it felt like a way to get oblivion and get release from feeling guilty.(Ben)

Daniel also spoke about his worries of suicide, which again provoked him to access professional help.

...after about three and a half years, I got to a point where I couldn't cope with it, decided to go and see a counsellor....I'd lost that belief myself that it would, that it would resolve itself....you're suddenly thinking, "I wonder how big the step is between thinking something like that, and then planning on doing something like that?" And that started to frighten you then...because you just wanted the pain to stop, you just wanted a rest from it. (Daniel)

The extracts above illustrate the degree of pain and despair experienced by Ben and Daniel. Similarly, Jane's extract below depicts her suicidal ideation, which precipitated her to seek help via her GP. The extract also illustrates how she construes her thoughts of suicide as "categorically" different. For Jane the drive to commit suicide is about "wanting to be non-existent", thus finding relief from her deep feelings of guilt and despair.

I'd made the appointment because I felt, I think in hindsight I was possibly very nearly suicidal, because I just couldn't cope with the guilt and the grief, and not knowing what was going to happen to me.....I say I was suicidal....but actually I think there's two categories of that....the suicide where you want to actually kill yourself, possibly because you feel angry with yourself, and I did feel that at one point. But then there's another sort where you feel you just don't want to exist, you actually just want to be wiped out of people's memories and thoughts – that has, been very frequent since then...immediately afterwards, yes it was thoughts of, "I need to die. I should be dead, I should kill myself to pay for it." But...since then, no it's more of a despair of, "I just want to be non-existent." And a couple of years ago that did come back, and I went to the GP....and I tried to explain it to her...she was very understanding....it's not because you want to kill yourself, it's just because you don't want to exist....I'm not like that now - but that is a feeling that has recurred over the years at bad times. (Jane)

Perhaps most notable in all three extracts is the ambivalence of wanting to live versus wanting the pain, guilt and sorrow to end. It seems that the three participants above were most at risk of suicide in the first year following the incident. However, the thoughts about suicide or wanting to be “*non-existent*” appear to re-occur over the years and instigate a recognised need for further professional support.

A further observation in the above extracts is the length of time that Jane, Daniel and Ben waited before seeking further professional help. Ben had spent ten years plus, battling with depression, alcohol misuse and suicidal ideation before reaching a point where he asked for support. Unfortunately, he then experienced difficulties with the referral process: it “*got lost*”. However, this obstacle appears to have been minimised by Ben, “*they’ll get to me when they get to me,*” illustrating conflicting approach and avoidance factors in his decisions to pursue help (Kushner and Sher, 1989). Kushner and Sher, (1989) suggest that psychological distress is an approach factor in seeking and accepting help, whereas possible treatment fears and cynicism regarding treatment efficacy are considered as avoidance factors (Rudd, Joiner and Rajab, 1995). This was evident in Ben’s account:

Psychological help really couldn’t fix anything for me.....nothing could ever change in terms of my response and my feelings about the accident. (Ben)

The prolonged period that participants coped alone also suggests a belief that their experiences did not warrant any help, and thus, negated help (Rudd, *et al.*, 1995). They suggest that the refusal to accept or pursue accessing available helping resources may be a likely function of a manifestation of feelings of hopelessness and pessimism. This may also perpetuate possible beliefs and feelings of undeservedness, and possibly self-punishment.

The initial seeking of support from outside agencies was not a simple process. Internal processes such as worries of feeling judged and social stigma created

barriers to disclose the reason for seeking help. Jane's extract below demonstrates her difficulties in communicating her needs to her GP. She talks about the quality of the relationship; the time pressure of the appointment; the presence of a student doctor and her internal battle with her thoughts.

I went to see a GP....he said, "What can I do for you?"....I ended up coming out with a packet of contraceptive pills. I couldn't tell him. I couldn't even tell him what I'd gone for..... [Sara: Why do you think that was? What stopped you, or what made it hard?] Because I didn't know him. I didn't know him, he was a stranger, and he had a student with him....I suddenly realised, "I've got all this to tell him and I've got a five minute appointment. I can't tell him in five minutes. He doesn't know me, he doesn't know I'm not a wicked person really..." I think really I needed some proper help. I didn't get any proper help for a long time. (Jane)

The difficulties Jane faced in disclosing her problems to her GP mainly centred on the quality of the relationship she had with her GP. Research by Ossvath, Michel and Fekete (2003) suggests that a consistent and personal, patient –doctor relationship is paramount and facilitates the communication of suicide ideation.

Other factors that appeared to be important for Ben were the use of prescribed medication, which seems to have helped him to accept and eventually to benefit from talking therapies. The use of pharmacotherapy to enhance access to psychological therapies is well documented (NICE, 2004), and appears to have been beneficial for Ben over the last year.

Well I think for a long time, over a decade, I've lived under the shadow that nothing could ever change...I've tried to access and get hold of that help that's actually going to do me some good. But, it hadn't been until late last year really, and partly under the influence of the Fluoxetine.....that I got to the point where I was going, "Well maybe things could change." (Ben)

Ben's acceptance of medication, many years after the accident, appears to have had a positive effect in helping him cope with his overwhelming emotions. In contrast, Sandra held beliefs that question the use of antidepressant medication, so she refused medication both shortly after the accident and in later years. She described wanting to feel and deal with her emotions, rather than suppressing or dampening them. Both Sandra and Ben illustrate a variation in their attitudes towards medication. Both positions hold meaning for the participant in how they cope with the experience.

...it's a bit like this has happened, and it's all very weird...but at the same time you don't want something to blank it out....you have to come back to reality. So it's a bit like, "Well I want to deal with it now" even though I didn't know what I was dealing with. (Sandra)

The journey of accessing professional help was also challenging for Daniel. He attended his GP for a physical complaint, but subsequently spoke about his feelings over the three and half year period following the accident. Seeking help was described as "difficult," particularly due to the waiting list times, again reminiscent of Ben's account. The waiting time appeared to increase a sense of ambivalence as to whether he needed professional help. He also spoke about challenging his views about mental health services and the associated social stigma.

....a three or four months waiting list and you're thinking, "Oh God, shall I do it, shall I do it?" And then you suddenly get the letter through, "Are you sure you really want to come?" and it's addressed from the Mental Health Unit. And you're thinking, "I'm not mental, I'm just, just deeply unhappy.".... she was, very good. I went to see her for about – it was about three or four months in the end. (Daniel)

Some participants attempted to get help on more than one occasion, but were unsuccessful. Despite Jane's previous unrewarding experience ie: leaving her

appointment with contraceptive pills. She attended a different GP surgery, sometime after, where she was diagnosed with post-natal depression (PND). This diagnosis was an attempt by her GP to deflect the stigma associated to mental health problems.

Yeah the GP said to me, "I'm going to put this down as postnatal depression because it will look better in the future." She said, "If I put you down as depression," she said, "it doesn't look good if you ever apply for jobs and things. So I'll put you down as postnatal depression, because people accept that as...an illness." (Jane)

Unfortunately, from Jane's description she received a treatment based upon a diagnosis of PND, rather than receiving a treatment based upon a comprehensive formulation. Jane experienced aspects of the treatment as helpful, such as enhancing her self-esteem. However, she described how the therapy avoided and in fact perpetuated the guilt.

....it didn't address the guilt....it didn't address, that wickedness inside me.... in a way it like transferred the guilt onto my parents and how they'd brought me up....I felt as if it was almost putting the guilt onto them, that I was feeling bad about myself because of the way my parents had treated me in childhood. So it didn't help, it didn't help. (Jane)

The key to any effective intervention is a thorough formulation, which is then shared with the client (Persons, 1989, Johnstone, 2000). This sharing of understanding is developed through active listening, respect, genuineness and empathy (Egan, 1975). It seems that Jane found the therapeutic work dismissing of her primary feelings of guilt and thus invalidating. Egan (1975) suggests that denial of acceptance and positive regard can inhibit the client's ability to relate the meaning of their experiences to themselves in a meaningful way. Ben also experienced a sense of feeling misunderstood during a course of cognitive behavioural therapy (CBT).

...CBT just – at least the approach that was chosen during the CBT based counselling I had experienced wasn't the right one....I'm certain that trying to assert that I'm not guilty your honour, is not the answer. I need something else, I need another approach. (Ben)

Attributing causation as a means to develop balanced thinking and help discredit 'maladaptive underlying assumptions' is common in CBT practice (Becks, 1976; Leahy, 2003). However, Ben experienced CBT as “*unhelpful*,” and his reference to the therapist as “*your honour*” may suggest that the therapist was experienced as persecutory and therapy was reminiscent of the court proceedings that he described as “*traumatic*.”

The use of CBT for survivors of RTAs has developed over the last decade. There are several manualised CBT treatment programmes for survivors of RTAs (Hickling and Blanchard, 2006). However, they only occasionally comment on the difficulties that the techniques may pose for clients who have caused accidents or fatalities. Their manual orientates towards those who are seen as the 'victim' or those 'done to', as opposed to being the cause of the accident. This may be a result of the samples used in the underlying evidence based research, which supports the treatment. The vast majority of the RTA treatment evidence-base (Blanchard and Hickling, 1997, 2004; Blanchard, Hickling et al, 1996; Ehlers, Mayou and Bryant, 1998; Harvey and Bryant's, 1998; Mayou, Ehlers and Bryant, 2002) derives from 'survivors' of RTA who have been recruited through A&E departments, thus creating a sampling bias for those physically injured. In the accidents that involve pedestrian fatalities, the driver is often not physically injured. In such cases, they are likely to be dealt with by other agencies, and thus not be available for recruitment to studies. This may have been part of the sampling bias found in Harvey and Bryant's (1998) study whereby only three drivers who had caused fatalities were recruited into their sample of 92 survivors of RTAs. From these three only one remained at follow-up and was subsequently diagnosed with PTSD.

Despite the difficulties that Ben experienced with his CBT therapist, he developed new insights and learnings that were no doubt of great benefit to him.

I can see that there is some merit to talking this through further with somebody, and exploring better ways to think about what I've experienced, and better ways to live with it. So for the first time in 12/13 years, the last six months has represented a bit of a change in thinking - six to twelve months, change in thinking and change in outlook for me. (Ben)

Others also commented on the value that their therapeutic encounters brought. Amy found the flexibility and regularity of telephone counselling helpful. She also commented on particular techniques, such as role-playing a court scenario, in preparation for the court proceedings. She described this as being “*really hard...But it was helpful*”.

Daniel reflected on his experience of therapy, the grief work and exploration of the relationship that he may have had with the man that died appeared to be a poignant aspect in his therapy. The concept of exploring a relationship with a person who has died is evident in the work of Reisman (2001). However, Reisman's (2001) research is in relation to those close attachments such as spouses, and not with people who are strangers. Regardless of the closeness of the relationship, there appears to be a relationship which is held in mind between the participants and the person who they accidentally killed. This is depicted in Daniel's extract below, and a previous extract from Sandra in the disenfranchised grief and trauma sub-theme, where she talks about her remembering and her grieving practice. Both depict a relationship to the person that had died despite being strangers that appears to be adaptive to their thinking and coping.

...she said, "If things with you had been ever so slightly different and, you'd been hurt, and the rider had been hurt, and you both ended up in hospital together," she said, "what sort of relationship do you think you would have

had?" I said, I don't know, probably would have got on OK...bonding, and recovering from the injuries it probably would have gone on. (Daniel)

Despite the positive experiences and support received from their therapists, Jane and Amy commented on disclosing information that they had not been able to reveal previously. Jane spoke about how she had "*never had the opportunity*" to speak openly about her feelings. She even felt unable to speak honestly to her psychologist for fear that the documentation regarding sessions would be used against her. This may be a residual feeling derived from the legal proceedings.

I've never had the opportunity to actually talk to somebody about things like this, and know that you're not going to write a letter to me GP, or it's not going into hospital notes that people might drag up years later. Because that's another thing, you defend yourself against....because you know that the psychologist you're seeing has got to write notes, and she's got to write back to your GP and things. (Jane)

Amy also commented on her openness to disclose during the research. These extracts demonstrate some evidence of the therapeutic value of qualitative interviews (Birch & Miller, 2000).

I mean as far as talking about it, this is quite – it's good to do. And there's things that I've told you that I haven't told anybody, even within counselling. And I think everybody needs to do it. (Amy)

The context and anonymity of the research perhaps allowed participants to express their most private thoughts and feelings. Whilst acknowledging the dilemma of the importance of talking and the difficulties of talking, it seems that even the context of therapy does not feel safe. Hickling and Blanchard (2006) and Mitchell (1997) suggest that legal issues can create difficulties for both the clinician and client in relation to RTAs, although they do not elaborate on this point. Perhaps the boundaries of confidentiality are difficult to negotiate, particularly if there are

ongoing legal issues present, meaning that the therapist's clinical notes could be subpoenaed at any time.

In summary, there is a strong narrative that seeking professional help is precipitated by deep feelings of unhappiness and suicidal thoughts. Participants' accounts demonstrate that the disclosure of psychological distress and the reasons for seeking help is a difficult process. Factors such as good patient-doctor relationships can influence these disclosures. However, the process of referral and waiting times appeared to create ambivalence regarding their perception of their psychological needs. Stigmatisation and for one participant the stigma expressed by their GP appeared to influence their decision making process. For one participant this led to a misdiagnosis, which had detrimental effects; the treatment received was not appropriate. It appeared that feeling misunderstood, invalidated and possibly experiencing therapy as persecutory and reminiscent of court proceedings, are likely to interfere with any therapeutic progress. Furthermore, issues around confidentiality appear to be potentially problematic for this client group due to legal processes. Despite numerous therapeutic difficulties, participants identified a number of helpful therapeutic experiences, such as the realisation that talking helps.

4.2.4 The process and struggle of recovery

All participants described recovery as a struggle or a difficult process. Sandra described it as *"being hell"* and *"not knowing"* how she had *"survived."* The participants spoke about how their psychological states have fluctuated in the years that have followed the accidents. All spoke about the *"uncertainty"* and *"fragility of life,"* given how the accident had challenged their assumptive worlds (Janoff-Bulman, 1992). They reflected on their experiences as a journey of survival.

...it's a bit like you just try to survive and go from day to day. (Sandra)

I remember thinking a short time after it happened, I remember saying to myself, "I'm going – you'll – you will feel better in time," and that really helped.

It didn't – take away from the pain of the moment, but it made me, yeah I know I'll be better in time. It's taken a long time, (laughs) I'm still not there.....there are days – I don't think about it every day now. I mean that was the master, not to think about it every day. (Amy)

In the extract above the passage of time appears to help the healing of emotional wounds. There is a sense of moving forward yet living with the pain of the moment.

The sense of survival involves a process of moving to a place where the distress of causing an AD becomes better accommodated as part of the vicissitudes of life. It was interesting that two participants drew on metaphorical descriptions involving nature when reflecting upon their experiences. Nature represents something that we cannot control. This may be synonymous to the powerlessness and uncontrollability of causing an AD. The metaphors below depict these changing circumstances, moving from an inhospitable and dangerous place, to an awareness that there is a place beyond, which seems symbolic of hope and growth.

Initially it would have been a forest full of brambles and snagging on me and not being able to see the way. Moving on to a younger forest, smaller trees, and you can actually see your way through them. And then, moving out to a big meadow where there's flowers and....it's very, very bright. And it's OK, and if you want to you can sort of wander back to that forest, but you don't get snarled any more, you can protect yourself and walk among it, but get out again if you want to, back to the meadow....the meadow is a good place to be. (Amy)

it's sort of like being stuck in a trap....a bear trap, or stuck in a pit, and really finding ways to live there....stuck in a dark, smelly, difficult pit and.....foraging around for anything that will keep you alive, but not really being able to get out of it...and sort of finding that there might actually be a way to get out is sort of the journey I've taken over the last twelve years.....and that last realisation has only been in the last few months really, on the basis of over a decade. (Ben)

The idea of a bright meadow, which is seen as “a good place to be”, and the awareness of a “way out” appear comparable with the concept of post-traumatic growth (Tedeschi, Park, and Calhoun, 1998). The possibility of growth does not dismiss the pain and trauma of the “bear trap”, “pit” or “forest”. These feelings remain, and as Amy suggested it is a place that she returns to from time to time, but feels able to protect herself and draw on her self resilience. It seems that both Ben and Amy have integrated this place as part of their life. These metaphorical descriptions appear to expand on the meaning of their experiences; developing an allegorical story that conveys emotional meaning better than literal speech. They also scaffold their experiences to mark change and re-orientate how they relate to their difficulties (Martin and Sugarman, 1997).

The concept of transforming trauma to growth is often dismissed in trauma research due to the focus placed upon the negative effects of trauma, particularly PTSD. Foeckler *et al.*, (1978) illustrated this point when they acknowledged that they had not included nor intended to find positive changes in the drivers who had caused a death, yet many drivers in their study expressed positive effects following the accident. These included renewed religious faith, a greater appreciation for the value of life, developing beliefs that life should not be wasted by heavy drinking, and becoming more determined to help others. Participants in this study mirrored all of these elements; they included a greater empathy for others, particularly in relation to their professional roles and friendships and a new appreciation for relationships and parenting. There is a sense that participants almost honour those that have died by making themselves better people through helping others, fostering compassion and empathy, thus channelling growth in a positive direction.

I think I'm keen now to, if you can do something for somebody, do it, and do it without any pay back at all...if you can do it without any great expense, or put yourself out, and it's, "Shall I do it or shall I?" well do it, just do it. (Daniel)

Others spoke about regenerative activities such as reflexology and evening classes, which helped in their healing process. Others renewed their driving skills, bolstering mastery and confidence in their abilities as drivers.

For me that was partly... a sort of a regenerative or recovery thing....can I extend my driving skills or riding skills to another vehicle? (Ben)

...after 12 months I still wasn't driving...I joined the Institute of Advanced Motorists and I did lessons....I told her exactly why I was doing them... normally you go with different volunteers each week, but they kept me with her all the time. (Jane)

Sandra simply spoke about the importance of having “*hopes and dreams.*” She felt that her aspirations about her future brought meaning to her life. She described them as what “*kept her going the most.*”

In summary, throughout the participants’ narratives, they demonstrated recognition of their strength and ability to endure great adversity, akin to Tedeschi, Park, and Calhoun’s (1998) concept of post-traumatic growth. The participants appeared to identify themselves as emerging from an emotional storm and a self-appraisal process with new resolve. It seems that trauma and tragedy can motivate personal growth and that this should not be neglected in the process and struggle of recovery.

4.3. A changed sense of self

This superordinate theme captures a spectrum of internal adjustments in the way that participants saw themselves following their accidents. There is a sense of struggle, as the loss of an established self, wrestles with unwanted and conflicting parts of self. Kelly’s (1955) conceptualisation of identity as a collection of multiple selves is a useful concept in relation to people who have caused an AD. In this theme, a responsible self, a guilty self, and a shameful self, come to the fore and participants describe living with these multiple selves. Reconstructing one’s self

involves attempts to integrate or fend off unwanted parts of self, which appears to be a continuous process, regardless of whether the accident occurred six or twenty years ago. However, all participants identified some aspect of a renewed or resilient self that emerges in the reconstruction of self. This aspect was also partially covered in the previous sub-theme of *process of recovery*. This present theme also captures the impact of the trauma, which created a loss of identity for some. For others the accident heightened a sense of identification with the person that they had accidentally killed.

4.3.1 The initial adjustment in their self view

Many authors such as McNally (2005) and Crossley (2000) have written about the disintegration of an established self, leading to a changed or adjusted sense of self in the aftermath of a serious trauma. The shattering of assumptions held about oneself following a trauma is believed in some instances to create a shift in the way that one views one's self (Janoff-Bulman, 1992). The participants in this study spoke consistently about their core sense of self as feeling in disarray or fragmented. They used terms and phrases such as, *"I just fell apart"*; *"I was just a... wreck"*; *"I must have been so disjointed"* and *"it just wasn't me"*.

In response to a question that I asked concerning his thoughts and feelings during the moment of learning about the death, Daniel spoke about a moment from the accident where he thought that he himself may have died. This association may suggest that Daniel, at the time of hearing the news, possibly felt that a part of himself had died as well, reinforcing his sense of a distinct change or disintegration in his sense of self.

...there was a split second where you're thinking, "I wonder if that – hey I wonder am I dead?".....I mean because there was just this whiteness in front of me and this sort of silence. The air-bag must have deflated, and then it's just all gone crazy. (Daniel)

The shift was also evident in participants' descriptions of self as they contemplated this new and unwanted dimension to their sense of self. Daniel describes his internal rejection of a killing identity:

What I found myself thinking was, "I don't want to be the guy who's, killed somebody else.." (Daniel)

Amy's use of the terms feeling "*absolutely alarmed that I had done that.*" illustrates the incongruence (Festinger, 1957) she experienced having learnt that she had caused a death.

The extract below captures how Ben struggled to integrate the experience as part of his self-narrative. The denial mechanism helped to maintain his established, familiar self, thus protecting against a perturbed, incongruent part of self. He also described a change in his sense of self, one that was "*enforced upon*" him. This imposed criminal identity almost jars with his former sense of self. This gave rise to uncomfortable and difficult feelings.

I've caused somebody's death and it's my fault....there was a long period of denial before I got to that conclusion. And that conclusion was sort of enforced upon me by law, it wasn't something that I naturally came to.... yeah, so difficult, difficult and traumatic. (Ben)

Amy also met challenges during the process of adjusting her view of self. She illustrated how she had to confront, challenge and adapt her existing beliefs, and "*prejudices*" to be able to accept the change that the accident had brought to her own view of self.

...when this happens...you're faced with all those prejudices that you've ever, actually all those feelings that you've ever had about anything you've ever read in the paper...And suddenly you're faced with all those, things that

you've actually said yourself, so it makes you start to look at things very differently....there is another side to it. (Amy)

In summary, the initial adjustment of participants' views of self, when trying to accommodate a new self dimension, ie: "a person that has killed", appears to be a difficult and challenging process. It sits uncomfortably and in opposition to the existing self view, that of a 'good' person.

4.3.2 An unwanted self

A significant feature of all participants' accounts was the intense struggle between a responsible self and a guilty and shameful self. This collection of selves was described as "unwanted" and "conflicted" with the view of what they perceived as a being a "good" person. This corresponds with Taylor (1989), who suggests that our moral identity develops and becomes negotiated in relation to what we see as 'good'.

When faced with such adversity, participants in the first instance drew upon social discourses that paralleled with their experiences of deep regret, responsibility and guilt. Phrases such as "an eye for eye" or religious scriptures such as "thou shall not kill" were used to reason with internal world experiences about the value of one's own life.

If you think that feeling responsible for killing somebody it makes your own perception of your own life value fall away to nothing progressively over time, because it really affects your thinking....you end up with that crude, simplistic an eye for an eye thing, "Well I've killed, so therefore I shouldn't be here either." (Ben)

Regardless of the source of judgement (i.e., whether it was internally or externally driven), all participants experienced a heightened sense of guilt and shame. They felt responsible for causing an AD. This finding supports Lowinger & Zoloman's (2004) study investigating PTSD and guilt in drivers who unintentionally killed. They

go on to suggest that for drivers who kill, the lack of legitimacy to externalise their feelings can be displaced into strong feelings of guilt (Lowinger, Zoloman, 2003). However, it is worth noting that their sample consisted of drivers charged with 'reckless driving' including drink-driving, which differs distinctly from the sample in this study.

The presence of guilt and shame was most evident and most dominant in Jane's narrative. The meaning she attributed to her thoughts at the time of the event complicated her feelings.

I think I could have done [driven away].....I think it's probably that feeling that makes me feel more guilty than anything actually, possibly more than what I did, the feeling that I could have run away from it, and lied and said, "It wasn't me, I wasn't there." I never told anybody that before. But I could have, I could have done, could have said, "No, no I wasn't there, it wasn't me." I think that's....the bad thing, that's the human instinct, isn't it, the denial? It was straight away..."It can't possibly have been me." (Jane)

To Jane the thought of "running away" seems almost as bad as actually doing it for real. This is similar to the concept of thought-action fusion (Berle and Starcevic, 2005). Thought-action fusion is the tendency for individuals to assume that certain thoughts either imply the immorality of their character, or increase the likelihood of catastrophic events. Jane internally appraised the presence of the thought of "running away" as "bad." As a result, she referred to her whole self as "evil", "wicked" and "bad". Not only was she internally appraising her self in such denigrating terms but her cognitive bias also dictated how she thought others might view her. Other participants also spoke about their worries of being judged by others as "bad" or "murderous" people.

[Sara: What did you think they were thinking?] About being evil, that I was wicked, that's how I felt – I don't now.... At the time I thought I just wanted to be invisible, I didn't want anybody to see me, because I just felt so

ashamed....I just thought they must think, "She's that stupid woman.....stupid to do what she did, or vindictive, or wicked." That was how I felt....I know it's completely irrational.....At the time I just felt such dreadful shame, and guilt.....I felt like a murderess, and in my heart that's what I was telling myself, that I was a murderer and I shouldn't be there. (Jane)

These global negative attributions relate to Wallbott and Scherber (1995) and Tangney's (1997) conceptualisation of shame. Despite the large empirical research base on shame, there appears to be little consensus on the meaning of shame and how it differentiates from guilt (Kubany & Watson, 2003; Harder, 1995; Lindsay-Hartz, De Rivera & Mascolo, 1995; Tangney and Fischer, 1995). However, some shame theorists appear to agree that one of the most distinctive features between shame and guilt is that shame involves depreciation of the entire self whereas guilt involves depreciation of specific actions or behaviours (Wallbott and Scherber, 1995, Tangney, 1997). In other words, with shame the emphasis is on 'a bad self – there's something wrong with me' – whereas with guilt the emphasis is on 'a bad behaviour – there's something wrong with what I did' (Tangney, 1997; Kubany & Watson, 2003).

Most participants feared public condemnation, which is likely to have increased their guilt and hindered their coping ability (Feockler, *et al.* 1978). Again, Jane was unique in how she moved from wanting to conceal her shame and guilt "*wanting to be invisible,*" to then presenting her accident to potential friends. By doing so, she subjects herself to the potential public condemnation and judgement, but also develops opportunities to hear forgiveness from others.

.....if somebody wanted to be my friend they had to like me for me good and me bad. So, anybody I met new, if I felt I wanted them into my life to be a friend with them, I had to tell them what I'd done....I had to expose myself almost to them, so that then they could decide to accept me or not accept me for....I still had this thing that I was such a bad person.(Jane)

Jane stated how she had never told anyone about her thoughts of wanting to drive away, which appeared most intrinsically tied to her deep sense of chronic shame and guilt. It seems that in Jane's narrative the relationship between shame and guilt is complex and cannot be easily separated. However, it is clear that the inability to talk to others and share these thoughts and feelings, and the meaning that they hold for her sense of self, appear to have hindered her ability to process these salient thoughts and feelings. The process of sharing experiences with others is a key mechanism in the development of self (Mead, 1967). Without such a process, Hickling and Blanchard (2006) suggest that there is a potential for self recrimination, which in turn can hinder the reestablishing of an adaptive self following trauma (MacNair, 2002).

In summary, there appears to be a complicated relationship between responsible, shameful and guilty selves. These multiple selves are intrinsically linked to negative thoughts and feelings. If these are not processed and spoken about there is a potential negative consequence for the reestablishment of an adaptive self after causing an AD.

4.3.3 Challenges to personal roles and identities

The experience of the accident and causing an AD had a huge impact on participants' sense of role identity. Four of the five spoke about their self view as mothers, fathers, spouses and their occupational roles, in relation to causing an AD.

In the extracts below, all three women reflected on their capacity as mothers during the time of the accident.

I mean for two or three days I forgot I had children. (Sandra)

...my son was eleven at the time.....that was quite hard because I was in a different place and I don't think I was always there for, him at that time really.
(Amy)

I think it came to a head one day. I don't swear, but it must have been six, seven, eight months after the accident, and my three year old said to me, "Mummy I'm hungry, can I have something to eat now?" (sobs) And I told him to eff off. How can you say that (sobs) to a three year old? I think I realised then. Because I couldn't do anything – I know now I was depressed – I just sat in the chair all day till the minute my husband came home....But...I couldn't function.....it shocked me when I said that to my child....I thought, "This isn't how a 3 year old should be treated." (Jane)

The loss of identity as a mother and a diminishing ability to function as a mother is evident for all the women in the present study. The described estrangement and temporary change in the quality of their relationship with their children, is similar to notions discussed by Wiffen and Oliver (2004). They identified changes in the familial and marital/couple relationships following traumatic experiences. Wiffen and Oliver (2004) conceptualise this shift in the relationship as “a shattering of the interpersonal bridge” (p.515) this seems to relate to Janoff-Bulmans (1992) theory of shattered assumptions, as discussed early in this chapter. The extract beneath further illustrates how Jane’s interpersonal bridge with her children became shattered. She consciously and intentionally detached herself from her children in order to protect him and herself from her predicted fear of imprisonment. However, Jane’s decision to mother from a distance has caused further guilt and psychological distress in later years.

I deliberately didn't bond so that – I still breastfed him, because I knew that was best for him physically. But mentally I didn't cuddle him as much as I should. (Sniffs) Because I thought that I would go to prison and I thought, "It's cruel to let a baby attach to his mother," because I've always been a full-time mum, and I thought, "It's – it's just cruel to do that." So I sort of kept him

at arm's length really....That actually did cause me problems last year, I ended up going to see a counsellor. (Jane)

Fatherhood featured in Daniel's account. Similar to the women, he was unaware of the impact on his children at the time. The conversation with his daughter revealed his anguish at the potential loss of fatherhood, something that has remained upsetting for Daniel.

...you think about how it affected them. It was three or four years later, I was driving somewhere with me daughter and, you know, she got chatting about it and...she said she can remember worrying that I'd get sent to prison at the time I didn't sort of notice any of this, you know, it was probably kept from me, I don't know. But...things like that upset you all that time afterwards. (Daniel)

Participants also identified with the roles and identities (i.e.: as mothers, fathers and children) of those that they had accidentally killed. In Daniel's extract below, he talks about his fantasies, and the sorrow and pain associated to the loss of father experienced by the daughter of the man he accidentally killed.

The guy who died...has a daughter...it absolutely crucified me then, that she was left with no father....I found that really hurtful....I remember being at a wedding reception and the groom got up to speak, and his father had died a few months beforehand.... And I was just sitting there thinking, "This guy's daughter is going to get married some day and.....traditionally it's about the bride, he's not going to be there....her father's not going to be there to give her away..." It's the hole that's left which was the hardest thing for me to deal with. (Daniel)

This type of identification and empathy for those who have died is also evident in literature relating to soldiers following combat (Hendin and Haas, 2004) and those involved in killings within their own communities or neighbouring villages such as in Bougainville (Thompson, 2001).

In summary, participants' sense of role identity, particularly in their functioning as parents appears to have become temporarily diminished following their experiences of accidentally killing. The loss of identity as a mother or father may mediate the shattering of the interpersonal bridge with their children in the immediate aftermath of the trauma. This fits with Janoff-Bulman's (1992) theory of shattered assumptions following traumatic experiences.

In this section I will present a summary of the study's findings in relation to the research questions and consider their clinical implications. I will then critically review the methodological strengths and limitations of the study and make suggestions for further research. Following this, I shall reflect upon my experiences of conducting the research and end with some concluding remarks.

5.1 Summary of findings

The primary aim of this study is to develop an in-depth exploratory account of people's experiences of causing an AD of another person for which they feel responsible.

5.1.2 Research question 1 and 2:

How do those who had accidentally killed experience their sense of mental health following the accident and what meaning were individuals able to find in their experiences?

The experience of accidentally killing represented a distinct life-changing moment for the participants in this study. Participants' sense of their mental and emotional well-being after learning of the death was experienced as overwhelming and unfamiliar. The uncertainty surrounding personal recollections and feelings, represent a great challenge for participants to make sense and meaning from their experiences. For those with amnesia the integration of a reconstructed self-narrative posed an even greater challenge. Participants' experiences seem to

extend beyond normative responses to stress into possible symptoms of trauma. It is possible that these intense emotional and cognitive experiences inhibit the early sense making process (Charney, Deutch, Krystal, Southwick and Davis, 1993). The experiences of accidentally killing and the pain associated to this were understood in the context of being part of their life experience, a part that has to be lived with and acknowledged rather than avoided.

5.1.3 Research question 3:

What helped or hindered participants' experience of coping with causing an accidental death?

The struggle to cope with accidentally killing placed a great demand on participants coping resources. Relational factors, particularly marital relationships, parent-child relationships, and other family relationships played an important role in the coping process. However, a pervasive lack of understanding left drivers who had accidentally killed feeling detached and socially distanced: traits characteristic of post-traumatic states. Mechanisms such as disenfranchised grief, trauma and experiential avoidance appear to contribute to the social negation of their experiences. These social processes perpetuate the internal processes and defence mechanisms that protect against the predicted criticism and judgement. However, all of the participants sought a connection with another who had similar life experiences. Most significantly, feelings of deep unhappiness and suicidal thoughts featured as approach factors for three of the four participants who sought professional support. However, fears of judgement, criticism and untimely referral procedures appeared to create barriers and ambivalence in seeking professional help. The types of therapy experienced were not consistent and for some it was experienced as detrimental. Furthermore, issues around confidentiality and disclosure appear to be particularly challenging even when legal proceedings are not current. Despite the trauma and their struggle to cope with the experiences of accidentally killing, all participants identified some aspect of new resolve and personal growth.

5.1.2 Research question 4:

How does the experience of causing an accidental death affect one's sense of self and identity?

Accidentally killing another person created a changed sense of self. The self-view as a person responsible for another person's death is initially rejected and the established self wrestles with a responsible, guilty and shameful self. This struggle re-emerges over the years and is an ongoing battle. Participants' sense of role identity, particularly in their functioning as parents appears to become temporarily diminished, shattering their interpersonal bridge. This corresponds with Janoff-Bulmans (1995) theory of shattered assumptions following traumatic experiences.

The qualitative and IPA approach to this study has generated the emergence of new understandings into a unique and under researched topic of investigation. Although it is a small study, the findings add useful knowledge to the current evidence-base relating to the aftermath of causing an accidental RTA death.

5.2 Implications for clinical practice

The struggle to cope with the psychological aftermath of causing an AD was evident in all participants, and for three of the five participants suicidal ideation featured as a recurrent theme. This finding has implications in relation to the Government's initiative (DoH, 1999; DoH, 2002) to reduce suicide rates by 20% by 2010. This group of people appear to be at a high risk of suicide particularly in the first year following the accident. Alcohol misuse, an inability to function in the work place and at home, and the recurrence of the deep feeling of guilt and shame appear to instigate feelings of suicide and attempts to seek help. At crisis point and often after many years of suffering, the referral process for these participants represented a further barrier to accessing appropriate professional help. Not seeking professional help when suicidal may have tragic consequences and is reflected in our current suicide statistics. At present it seems that our health

services operate on a 'treatment strategy', ie: late professional help, if any at all and adopts a 'wait and see, and cure if necessary' stance. This is a traditional medical practice assumption: that traumatised and bereaved individuals will act upon, define and present their problems to professionals, and actively ask for help (Dyregrov, 2004). This study demonstrates how challenging it is for this group of people to access professional support, and receive the support they need. This highlights a need for greater awareness amongst GPs of the possible detrimental psychological affects of causing an AD. This in turn may facilitate earlier and timelier referrals to appropriate secondary mental health services.

Despite the small nature of the current study, the findings illuminate some interesting clinical needs for drivers who have accidentally killed. It appears that drivers are likely to benefit from early intervention support, or crisis intervention. This may serve as a preventative strategy against the development of more serious trauma responses and complicated grief reactions (Murrey, Terry, Vance, *et al.*, 2000). The findings suggest that such provisions might include empathic emotional support during the often terrifying period of initial shock and development of trauma symptoms. Information provision also appears to be key, particularly offering information about potential trauma responses and how they and their family can recognise the progression into more serious PTSD symptomology. This information may be beneficial, together with information on how and where to access mental health services. The absence of such knowledge appeared too contributed to the participants' distress and uncertainty. The findings also suggest a need for signposting practical assistance, e.g.: informing people about the criminal justice system and procedures. Drivers who cause ADs may also benefit from support groups or speaking with others who have also experienced causing an AD. This type of psychosocial assistance is not akin to 'debriefing' practices. The task may be to normalise and bring some order, mainly through information provision, to the lives of those who have accidentally killed.

Early intervention support as suggested above already exists for people bereaved in RTAs. However, they only serve the interests of family members of the deceased victim. For them, support in the form of self-help books and support groups are available through a number of charitable organisations (Brake, Road-Peace, Road Victims Trust, Assist). The research highlights that the experiences and needs of those who have caused an accidental death are equally as important as those who are traditionally viewed as 'the victims'. Unfortunately, there is no such support for those drivers who have caused an AD. As a society, we appear to turn away from these drivers' pain and needs and therefore maintain their experiences of disenfranchised trauma and grief. Perhaps the simple provision of information in the form of self-help leaflets may facilitate recognition of their experiences and encourage timely up-take of appropriate services.

Furthermore, those who are considered victims are designated a Family Liaison Officer (FLO): either a police officer or from local social service authorities. It is worth noting that agencies such as BRAKE and Road Peace participate in training FLOs and other professionals responding to road injury and deaths (Road Peace, 2008). However, these organisations represent the interests of victims bereaved and injured through road crashes. Given the agenda of services such as BRAKE and Road Peace, it is possible that there is a serious lack of training for police officers, hospital personnel, and social service workers about how to respond to drivers' distress and that of their families, even though their reactions can have detrimental long-term effects. It is possible that through further research into the experiences of drivers who accidentally kill, clinical psychologists could provide training and supervision to front-line workers to help provide drivers of RTA fatalities with the much needed emotional and practical support that is currently missing.

When those who have accidentally killed do come to the attention of clinical services, there is very little literature to inform clinical practice. Clinicians must therefore extrapolate skills and apply them to this population. However, the

difficulties faced by drivers who accidentally kill are likely to be different and much more complex in relation to victim's families. For example, interventions that target an array of PTSD symptoms do not fully capture the struggle to understand the nature of responsibility and acceptance of their role in a person's death, nor does it find a measure of redemption or meaning. Each of these areas could be topics for further investigation, which in turn may influence potential treatment strategies for this population.

The findings of this study also suggest that perhaps the boundaries of confidentiality within a clinical context are difficult to negotiate, particularly if there are legal issues present, meaning that the therapist's clinical notes could be subpoenaed at anytime. Hickling and Blanchard (2006) comment on the difficulties that legal proceedings place on both the clinician and client. However, the findings from this study suggest that, even when legal proceedings were historical (for some twenty years ago), there is a residual effect on the establishment of therapeutic trust which may hinder disclosure of very painful and often shameful thoughts and feelings. These thoughts and feelings may underlie clients' presenting problems. Such findings imply that clinicians should be mindful, consider the impact of such experiences in relation to confidentiality, and discuss this openly with their client. This may re-affirm trust and safety to disclose, ultimately leading to a more beneficial therapeutic experience.

We, as researchers and clinicians hold a responsibility to generate greater awareness of the potential negative psychological consequences for drivers that have accidentally killed; we need to promote greater access to mental health services and promote the possibility of turning trauma into personal growth.

5.3 Strengths and limitations of the study

In this section, I will consider strengths and methodological limitations of this study. I will also discuss reflections of the experiential process of conducting the research. These are presented in the hope that they, in combination with the clinical,

research and methodological issues, may help the reader to place the research in its social and cultural context.

In undertaking this study, I have attempted to be rigorous and transparent in the analytical process, as well as to adhere to recommendations for ensuring the credibility of results (Yardley, 2008, See Appendix I). These are considered to be strengths of the study. However, the study's findings are based on the experiences of a small and homogenous group of people. Thus, the study is modest in its claims, acknowledging that the findings may or may not resonate with the wider population of drivers that have caused an AD. In addition, the sample was self-selected, and for this reason, they may not have been representative of drivers who have accidentally killed. Nevertheless, a further strength in this study lies in the attention it draws to the large numbers of people involved in accidentally killing.

Furthermore, the limitations of a cross-sectional design must be considered. Given more time, a longitudinal design may have yielded greater depth and allowed for the development of an account more steeped in the cultural, social and historical contexts of participants. Thus, capturing the processes by which they develop a temporal understanding of their experiences of accidentally killing.

5.3.1 Reflexive considerations

Reflexivity in qualitative research is imperative in terms of considering how personal, cultural and political values influence the researcher and their interaction with the analysis. Furthermore, the context of the research and the needs of the participants to present a particular story affect their accounts (Elliot *et al.*, 1999). All of these issues were considered, documented and discussed within supervision. However, in presenting some of my reflections, I acknowledge how I, as the researcher, may have contributed to shaping the findings; through my interactions with participants and also through my own assumptions and beliefs. It is hoped that these reflections might be helpful for others conducting similar projects.

During my experience of conducting the interviews, I became aware of the richness and openness of the participants to disclose their experiences, thus demonstrating why they were considered as the experiential experts. The story of being silenced and not permitted to talk about their experiences was one that I had expected as a result of a pilot interview with Kelly Connor. My motivation to study this topic was increased as the silence appeared to extend into the academic arena, demonstrated by the stark absence of research in this area. This motivation is likely to have influenced the issues pursued within the interview and analysis. For example, whilst analysing the first interview I became aware that I had a desire to highlight instances of being silenced, possibly at the expense of acknowledging instances where participants had had an opportunity to talk to others. However, this was discussed in supervision, and attempts were made to approach the transcripts with a more open mind.

During the interview process, I found it very difficult to end the interviews. On reflection, this challenge may have been a consequence of not wanting to repeat the pattern of silencing and wanting to stay with difficult emotions, rather than moving swiftly on. These instances represented my dilemma of moving between clinical and researcher positions. They all engaged in the interview process quickly and again on ending were very grateful and thanked me for listening. I understood this as a reflection of the lack of opportunity that participants had to talk openly about their experiences.

As part of the ethical considerations, I considered not only the possible negative impact for participants, but also the impact on myself as a researcher when exploring issues of trauma. During the latter interviews and throughout the analysis process, I believe that I experienced some symptoms of vicarious traumatisation. I first became aware of this when I began to feel anxious whilst driving; this fluctuated throughout the process of this research. However, through reflection, I am aware of where this anxiety had come from, and through good supervision and peer supervision, I was able to discuss these feelings.

Another experience of vicarious trauma emerged through my dreams. This was mainly experienced during the analysis process, and it has given me a new understanding of the terms 'immerse yourself in the data' (Smith and Osbourn, 2008). My vivid dreams seemed to be one of the mechanisms in which I was processing the participant's stories; they distinctly mirrored the lived experiences of the participants. Despite being challenging, these experiences have given me new insights, which have helped to inform me about the possible position of my participants. Such experiences also provide information regarding the potential challenges of working clinically with this group of people. Again, the use of supervision and peer supervision were essential in helping me to reflect and process these experiences.

5.4 Suggestions for further research

The Government drive is to reduce the cost on mental health services. Furthermore, large-scale epidemiological studies demonstrate that PTSD and other trauma related diagnoses such as anxiety, depression, specific phobias and substance misuse, are amongst the most common diagnoses given to individuals and RTAs are the most common cause (Norris, 1992). Thus, it seems appropriate that research into the experiences of drivers who have caused an AD should be prioritised, regardless of the pragmatic challenges that it faces, such as recruitment and medico-legal issues. The frequency of road fatalities is currently at nine each day in Britain, possibly leaving a large number of drivers to cope with the immense psychological aftermath of accidentally killing, as identified in this study.

This study represents a new area of research. I propose that the evidence-base for trauma research in relation to accidental killing would benefit from a larger scale qualitative approach. Were a similar study to be conducted in the future, it may be beneficial to consider more than one contact with participants. A longitudinal design could assist in developing a more comprehensive understanding of the cultural, social and historical contexts in which their experiences and views were constructed. Based on greater depth and understanding into the experiences of

drivers who have accidentally killed, it may become possible for researchers and clinicians to continue to formulate and speculate about the underlying mechanisms that drive the high levels of psychological distress experienced by this population.

6. CONCLUSION

This study aimed to gain an insight into the lived experiences of drivers who have caused an AD. The experience of accidentally killing represented a distinct life-changing moment for drivers in this study and was described to be “*like no other stressor*.” The incident created a wave of destruction and uncertainty that seeped into all domains of the participants’ lives, creating existential questioning as they wrestled with the feelings of responsibility, guilt and shame; challenging their relationships with others; changing their self-view; and diminishing their abilities to function at home and at work. These experiences most closely resembled Janoff-Bulmann’s (1992) theory of shattered assumptions. However, through the passage of time and with the opportunity to express their experiences, most participants appeared to begin “re-weaving a web of meaning” (Orr, 2002).

It is hoped that this study will serve as a catalyst and inspire discussion in the development of further research examining the experiences of people who have accidentally killed another person. Given the stark absence of literature on this topic, we, as researchers and clinicians must ask the questions that facilitate people to voice their often unspoken stories, rather than shy away from these painful and difficult experiences. As demonstrated by Ben, psychological interventions can provide a mechanism to break a destructive cycle; people who accidentally kill can find the words to express themselves. In the extract below (first quoted at the beginning of this thesis), Ben illustrates that despite such adversity, resilience and strength can prevail in the process of accepting, adjusting and living with the experience of accidentally killing.

...it's sort of like being stuck in a trap....a bear trap, or stuck in a pit, and really finding ways to live there.....stuck in a dark, smelly, difficult pit ...foraging around for anything that will keep you alive, but not really being able to get out of it,...and sort of finding that there might actually be a way to get out, is sort of the journey I've taken over the last twelve years in very simple terms. And that last realisation has only been in the last few months really, on the basis of over a decade. Ben

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8. Appendix

8.1 Appendix A: Participant Information letter about the study

8.2 Appendix B: Participant consent form

8.3 Appendix C: Personal background information form

8.4 Appendix D: Participant debrief information and sources of support

8.5 Appendix E: Approved Ethics Application University of Hertfordshire

8.6 Appendix F: Interview guide and topics

8.7 Appendix G: Interview process personal reflections sheet.

8.8 Appendix H: Yardley (2008) Criteria for demonstrating the validity of qualitative research

8.9 Appendix I: IPA, an example of the analytic process

8.10 Appendix J: Online recruitment advertisement

8.1 Appendix A: Participant Information letter about the study



University of Hertfordshire
Doctorate in Clinical Psychology

INFORMATION SHEET FOR PARTICIPANTS

Research Title: Experiences of causing an accidental death: An exploratory study.

Introduction

You are invited to take part in a research study exploring the experiences of people who have accidentally caused the death of another person(s). Before you decide whether you would like to give consent to take part, please take the time to read the following information which I have written to help you understand why the research is being carried out and what it will involve.

The researchers

The study is being carried out by Sara Rassool MSc, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology. The study is supervised by Dr Pieter Nel, Academic Tutor and Chartered Clinical Psychologist.

What is the purpose of the study?

This research is interested in finding out about peoples experiences of accidentally causing the death of another person(s). Thousands of people each year in the UK die due to an accidental death. The latest Government statistics (2000), show that approximately three thousand people died from road traffic accidents. It is conceivable that a similar number of people may have been involved in the deaths of those people. Despite the enormity of this traumatic experience, health care professionals know very little about the experiences of this group of people. We have very little academic literature investigating such experiences from the perspective of those who have caused an accidental death.

There appears to be a profound silence within the academic arena and from those who have experienced such a trauma. This piece of work will begin to address this silence by giving a voice to those who have accidentally caused the death of another person. Whilst this research is not intending to be generalised to all people who have caused an accidental death, it is an important pioneering piece of research, that will help clinical psychologists and other health care professionals to better understand the experience of causing an accidental death. This exploratory

study will be a foundation on which discussions regarding theory and service development for intervention can begin.

What is involved?

If you decide that you would like to take part you will be asked to sign a consent form and complete a brief information sheet about yourself this will include some information about the accident. You will be invited to participate in no more than an hour long in-depth semi-structured interview [the interview will be guided by a number of topics, but few set questions]. This will be carried out in your own home or at Hertfordshire University which ever feels most comfortable for you. During this time we will discuss your memories about what happened and your memories, thoughts and feelings of the days/weeks that followed. We may talk about what was most difficult during this time and what things if any were helpful for you, and how you feel now reflecting up on that experience. All interviews will be tape recorded and later transcribed verbatim. Tapes will then be destroyed.

Who is taking part?

This study will include males and females aged 18 years and above. A maximum of 8 people are required. All participants must have caused the death of another person(s).

Do I have to take part?

No. If you do not want to take part, or you change your mind *at any time* during your participation in this study, you do not need to give a reason. Participation is entirely voluntary and you can withdraw at any time.

What do I have to do?

If after reading this information sheet you would like to take part in the research, you will be given a consent form to sign. I will then send out the information sheet and contact you to arrange a suitable time and place to meet.

Will taking part be confidential?

Yes. If you agree to take part in the study your information will be stored in a safe locked location which will only be accessible by the researchers. The overall findings of the project may be published in a research paper, if your stories are used in the research I will do my best to conceal your identities for example change names and recognisable details.

If during the interview I have serious concerns about harm to yourself or the safety of others I am compelled by my duty of care to inform others.

What are the benefits of taking part?

From many years of clinical experience and research we know that talking about and reflecting upon traumatic events can be helpful. This research will give you an opportunity to speak openly and honestly about your experiences. It is hoped that this research will help to begin the development of psychological understanding of

the experiences of people who have accidentally caused the death of another person(s).

What are the potential difficulties that taking part may cause?

I am aware from my clinical experience of working with distress and trauma that this topic can be very emotive and it may cause some discomfort and distress. If this does occur you can take a break and you can stop the interview at anytime. Despite these potential difficulties, some researchers suggest that people taking part in research interviews can find the process of talking through their experiences therapeutic and beneficial. You will be given a number of contact details following the study, should you feel that you require support.

What if I have questions or concerns?

If you have any further questions about the research, please feel free to contact me via email, telephone or post, details of which are below.

Who has reviewed this study?

This study was reviewed by University of Hertfordshire Research Ethics Committee and was given ethical approval.

Thank you for taking time to read this.

Contact details of the researcher:

Sara Rassool

Email address: s.b.rassool@herts.ac.uk

Telephone number: 01707 286 322

Postal address: Doctor of Clinical Psychology Training Course
University of Hertfordshire
Hatfield, Herts., AL10 9AB

8.2 Appendix B: Participant consent form



University of Hertfordshire
Doctorate in Clinical Psychology

Participant Consent Form

Title of Project: Experiences of Causing an Accidental Death: An Exploratory Study.

Researcher: Sara Rassool Trainee Clinical Psychologist

Please

initial box

1) I confirm that I have read and understand the information sheet dated () for the above study. I have had the opportunity to consider the information and if needed ask questions that were satisfactorily answered.

2) I understand that participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3) I understand that my information will be filed in a locked cabinet and the information I provide will be anonymised for the use of the study.

.....

Name of participant

Date

Signature

8.3 Appendix C: Personal background information form

Background information

Initial:.....

1.Age.....

2. Male or Female (*please circle*)

3. How would you describe your ethnicity?
.....

4. Would you describe yourself as a spiritual person?

5. Are you a member of a religious group? If yes, which affiliation?

6. What is your current educational level?

7. What is your occupation?

8. What was your age at the time of accident?

9. What year did the accident happen?

10. In what country did the accident happen?

11. What was the court verdict / outcome of your case? ..
.....
.....

12. How long ago was the accident prior to volunteering for the study?

13. At the time of accident were you:
single partner married separated divorced (*please circle*)

14. At the time of interview are you:
single partner married separated divorced (*please circle*)

15. What was your relation to the person(s) that died (e.g.: friend/family/stranger)
.....

Thank you for your time.

8.4 Appendix D: Participant debrief information and sources of support



University of Hertfordshire
Doctorate in Clinical Psychology

DEBRIEFING INFORMATION SHEET

Thank you very much for making this study possible.

This study aimed to explore the experience of causing an accidental death. I was interested in:

- how you constructed your story about this experience
- how you experienced your sense of mental health before and after the event
- what you found was helpful or unhelpful
- whether or not you were able to find meaning in your experiences
- what changes you felt this experience had had on your life and your identity

The current academic literature in this field is almost non-existent, however, some authors and poets have written about their personal experiences of such an event. From these sources it seems that causing the accidental death of another person(s) is like no other traumatic event. For some, finding meaning is a difficult and a slow process. Yet with time, it seems that people are incredibly resilient and are able to move forward with their lives. As a health care professional I and my colleagues are familiar with the large range of traumatic experiences, yet causing the death of another person(s) from your perspective is an area that we know so little about. It is hoped that this exploratory research will help us to gain an insight into your experiences and provide a foundation on which discussion regarding psychological theory and trauma treatment specifically aimed at this type of trauma can begin.

SOURCES OF COMFORT AND HELP

Talking about your experiences may have left you feeling low or upset, this is quite normal and often passes after a few days. However, if these feelings persist there are local sources of support and comfort which may already be familiar to you.

1. The most immediate sources of comfort and help are likely to be *your own family and friends*.
2. Accidental deaths are unexpected and often violent; people bereaved in this way are often traumatised as well as grief-stricken. Some health care professionals, such as counsellors or psychologists have a particular specialism in helping people who are traumatised. *Your GP* may be able to refer you to more specialised local support services such as these.

The following national organisations offer support:

3. *Cruse Bereavement Care*

Telephone: Helpline 0870 1671677 (Monday to Friday, 9.30 to 5pm)

www.cruse.org.uk

Cruse is a national charity offering free support to anyone who has been bereaved. Cruse volunteers, who are trained and live locally, can visit you in your home or talk to you over the telephone. If you call the national telephone number they will put you in touch with your local branch.

4. *The Samaritans*

Telephone: 08457 909090

www.samaritans.org

The Samaritans is a helpline which is open 24 hours a day for anyone in need. It is staffed by trained volunteers who will listen sympathetically.

I acknowledge that people from these voluntary agencies are not trained in this specific type of trauma; nonetheless they are the best available.

8.5 Appendix E: Approved Ethics Application University of Hertfordshire

SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL

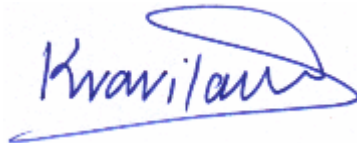
Student Investigator: Sara Rassool

Title of project: Experiences of Causing an Accidental Death: An Interpretative Phenomenological Analysis Study

Supervisor: Pieter Nel

Registration Protocol Number: PSY/07/07/SR

The approval for the above research project was granted on 23 July 2007 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.



**Signed:
Dr. Lia Kvavilashvili**

Date: 23 July 2007

**Chair
Psychology Ethics Committee**

STATEMENT OF THE SUPERVISOR:

From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.

Signed (supervisor):

Date:

SCHOOL OF PSYCHOLOGY ETHICS APPLICATION FORM

Status: DCLinPsych

Course code (if student):

Title of project: Experiences of Causing an Accidental Death: An IPA Study

Name of researcher(s): Sara Rassool

Contact Tel. no: 07985 990940

Contact Email: s.b.rassool@herts.ac.uk

Name of supervisor Dr Pieter Nel

Start Date of Study: July 2007

End Date of Study: April 2008

Number of participants: 6-8

		YES	NO	N/A
Q1	Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?			√
Q2	Will you tell participants that their participation is voluntary?	√		
Q3	Will you obtain written consent for participation?	√		
Q4	If the research is observational, will you ask participants for their consent to being observed?			√
Q5	Will you tell participants that they may withdraw from the research at any time and for any reason?	√		
Q6	Will you tell participants that their data will be treated with full confidentiality and that, if published it will not be identifiable as theirs?	√		
Q7	Will you debrief participants at the end of their participation (i.e., give them a brief explanation of the study)?	√		

IMPORTANT NOTE: If you have indicated **NO** to any question from **1-7 above**, but do not think this raises ethical concerns (i.e., you have **ticked box A** on page 3), please give a full explanation in **Q19** on page 2.

		YES	NO	N/A
Q8	Will your project involve deliberately misleading participants in any way?		√	
Q9	Will your project involve invasive procedures (e.g. blood sample, by mouth, catheter, injection)?		√	
Q10	Will the study involve the administration of any substance(s)?		√	
Q11	Will the study involve the administration of a mood questionnaire (e.g. BDI) containing a question(s) about suicide or significant mental health problems? (If yes, please refer to Psychology Ethics Guidelines for a standard protocol)		√	
Q12	Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort?	√		

Q13	Does your project involve work with animals?			√	
Q14	Do participants fall into any of the following special groups? If they do, please refer to BPS guidelines. Note that you may also need to obtain satisfactory CRB clearance (or equivalent for overseas students)	Schoolchildren (under 18 years of age)		√	
		People with learning or communication difficulties		√	
		Patients		√	
		People in custody		√	
		People engaged in illegal activities (e.g. drug-taking)		√	

IMPORTANT NOTE: If you have indicated **YES** to any question from **8 - 14** above, you should normally **tick Box B** below. If you ticked **YES** but think that your study does not raise ethical concerns, please, provide a full explanation in **Q19** in the section below.

There is an obligation on the lead researcher to bring to the attention of the Psychology Ethics Committee any issues with ethical implications not clearly covered by the above checklist

Please answer **Q15-19** below. Provide appropriate information with sufficient detail. This will enable the reviewers to assess the ethical soundness of the study without asking you additional questions and will speed up the review process (**PLEASE, PROVIDE AT THE END OF THIS FORM AN EXAMPLE OF THE INFORMATION AND CONSENT FORMS, QUESTIONNAIRE(S), IF USING, AND ANY OTHER RELEVANT FORMS, E.G., DEBRIEF SHEET, ETC.**)

Q15	<p>Purpose of project and its academic rationale (preferably between 100 - 500 words):</p> <p>For the purpose of this study, accidental killing is defined as a disastrous event that occurs suddenly, unexpectedly, without planning or intention and results in the death of a person (Kastenbaum & Aisenberg, 1979).</p> <p>Accidental death (AD) was the cause of 2% of all deaths in the UK during 2000 (Government Statistics, 2000). This represents over 13,000 people. From this statistic, approximately 3.2 thousand people died from road traffic accidents (RTA) during 2000.</p> <p>The recognition of road traffic accidents as a traumatic event has been well documented in the literature (Kinzie, 1989). This type of trauma has been implicated as a contributing factor in agoraphobia and driving phobias (Parker, 1977), anxiety (Mayou, 1992), depression (Blanchard, Hickling & Taylor, 1991) and posttraumatic stress disorder (PTSD) (Bryant & Harvey, 1996). However, almost all of the literature to date focuses on the people injured or the 'victim's' family and friends, not the drivers. Only a small amount of the academic literature concerns those who actually killed another person, or who at least feel responsible for another's death (Chesser, 1981).</p> <p>However, the experience from the perspective of the person who has caused an accidental death has been expressed in poetry (Orr, 2002) and biographies (Connor, 2005). Together these sources reveal huge emotional, cognitive, religious, familial, lifestyle and in some cases physical changes after the event. For some, such consequences can have a profound negative affect upon the person's psychological well-being, whilst for others resilience and post-traumatic growth seem to facilitate the integration of such a traumatic event into the lives of these individuals and their sense of self.</p> <p>Authors such as Kelly Connor (2005) have begun to raise awareness of the experiences of accidentally causing the death of another person. She has given many seminars and conference lectures to an array of health care professionals, including Clinical Psychologists and Psychotherapists, yet she has yet to meet one professional that has treated a person who has accidentally killed another person. This raises the question of why this might be the case given the adverse psychological consequences of such a traumatic life changing event. Even if we were to meet such people in our</p>
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	<p>clinical practice how we would begin to understand their experiences as being different from the family of those killed. We have bereavement and PTSD literature to guide our interventions, but is their something fundamentally different for those who have caused the accidental death of another?</p> <p>The scarcity of literature is surprising if one estimates that the number of people involved in accidentally killing another person, may be almost as great as the number of people who have died as the result of an accident. As highlighted by Chesser, (1981) and Conner (2005), there appears to be a gap in our current knowledge. Collating the themes that have emerged from the work of Chesser, Conner and Orr (2002) suggests that exploring people's experiences of accidentally killing another person is of interest to clinical psychology. The current study will attempt to contribute to this area of research by giving a voice to people that have accidentally killed.</p> <p>The main objective of this exploratory study is to gain an insight and detailed description of the lived experience of causing the death of another person.</p> <p>The following areas of interest will be explored with people who have caused an accidental death:</p> <ol style="list-style-type: none"> 1. memories of what life was like prior to the accident and how it feels now to look back at that time 2. memories of the event and what happened during the days/weeks that followed 3. what factors effected how they reacted/coped with the event (family/friends, professional help, their relationship proximity to the person killed, whether they perceived their treatment/punishment as just/too easy/too heavy) 4. experiences of change in their life as a result of the accident 5. reflecting on the experience what sense or meaning does the individual make of the experience and their feelings about the future.
Q16	<p>Brief description of methods and measurements:</p> <p>To address the research questions, in-depth individual semi-structured interviews will be carried out with people who have accidentally caused the death of another person(s). This method rather than questionnaires was thought to be most appropriate to avoid forcing preconceived ideas onto the participant's experiences. This method will also generate detailed, rich data. Furthermore this methodology is preferred when exploring a relatively new and unknown area.</p> <p>Example of types of questions are listed below, (words in bracket indicate</p>

	<p>interviewer prompts if needed). The questions will not have to be asked exactly as written and may be adjusted to ensure enough information relating to the principle research question is generated:</p> <ul style="list-style-type: none"> - What are your memories of what life was like prior to the accident? How does it feel now to look back on that time? - What are your memories of the accident? What are your memories of how it effected you as an individual during the days/weeks that followed (emotional consequences [guilt/shame, times when this was worse], their sense of mental well-being, methods of coping, seeking professional support [if not why not], what was helpful/unhelpful). -What effect did contact with others have on your experience such as the police/legal system? How did they make you feel? Relationships with family, friends and work? Who do you think was most supportive? (why? what did they do?) -Do you think that your relationship to the person that died has effected how you cope with this experience? If so how? How do you feel about the verdict? - How do you think you have changed as a result of the accident? (emotional, mental-well-being, spiritual/religious beliefs, relationships [home/family, work, social]) How do you feel about these changes? -Reflecting on up on your experience what sense or meaning do you make it? -How are you feeling about the future? (ambitions, worried, views on life) <p>Participants will be interviewed in a comfortable environment of their choice, either in their own homes or at the university. This will help them to feel comfortable and thus facilitate a safe and supportive environment to talk in depth about this sensitive topic.</p>
<p>Q17</p>	<p>Participants: recruitment methods, age, gender, exclusion/inclusion criteria:</p> <p>The nature of the research area requires a purposive sampling approach. I aim to recruit a minimum of 6 and a maximum of 8 participants for the study. The inclusion criteria will aim to recruit both males and females aged 18 years and above and all participants must share a central concept i.e.: 'drivers that have caused an accidental death'. (At this stage, it is unknown whether sufficient numbers of drivers will volunteer. As a contingency plan, I will broaden the central concept from drivers to include other types of accidental killing).</p>

	I intend to recruit participants through an advertisement placed in the local paper and Kelly Connor's website www.kellyconnor.com . She has a link on her site where others can voluntarily tell their stories. I intend to provide contact information to be distributed by Kelly Connor at her performances and discussion seminars. Another possible source may be through the local traffic police and word of mouth.
Q18	Consent and participant information arrangements, debriefing: Consent forms will be given to all potential participants fulfilling the inclusion criteria, a copy of this form will be kept for the researchers record. A debriefing sheet will be offered to the participants. (Please see attached sheet for: Information sheet, consent form, background information sheet and debriefing information sheet)
Q19	Any other relevant information: A number of potential participants have already contacted me and have offered to take part in research. They have heard about the research proposal through word of mouth.

PLEASE TICK **EITHER** BOX A **OR** BOX B BELOW AND PROVIDE RELEVANT ADDITIONAL INFORMATION IF YOU TICK **BOX B**. THEN PASS THE FORM TO YOUR SUPERVISOR

Please tick

A. I consider that this project has no significant ethical implications to be brought before the Psychology Ethics Committee.	<input type="checkbox"/>
B. I consider that this project may have ethical implications that should be brought before the Psychology Ethics Committee	<input checked="" type="checkbox"/>
<p>Ethical considerations:</p> <p><i>Participants during the interview:</i> Talking about experiences of accidentally killing may cause the participants distress. They may experience a range of emotions from low mood to more extreme reactions for example, re-experiencing (flash-backs) the event during the interview.</p> <p>Depending upon the level of distress, I will take the following action :</p> <ul style="list-style-type: none"> • I will remind participants that they do not have to answer questions that they do not wish to answer, I will not insist. • I will ask the participants if they would like to stop the interview and take a break. • I will draw upon my clinical experience of working with people who are distressed following trauma. I will use my person centred clinical skills to be empathic, listen and contain the participant's distress. • If participants show signs of more extreme discomfort (for example, re-experiencing). I will again draw upon my experience of working with traumatised people and use my 	

- clinical skills, for example, grounding techniques such as mindfulness.
- I will re-assure participants that they do not have to continue with the interview.
- If participants express suicidal ideation, I will assess the level of risk (also bearing in mind child protection issues). In the unlikely event of someone presenting with imminent risk, I will remind participants of the limits of my confidentiality and discuss with them how best to inform an appropriate professional (for example, GP and/or agency).

Participants post interview:

- All participants will receive a debrief sheet, this will provide information about sources of support and help in the event that participants continue to feel distressed in the days that follow the interview.
- Some participants may find the experience useful and would like to continue to talk through their experiences. This is supported by Birch and Miller (2000) they suggest that semi-structured research interviews may have a therapeutic effect. The contact details provided on the debrief sheet will also facilitate this type of talking support.

(Please see attached sheet: Debriefing Information and Sources of Help and Support).

Researcher considerations:

Due to the nature of the research topic, it is possible that I as the researcher may experience vicarious traumatisation. The interviews also have the potential to raise other issues and feelings for the researcher.

- I am aware of my own self-care and I have a number of support mechanisms in place. These include: access to a research supervisor (Dr Pieter Nel) an experienced Clinical Psychologists and for more extensive issues I have a personal tutor (Dr Saskia Keville) an experienced Clinical Psychologist with whom I am able to talk with.

Birch, M. & Miller, T. (2000) Inviting intimacy: the interview as therapeutic opportunity. *International Journal of Social Science Methodology*, **3**, 189–202.

This form (and all attachments) should be submitted (via your Supervisor for MSc/BSc students) to the Psychology Ethics Committee, psyethics@herts.ac.uk where it will be reviewed before it can be approved.

I confirm I am familiar with the BPS Guidelines for ethical practices in psychological research.

Name ...Sara Rassool.....Date

(Researcher(s))

Name...Dr Pieter Nel.....Date.....

(Supervisor)

CHECKLIST FOR REQUIRED APPENDICES (appended at the end of this form)

1. YOUR CONSENT FORM *(please refer to Appendix B)*

2. YOUR INFORMATION SHEET (*please refer to Appendix A*)

3. YOUR DEBRIEF SHEET (*please refer to Appendix D*)

8.6 Appendix F: Interview guide and topics

Rationale for the interview procedure:

The key aim of the study was to be 'person centred' (Frosh, *et al.*, 2002) and allow the participants to be the experiential experts (Eatough and Smith, 2006). This is reflected in the interview procedure, which allows drivers who have accidentally killed, to influence the direction and pace of the interview. Therefore, the schedule was only used as a guide if needed. The questions were not followed in sequence, nor was every question or probe asked of each participant or asked in the exact manner presented (Smith and Osborn, 2008). Rather, questions were formulated and asked in response to my sense of how the participant was responding and the effect that the interview had on the respondent. Rather than imposing set questions, I held in mind a number of fields that I wished to cover and probe as they emerged. Therefore, the links between these fields are open and the order in which they are addressed, as well as the time spent on each one, will be specific for each interview. I was also open to the exploration of unanticipated, new and interesting topics. Thus, this flexibility in questioning, accommodated and adapted to the reality of what people had experienced. The interviewing process is therefore reflective, to incorporate the responses of participants. Minimal probes were often all that was required, such as "Can you tell me more about that? What was that like for you? How did you feel about that?"

Interview opening statement:

*Reaffirm: "This will be a semi-structured interview which **is time limited**. But if you feel that there is anything that **I did not ask** you or something you wanted to tell me about which **we did not cover**, we will have some **time at the end**"*

I chose to begin all interviews with a fairly standard open question:

- What are your memories of or can you briefly describe the day of the accident? and the days and weeks that followed?
- Probes: what happened next? What was that like for you?

The purpose of this opening question was to: gain a shared understanding, establish rapport and enhance engagement.

Themes held in mind included:

Impact on self in the days/weeks that followed the accident.

- What was your sense of your mental well being before and after the accident? Probes: emotional consequences, times when this was worse/better?
- How did you experience your.....thinking, physical well-being, family and friendships at that time? (social, relational functioning)
- what did you think about what was happening to you? (meaning)

Interactions with the legal system

- The contact that you've had with the legal system....how did they make you feel?
- What were your thoughts about that process?
- How long was it between finding out about X and the court and or coroners proceedings? What was going on for you between those times?...what was that period like for you?

Support & Relationships

- Who do you think was most supportive? why? what did they do?
- Where there things that people did that were unhelpful to you? What? and why?
- Do you think the accident effected your family relationships?
- Probe: spouse, children, friends and work?

Coping/seeking help

- thinking back, what do you think was most helpful?.....(activities)
- What helps you now?
- Have you sought professional support? How? When? Why?
- if not, why not? What issues got in the way? (barriers)
- What was helpful/unhelpful about the support you received?
- Looking back, what do you think would have been helpful to you then?

Changes over time

- Looking back, are there any particular *turning points* that stand out for you? (coping? changes in self view?)
- Any particular positive changes that have come out of the accident?

Sense of self

- Reflections – looking back X years....
- Has the accident made a difference in how you see yourself?
- How have you changed as a result of the accident....

- Probes.....emotional, mental-well-being, spiritual/religious beliefs, relationships, home/family/work roles, social life....feelings about these changes?
- Do you think others see you differently? (family/friends/work colleagues)

Meaning:

- Reflecting on your experience what sense or meaning do you make of what has happened for you?
- (Probes throughout)...how did you understand that?.....what sense did you make of....? What did you think about

Feeling about the future

- What, if any are your..... ambitions for the future?.....worries.....views on life?

Experience in a metaphor (time to think)

- If you could describe your experiences in a metaphor, what would it be?

Was there anything important not spoken about or asked about that you wanted to say?

8.7 Appendix G: Interview process personal reflections sheet.

Personal Reflections

Date & Time:

Participant number:

Interview, where & when:

Comments on rapport and How did the interviewee make me feel?

What were the most salient themes to emerge?

Any links to theory?

Topics/Issues to explore in future Interviews?

How did I feel the following day/night?

Any other comments?

8.8 Appendix H: Yardley's (2008). Criteria for demonstrating the validity of qualitative research.

This is adapted from the work of Yardley (2008) who suggests core principles for evaluating qualitative research.

CORE PRINCIPLE

HOW THE STUDY DEMONSTRATES FEATURES OF VALIDITY

a) Sensitivity to the context of existing theory and research in the development of the research topic.

The study identified a specific gap in the existing research and theory and formulated a research question that has not yet been addressed: What are the experiences of people who accidentally kill, how do they cope with this experience and what influence might such an experience have for their sense of self.

b) Sensitivity to how the perspectives and position of participants may influence whether they feel able to take part and express themselves freely

Participants were invited to participate in the study. They were given a choice of whether they would like to be interviewed at the University of Hertfordshire or a neutral private place or in their own homes. Most participants opted for the latter. Thus, maximising privacy and security. The construction of open ended interview questions was held in mind, however, participants were encouraged to respond freely, revealing what was important to them. All participants were asked the same starting question, which was "what do you remember from the day of the accident?". This created an opportunity to build rapport, engage empathically with participants, and it helped to join with participants to create a shared context or basis from which the interview could evolve. Participants were considered experiential experts.

(Continuation....)

CORE PRINCIPLE

HOW THE STUDY DEMONSTRATES
FEATURES OF VALIDITY

- | | |
|---|--|
| c) Commitment to rigour in the recruitment of participants who will represent an adequate range of views relevant to the research topic | Five people were purposively sampled, two males and three females were recruited from across the UK. |
| d) Transparency in the analysis of data | A detailed description is provided outlining the analysis process. An example section of data is presented (audit trail) illustrating the analytical process. |
| e) Coherence between the qualitative design and the analysis and presentation of data | The qualitative epistemological perspective supported the use of IPA as a method of data analysis. Verbatim extracts are presented to demonstrate participants experiences. Both convergences and divergences are presented, illustrating the complexity and differences found in their experiences. |

8.9 Appendix I: IPA, an example of the analytic process

1. ANALYSIS: Initial List of Themes (Jane)

An evil bad self 67, 614

The Guilt of wanting to drive away 70

Things Unclear/Uncertainty 85, 106

Support /others reassurance/kindness 90, 109

Protected from the truth 175, 183

Horrible terrible feeling of responsibility 122

Isolated and alone/The silence 640

Manic Defences during recall 195

Disorientated

Disbelief and Learning about the Death

Connection to near death of child

Life changing moment, 960, 981,

Feeling paranoid

Trying to find meaning

Trying to make sense, 955,

Unable to make sense 966-980

Unable to make sense, 937

Others can't make sense 946

Feeling remorseful

Needing to be 792-(Sex), 798, 2042,

Deserving of punishment 1196, 1199,

Irrational meaning of death

Lack of social support

Hiding a part of herself and coping alone

Ambivalence, needing support Vs Being a burden, 809

Revealing her unwanted self to seek support 825

Actively seeking support from spouse, 1730, 1739,

Seeking professional support (assertiveness), 1748

A generalised responsibility and asking others for forgiveness, 1760, 1768-

1777, 1502-1514

Uncontained need to be judged and forgiven (punishing herself?), 1792-1801

Seeking forgiveness from others (temporal) 1814

Religious faith provides support and meaning, 1832, 1853-1867, 1881

Forgiven by God Vs Unable to forgive self, 1867 1881

Feeling judged by others

Self as evil/wicked

Shameful self

Shameful guilty self

Self as a murderer L606,

Feelings of suicide

 Seeking support unable to cope with guilt/ shame/grief

The possibility of suicide 808, 2023

Making sense of feelings of suicide, 2026-2045-2053

Uncertainty of the process

Shameful self – obstacle to seeking support

Shameful/wicked self obstacle to seeking support (GP)

What I need L618, 776-787

Needing to escape L629, 636,

Realisation of negative impact on her children L650, 660, 663

A depressed self L652, L658

Assessing professional support 669,

The flexibility of service provision 673,

Clinician not looking beyond diagnosis, 683,

The stigma of mental health labels, 700, 708,

Uncertainty of court process, 721, 864,

Treatment ignored the root emotion – guilt 744, 755,

 The guilty feelings overriding (treatment) 842

Trying not to feel guilty 850

Treatment Perpetuating the guilt, 760, 765, 787

Negative impact on marital relationship 795-(Sex)

Strengthening the marital bond, 805

Wanting to make amends 852, 856, 873, 878-888

Support of the police officer, 907,

Things people say are unhelpful, 950

**Regrets loss of motherhood– mothering from a distance, 996, 1009, 1017,
1024, 1028, 1033, 1039, 1045, 1047,**

**Reflection on mothering from a distance, 1070, (sadness)-1084, systemic
impact-1090**

**Guilt (perpetuating) and worry about mothering from a distance, 1123, 1131-
1144,**

Making sense of mothering from a distance 1424-1450

Seeking professional support 19 yrs later, 1050, 1112,

Accumulative stressor, 1096

Rejecting medication/label depression 1105, 1114,

A lasting negative impact on self, 1117,

Lack of information about legal process, 1019,

**Early trauma: not functioning, 1178, 1185,
Overwhelmed by the emotion, 1188
Loss of motherhood identity, 1182,**

Unprocessed feelings remain, 1205, 1881,

Unprocessed trauma (flash backs, dissociation), 1350, 1959-1960

Dissociation and shock 1961-1986 (then and now)

Prior self as happy go lucky, 1231,

Resilient self, 1232, 1236, 1246,

Reflections on interview, helping others 1240,

Openness & Meaning of the interview, stage: 2067-2100

**Wanting to help others similar situation: 2124,-2132
Comparison to others unhelpful (set back in recovery): 2150-2164**

A changed self, 1251,

**An indecisive self, 1256-1273
Loss of ability to make decisions 1257,1259,**

Coping with driving again, 1278, 1287, 1299, 1305, 1339-1346,
Unable to make new friendships – Good self vs Bad self, 1314, 1320, 1325,
1333, (still happens)-1485-1492
Recovery is a slow process, 1689, 1700, 1711, 1686, 2054-2063,
(interview/last stage: 2067-2100
Unforgiving self hinders recovery, 1890, 1896, 1905, 1913
Early trauma response (dissociation – metaphor question), 1948
Unwanted shameful self (current), 1422
Family secrets and betrayal/punished, 1382-1400, 1412, 1459
Justifying feelings of anger at self, 1518
New uncertainty: trying to make sense of the badness, 1540-1553
Recent Counselling unhelpful/invalidating her memories and
uncertainty, 1554-1687, 1591-1598, 1615-1620.
Coping with new new uncertainties (positive self talk)
Grief: remembering everyday, 1645
The thought of a dishonest self is the ‘bad thing’: 1192-2006
Openness in interview: 1999
Disowning part of self, 2015

2. ANALYSIS: Themes Clusters & Supporting text (Jane)

Early trauma response & Lasting residual trauma:

Disorientated, 6.L188, not functioning, 1178, 1185, Overwhelmed by the emotion, 1188, dissociation – (metaphor question?)- 1948, Feeling paranoid/flipped L255 L255, 271,

Isolated and alone/The silence, L175 6.L183 L640, 5.L144, 5.L151, 148,187, 197

The Lasting Residual trauma:

Unprocessed feelings remain, 1205, 1881,

Unprocessed trauma (flashbacks, dissociation), 1350, 1959-1960

Dissociation and shock 1961-1986 (then and now)

Trying to make sense of this life changing moment

Disbelief and Learning about the Death, L201-3, Life changing moment, 287, 960, 981,

Things Unclear/Uncertainty/Unable to make sense, 937, 966-980

Trying to find meaning/make sense 275, 300, 304, 324, 353, 955, 228

Others can't make sense 946

Context of accumulative stressor, 1096

Uncertainty of court process, 721, 864, 1019,

Trying to cope with the experience of causing a death

Wanting to help others in a similar situation (set back):2124,-2132, 2150-2164

Religious faith provides support and meaning, 51.1832, 1853-1867 the bible, 1881

Forgiven by God Vs Unable to forgive self, 1867 1881

Manic Defences during recall

Resilient self, 1232, 1236, 1246,

Needing to escape L629, 636,
Feelings of suicide

Seeking support unable to cope with guilt/ shame/grief

The possibility of suicide 808, 2023

Making sense of feelings of suicide, suicide answer to non-existence.
2026-2045-2053

**Coping with the Grief: remembering everyday, 1645 ,Seeking support
unable to cope with guilt/shame/grief (disenfranchised grief?)**

The process of recovering

Coping with driving again, 1278, 1287, 1299, 1305, 1339-1346

Recovery is a slow process, 51.1689, 1700, 51. 1711, 1686, 2054-2063,

*The meaning and reflections on the interview – (coping -
recovery) last stage: 2067-2100*

Reflections on interview, helping others 1240,

Openness & Meaning of the interview, stage: 2067-2100

Openness in interview: 1999

Unforgiving self hinders recovery, 1890, 1896, 1905, 1913

Support & lack of support from others

- Support /others reassurance/kindness

Lack of social support 451

Hiding a part of herself and coping alone 461

Ambivalence, needing support Vs Being a burden, 809

Revealing her unwanted self to seek support 825

Actively seeking support from spouse, 1730, 1739,

Support of the police officer, 907,

Things people say are unhelpful, 950

Seeking professional support

Seeking professional support (assertiveness), 1748

What I need L618, 776-787

Assessing professional support 669,

The flexibility of service provision 673,

Clinician not looking beyond diagnosis, 683,

The stigma of mental health labels, 700, 708,

Rejecting medication/label depression 1105, 1114,

Treatment ignored the root emotion – guilt 744, 755,

The guilty feelings overriding (treatment) 842

Trying not to feel guilty/amends 850

Treatment Perpetuating the guilt, 760, 765, 787

Seeking professional support 19 yrs later, 1050, 1112,

New uncertainty: trying to make sense of the badness, 1540-1553

**Recent Counselling unhelpful/invalidating her memories and
uncertainty, 1554-1687, 1591-1598, 1615-1620.**

Coping with new uncertainties (positive self talk)

The relationship between undesirable feelings –responsibility, punishment, guilt, shame, forgiveness

The Guilt of wanting to drive away

Horrible terrible feeling of responsibility, .L122

Feeling paranoid

Feeling remorseful, 9. 265

Needing to be punished 792-(Sex), 798, 2042,

Deserving of punishment 1196, 1199,

**A generalised responsibility and asking others for forgiveness, 1760,
1768-1777, 1502-1514**

**Uncontained need to be judged and forgiven (punishing herself?),
1792-1801**

Seeking forgiveness from others (temporal) 1814

Wanting to make amends 852, 856, 873, 878-888

Feeling judged by others

Unwanted self

An evil/ bad / wicked self L68, 75, L614

Shameful self

Shameful guilty self

Self as a murder L606,

Shameful/wicked self obstacle to seeking support

Unwanted shameful self (current), 1422

Family secrets and betrayal/punished, 1382-1400, 1412, 1459

**Good self vs Bad self, (Unable to make new friendships) 1314, 1320,
1325, 1333, (still happens)-1485-1492**

Disowning part of self, 2015

The thought of a dishonest self is the 'bad thing': 1192-2006

A changed self

A depressed self L652, L658

A lasting negative impact on self, 1117,

A changed self, 1251,

An indecisive self, 1256-1273

Loss of ability to make decisions 1257,1259,

Prior self as happy go lucky, 1231,

Systemic impact

Realisation of negative impact on her children 650, 660, 663

Negative impact on marital relationship 795-(Sex)

Strengthening the marital bond, 805

Regrets: mothering from a distance

**Regrets loss of motherhood– mothering from a distance, 996, 1009,
1017, 1024, 1028, 1033, 1039, 1045, 1047,**

**Reflection on mothering from a distance, 1070, (sadness)-1084,
systemic impact-1090**

**Guilt (perpetuating) and worry about mothering from a distance, 1123,
1131-1144,**

Family Secrets: the worry and guilt

Family secrets and betrayal/punished, 1382-1400, 1412, 1459

Making sense of mothering from a distance 1424-1450

Loss of motherhood identity, 1182,

3. ANALYSIS: Titled Theme clusters (Jane)

A) TRYING TO MAKE SENSE AND FIND MEANING

- 1. Early trauma response & the Lasting Residual trauma**
- 2. Trying to make sense of a life changing moment**

B) TRYING TO COPE WITH THE EXPERIENCE

- 1. Trying to cope with the experience of causing a death**
- 2. Seeking support unable to cope with guilt/ shame/grief**
- 3. Coping with the Grief**
- 4. The process of recovering**
- 5. Support & lack of support from others**
- 6. Seeking professional support**

C) SENSE OF SELF

- 1. An Unwanted self**
- 2. The relationship between responsibility, punishment & forgiveness**
- 3. A changed self**

D) SYSTEMIC IMPACT OF THE TRAUMA

- 1. Systemic impact of the trauma**
- 2. Regrets: mothering from a distance**
- 3. Family Secrets: the worry and guilt**

8.10 Appendix J: Online Recruitment advertisement



University of Hertfordshire

DO YOU FEEL RESPONSIBLE FOR A FATAL ACCIDENT?

RESEARCH PARTICIPANTS WANTED:

Doctorate researchers at the University are interested in the experiences of people who feel responsible for a fatal accident including fatal road accidents.

Whilst much has been written about the experiences of the families and friends of those who have died, health care professionals know very little about the experiences and the impact of such accidents, for those who have caused an accidental death. Results from the study will be fed back to the relevant services, to help them be more responsive in meeting the needs of people who have been through this experience.

If you are interested in confidentially sharing your story, please contact Sara for further information:

Tel: 01707 286322
S.B.Rassool@herts.ac.uk

CHAPTER SIX: JOURNAL ARTICLE

Experiences of Causing an Accidental Death: An Interpretative Phenomenological Analysis Study

**Doctorate of Clinical Psychology
University of Hertfordshire**

Sara B Rassool

Student Number: 05108127

Submitted: July 2008

Words: 5048

Abstract

Accidentally killing or feeling responsible for another person's death constitutes an event unique from any other traumatic stressor. Research exploring the perspective of those who have accidentally caused a death appears extremely sparse. This study aimed to gain an insight into the lived experiences of people who have caused an accidental death. Five participants were recruited through an on-line advertisement; all were drivers directly involved in a road traffic accident that occurred unexpectedly, without intention and resulted in a person's death. An interpretative phenomenological approach was used to analyse data collected through semi-structured interviews. Three main themes emerged from the participants' accounts: trying to make sense of a life changing moment; struggling to cope with the trauma of causing a death and a changed sense of self. These findings are considered in relation to relevant literature and the clinical implications are outlined.

Introduction

Accidental killing or causing an accidental death (AD) is defined as a disastrous event that occurs suddenly, unexpectedly, without planning or intention and results in a person's death (Kastenbaum & Aisenberg, 1979). Road traffic accidents account for a considerable number of ADs; most recent statistics equate to 3,172 road deaths a year; that is nine deaths every day in Britain (DfT, 2006). Undoubtedly a number of these deaths are caused by 'dangerous driving' (DfT, 2008) while others are simply ill-fated. When bad things happen to good people (Kushner, 1981), particularly when it results in another person's death, those who feel responsible may experience a spectrum of shattered assumptions about themselves and the world (Janoff-Bulman, 1992).

Numerous psychological consequences have been implicated in the aftermath of RTAs. These include: posttraumatic stress disorder (PTSD); acute stress disorder (ASD), anxiety, depression, specific phobias, insomnia and substance misuse (Kuhn *et al.*, 2006; Mayou, Bryant & Ehlers, 2001; Schnyder *et al.*, 2001;

Shalev *et al.*, 1998; Parker, 1977). However, an extensive literature review has revealed only three papers explicitly examining the perspective of those who have caused or feel responsible for an AD (Foeckler *et al.*, 1978; Chesser, 1981; Lowinger & Zoloman, 2004). All highlight a host of psychological, physical and psychosocial consequences, of which PTSD, ASD, driving phobias, anxiety, depression, substance misuse and corrosive experiences of guilt and shame were highly prevalent. Chesser's (1981) study considering ten participants who had caused ADs suggested the role of family members, friends and the community were important in the coping process.

It is noteworthy that almost all of the literature examining the psychological impact of RTAs focus on those considered as 'victims' and their families, and neglects the drivers who caused an AD. Mitchell (1997) suggests there are two possible factors for this. Firstly, she suggests that it may be because drivers are often not physically injured. Most RTA studies recruit from A & E departments; uninjured drivers may be dealt with by other agencies, such as the police, and are therefore not recruited into studies. Secondly, she proposed that in a legal context, drivers are often considered blameworthy (Mitchell, 1997). Here, we enter a complex ethical area of making moral judgements and decisions about who is and is not worthy of clinical exploration and thus the development of appropriate intervention.

Given the high frequency of RTA fatalities, how is it that such a large population seeming vulnerable to mental health difficulties have been ignored for so long? A pervasive silence may be an attempt to escape and avoid the unpleasant emotions that causing a death evokes for us individually and as a society. Nonetheless, in my view this is no reason to avoid exploring such challenging issues. This study hopes to address the silence by giving a voice to people who have caused an AD and to open a forum to discuss and understand this topic.

The primary aim of this study was to develop an in-depth exploratory account of people's experiences of causing an AD for which they feel responsible. How do those who had accidentally killed experience their sense of mental health and what meaning are individuals able to find in their experiences? What helped or hindered their experiences of coping with causing an AD? How does the experience of causing an AD impact on their sense of self and identity?

Method

Participants

Following Ethical Approval from the University of Hertfordshire, five participants were recruited through an on-line advertisement. All were drivers directly involved in a RTA that occurred suddenly, unexpectedly, without planning or intention and resulted in a person's death. None were charged with dangerous driving or imprisoned as a result of the accident, two were male and three female. Their ages ranged from thirty-six years to fifty-seven years. One was from overseas, one Irish and the three British. The accidents that caused the death ranged from six years to twenty years previously. Two of the participants were acquainted with the person who died.

Data collection

Participants were interviewed in their homes or at an agreed university site using semi-structured Interviews lasting between sixty and seventy minutes. Participants were considered to be 'experiential experts' (Eatough and Smith, 2006). Consent for the interview and audio recording was sought prior to each interview.

Data analysis

Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2008) was used to analyse the transcripts. The process was informed by guidelines for ensuring quality in qualitative research (Yardley, 2008).

Results and discussion

This account should be viewed as socially constructed, partial and incomplete in line with the study's underlying theoretical orientation (Burr, 1995; Smith & Osborn, 2008). Names and other identifying information have been changed to ensure anonymity. Themes are presented and discussed in light of the relevant literature (Smith & Osborn, 2008).

Trying to make sense of a life changing moment

The initial context of shock created immense uncertainty for the participants. The 'not knowing' and the fragmented nature of memories from the accident rendered sense-making almost unobtainable, making it difficult to organise the pieces of this experience into a coherent narrative.

...everything was in slow motion...you want to call for help but you can't seem to. It's really a strange feeling. [I] never realised all the windscreen was shattered...I think the more you tried – of course initially you try to put it together. (Sandra)

Conversely, trying to make sense with a complete absence of memory, as described by two participants, further complicates the process of creating sense and making meaning. Particularly when the new self-narrative is reconstructed within a highly intellectualised legal context, as depicted by Ben.

...I had been told all this [during the legal process] and...I initially went through a long period of denial..."no, I can't be responsible for this, and I can't remember it, so how can I take responsibility for it? It's just crazy. (Ben).

The cognitive disorientation and emotional unfamiliarity seemed to persist and extend beyond normative responses to stress; fitting to some extent to more formal descriptions of traumatic responses, such as Acute Stress Disorder and PTSD (American Psychiatric Association, 2000). These were depicted in

participants' descriptions of intrusive thoughts and recurrent dissociative experiences. It is possible that these intense emotional and cognitive experiences inhibited the sense-making process (Charney *et al.*, 1993). Daniel captures the ruminative and relentless feelings over the years aptly in the metaphor below.

...it was like it was switched on all the time... So you couldn't just think about ordinary things...It's a bit like being a bit of driftwood in a storm....when it's really stormy you don't really know which way is up and which way is down, you just hope that your head's going to pop up often enough to get a breath...you just hope that, however long the storm lasts, that eventually it will calm, and eventually you'll... reach...dry land. But it's...not knowing how long it's going to last for or...how choppy the waters are going to be. (Daniel)

For all participants the accident represented a life-changing moment personified by a loss of control and powerlessness. The accident represented a clear punctuation distinguishing life before and after.

I can remember thinking..."My life's changed now."...you just knew that there was going to be a 'before this and after this' sort of aspect to me life. (Daniel)

Shock and confusion remained dominant features for all participants, particularly during the first year following the accident. Police investigations, coroner's court and court proceedings undertaken within this context were described as "traumatic" and "harrowing." The lack of knowledge around legal proceedings was particularly devastating for Jane.

I really thought I would go to prison...so unfortunately, my new baby, I didn't bond with him at all...I deliberately didn't bond with him.....Because I thought, "Well I'm going to go to prison and this poor baby is going to be left not knowing his mother." (Jane)

These extracts correspond to Janoff-Bulman's (1992) theory of shattered assumptions, whereby the personal assumptions we hold about the world as being a safe and predictable place become obliterated. Personal agency is replaced by fear, powerlessness and loss of control. Hendin and Haas (1984) have discussed similar experiences in relation to soldiers' experiences in Vietnam. However, the circumstances and meaning might be very different, particularly given the social legitimacy of killing for which soldiers are trained.

Both researchers and clinical theorists emphasise the central role of 'sense-making', or the formation of a subjective understanding of the trauma and loss in the restoration process following the shattering of assumptions (Currier *et al.*, 2006; Niemeyer & Anderson, 2002). Whilst this process of assimilation or accommodation has been written about in relation to violent loss and bereavement, it does not consider those who have actually contributed unintentionally to a violent death. Such populations may face greater challenges in the process of making sense in a personally meaningful way. However, sense making appeared to develop for participants in this study. For some this included an understanding within a spiritual framework, as described by Jane.

.....ministers who've been very supportive and shown me from the Bible that there's a scripture... "Time and unforeseen occurrence befalls all men." Meaning that things aren't foreordained....it's not fate. It's just being in the wrong place at the wrong time where imperfect things happen. (Jane)

However, a lack of meaningfulness created an existential crisis that led to Ben "disembarking" from his "Christian world view."

...what kind of help the Christian faith and a Christian God could be in a world where this had happened....I can't believe in a God that has a relationship with people, and then lets this kind of stuff happen to them. So I'd left my Christian world view...it never seemed to make any difference or help me resolve any of the feelings of guilt or responsibility (Ben)

This type of weakening or abandoning of religious faith is one of the most common and pervasive difficulties experienced in the face of trauma (Calhoun & Tedeschi, 1999; Decker; 1993, Ano & Vasconcelles, 2005). Regardless of whether faith was strengthened or weakened, existential questioning was common to all participants.

What's it all about, and why did that happen?...If only I hadn't left at that time. (Amy)

A temporal component suggests that for some it is possible to reflect and develop new meanings.

....maybe I'm here because there is a reason why I should be here, you know, maybe if it is about helping other people... then...that feels like a very difficult thing to say, because it feels very selfish...it feels like I'm making a judgement about my life over and above her life....(Amy)

Consistent with constructivist theorists' literal truths and facts are not important, but rather seeking a truth that can be lived with, a narrative meaning is of importance (Neimeyer, 2008; Spence, 1984). Amy's extract demonstrates her current sense-making of the accident and death in illuminating her role in helping others, yet she also draws attention to pain and discomfort of this meaning.

The struggle to cope with the trauma of causing a death

Participants described a range of helpful and unhelpful coping processes with relational factors featuring in both domains. Participants voiced a pervasive lack of understanding leading to detachment and social distancing. Daniel's extract captures this notion and draws attention to his psychological pain.

...it felt like nobody really understood, how hurting...how all-consuming it was.....they're almost treating it the same as...."it's just a bad day".....It's

not a bad day, it's a tragedy....I think that's the hardest thing in the whole world, is if it's physical injuries people can see the cast on your leg or they can see the scars.....when it's sort of emotional or psychological damage nobody can see it.(Daniel)

In relation to systemic factors, family relationships were reported as important in the coping process, as identified by Chesser (1981) and Feockler *et al* (1978).

...it's brought my husband and I closer together, because he has supported me through it all...without him I...wouldn't be here. (Jane)

Conversely, for some the accident had detrimental familial effects, resulting in divorce and experiences of closed communication, silencing attempts to seek empathy and support. Again, Chesser (1981) reported similar findings.

...I saw my father, who I was always able to talk to....But when I was trying to tell him about this....It was a bit like 'end of conversation'. (Sandra)

Perhaps one of the most complex barriers to recovery was the dilemma between wanting to talk about their experiences of accidentally killing, but feeling a strong sense from others that talking about it was not acceptable.

Others just couldn't mention it....Again that was quite hard... the idea of blame, I think that made it even more difficult for people to talk about. (Amy)

....there's nothing worse than people ignoring it as if it hasn't happened. It makes you feel absolutely alone, "Oh pretend it didn't happen." How can you take that view? (Daniel)

Their experiences of trauma and grief seemed to be socially unspeakable. This can hinder the process of adjusting and recovery (Lazare, 1979; Worden, 2002).

Sandra spoke at length about how not talking, or others not wanting to listen, can have a detrimental affect on people's mental health.

...I envy people that they appear to put everything to the back of their mind. But then probably that's why they end up in a psychiatric hospital, because they try to suppress these things...Why do we have to wait until somebody is diagnosed as being mentally ill, and suddenly we're all listening to them?" There should be lots of support out there... (Sandra)

Doka's (2002) work regarding disenfranchised grief resonates with this finding. However, for drivers who have caused an AD it could extend beyond grief to include disenfranchised trauma. Whilst some literature acknowledges the concept of perpetration-induced traumatic stress (MacNair, 2002; Nader *et al.*, 1993), most of the research concerns socially sanctioned killings among police officers (Mann & Neece, 1990; Manolias & Hyatt-Williams, 1993) and soldiers (MacNair, 2002; Grossman, 2005). Drivers who have caused an AD are considered unlawful, despite the accidental nature of the killing and as a result, their trauma potentially remains disenfranchised.

Regardless of this social negation, some participants spoke about their private ongoing relationship with the person they had killed, despite that person being a stranger and hence a socially unrecognised relationship (Doka, 2002). Sandra described how she used culturally accepted means to mark his death as if he were a friend or family member, demonstrating the quality of the relationship.

I still was having mass said for him, because it's something I do anyway for friends, family, and at the anniversary of his death...I've often thought to myself...I have to live with it. He died and I think it's my duty to remember him in some specific way. (Sandra)

Contrasting with the social negation message, there are internal defence mechanisms that seemed to protect against a predicted negative response. When asked how others would react, Sandra responded:

....I thought, if you talked about it too much, they'd probably say "Oh maybe it was your fault," or "Did you do this, or did you do that?" (Sandra)

This typifies the experiences of participants, demonstrating how beliefs about what others might think can prevent speaking about their thoughts and feelings. In this way, the predicted experiences of judgement, blame and criticism and the related negative emotions are experientially avoided (Hayes, Strosahl & Wilson, 2003). This is further compounded by the external avoidance imposed by society.

For three participants who sought and accepted professional support, a strong narrative emerged that this was precipitated by deep feelings of unhappiness and recurrent suicidal thoughts.

I got really to rock bottom probably about two years ago...I'd felt suicidal in the year after the accident, but had never done anything about it. Contemplated it at one point and made a plan, but then decided well actually I want to live, and grit my teeth and got on with it, and felt very conflicted about that at the time...and then...more recently [felt] suicidal to some degree again...and ended up...having difficulties coping at work, drinking more and more because it felt like a way to get oblivion and get release from feeling guilty. (Ben)

Participants' accounts demonstrate that disclosing such psychological distress and their reasons for seeking help was a difficult process.

I went to see a GP...[and] .I ended up coming out with a packet of contraceptive pills. I couldn't tell him. I suddenly realised, "I've got all this to tell him I can't tell him in five minutes....he doesn't know I'm not a wicked

person really...I think really I needed some proper help. I didn't get any proper help for a long time. (Jane)

The difficulties Jane faced in disclosing her problems to her GP mainly centred on the quality of the relationship. Research by Ossvath *et al.* (2003) emphasise the importance of the patient–doctor relationship in facilitating communication of suicide ideation. However, the process of referral and waiting times appeared to create further ambivalence, as illustrated by Daniel.

....a three or four months waiting list and you're thinking, "Oh God, shall I do it, shall I do it?" And then you suddenly get the letter through, "Are you sure you really want to come?" and it's addressed from the Mental Health Unit. And you're thinking, "I'm not mental, I'm just deeply unhappy."

Participants' awareness of stigmatisation around mental health issues was further compounded for one participant, when her GP reinforced the negative consequences of seeking help for this type of experience.

...Yeah the GP said to me "I'm going to put this down as postnatal depression because it will look better in the future." She said, "If I put you down as depression,"... "it doesn't look good if you ever apply for jobs and things..." (Jane)

Unfortunately, Jane received a treatment based upon a diagnosis of postnatal depression. As a result, she described how the therapy avoided and in fact perpetuated her feelings of guilt.

....it didn't address the guilt...in a way it like transferred the guilt onto my parents...putting the guilt onto them...I was feeling bad about myself because of the way my parents had treated me in childhood. So it didn't help... (Jane)

It appeared that feeling misunderstood and invalidated impeded therapeutic progress. Egan (1975) suggests this can inhibit a client's ability to relate the meaning of their experiences to themselves in a meaningful way. This appeared evident for Jane in the extract above and Ben.

...the CBT based counselling I had experienced wasn't the right one....I'm certain that trying to assert that I'm not guilty your honour, is not the answer.... (Ben)

Ben experienced CBT as “unhelpful” and his reference to the therapist as “your honour” maybe suggestive of a reminiscent feeling of persecution from his court experiences.

Participants' therapeutic encounters appeared to raise problematic issues around confidentiality. Two participants spoke about feeling unable to be completely open and honest with their therapists. Jane described needing to defend herself and worried about session documentation, a likely residual feeling derived from legal proceedings.

I've never had the opportunity to actually talk to somebody about things like this, and know that you're not going to write a letter to me GP, or it's not going into hospital notes that people might drag up years later. Because... you defend yourself against....because you know that the psychologist you're seeing has got to write notes, and she's got to write back to your GP and things. (Jane)

Despite numerous therapeutic difficulties, participants identified a number of helpful therapeutic experiences, such as preparatory work for the court process, like role playing, exploring the imagined relationship with the person who died and learning new insights that talking helps.

I can see that there is some merit to talking this through further with somebody, and exploring better ways to think about what I've experienced, and better ways to live with it. So for the first time in 12/13 years, the last six months has represented a bit of a change in thinking and change in outlook for me. (Ben)

All participants described recovery as a struggle and difficult process. However, throughout the participants' narratives they demonstrated recognition of their strength and ability to endure great adversity, akin to Tedeschi, Park, and Calhoun's (1998) concept of post-traumatic growth. The participants appeared to identify themselves at times as emerging from an emotional storm and a self-appraisal process with new resolve, symbolic of hope and growth.

...it's sort of like being stuck in a trap....a bear trap, or stuck in a pit....stuck in a dark, smelly, difficult pit and....foraging around for anything that will keep you alive, but not really being able to get out of it...and sort of finding that there might actually be a way to get out, is sort of the journey I've taken over the last twelve years.....and that last realisation has only been in the last few months really, on the basis of over a decade. (Ben)

...Initially it would have been a forest full of brambles and snagging on me and not being able to see the way. Moving on to a younger forest, smaller trees, and you can actually see your way through them. And then, moving out to a big meadow where there's flowers and....it's very bright. And it's OK, and if you want to you can sort of wander back to that forest, but you don't get snarled any more, you can protect yourself and walk among it, but get out again if you want to, back to the meadow....the meadow is a good place to be. (Amy)

Metaphorical description appeared to expand on the meaning of participants' experiences; developing an allegorical story conveys emotional meaning better than literal speech (Martin and Sugarman, 1997). They demonstrate how trauma

and tragedy can motivate personal growth and that this should not be neglected in the process and struggle of recovery.

Moreover, participants in this study spoke about bolstering their confidence by “regenerative” activities; feeling a new appreciation for life as they reflected on life’s fragility; feeling greater empathy for others; valuing their friendships and gaining a new appreciation of parenting. There is a sense that participants almost honour those who have died by making themselves better people through helping others and fostering compassion, thus channelling growth in a positive direction.

... if you can do something for somebody, do it, and do it without any payback at all...if you can do it without any great expense, or put yourself out, and it's, “Shall I do it or shall I?” well do it, just do it. (Daniel)

A changed sense of self

Many authors such as McNally (2005) and Crossley (2000) have written about the disintegration of an established self, leading to a changed or adjusted sense of self in the aftermath of a serious trauma. The shattering of assumptions held about oneself following a trauma is believed in some instances to create a shift in the way one views one’s self (Janoff-Bulman, 1992). The participants in this study spoke consistently about their core sense of self as feeling in disarray, fragmented and unfamiliar. They used terms and phrases such as, “I just fell apart”; “I was just a.... wreck”; “I must have been so disjointed” and “it just wasn’t me”. This was evident in four of five participants’ descriptions of their functioning as parents, which appeared to have become temporarily diminished, shattering their interpersonal bridge (Wiffen & Oliver, 2004).

I mean for two or three days I forgot I had children. (Sandra)

...my son was eleven at the time.....that was quite hard because I was in a different place....I don't think I was always there for him at that time really. (Amy)

The shift from an established self was evident in participants' descriptions as they contemplated this new and unwanted dimension to their sense of self. Daniel describes his internal rejection of a killing identity:

What I found myself thinking was, "I don't want to be the guy who's, killed somebody else." (Daniel)

Reconstructing one's self involves attempts to integrate or fend off unwanted parts of self, which appears to be a continuous and recurrent process. Kelly's (1955) conceptualisation of identity as a collection of multiple selves is a useful concept in relation to people who have caused an AD. There is a sense of struggle, as the established self wrestles with a responsible self, a guilty self, and a shameful self. These come to the fore and participants describe living with these multiple selves. The extract below captures how Ben struggled to integrate the experience as part of his self-narrative.

I've caused somebody's death and it's my fault....there was a long period of denial before I got to that conclusion...that... was sort of enforced upon me by law, it wasn't something that I naturally came to.... yeah, so difficult, difficult and traumatic. (Ben)

The denial mechanism helped to maintain his established self, thus protecting against an incongruent part of self. The imposed criminal identity almost jars with his former sense of self, giving rise to uncomfortable and difficult feelings. When faced with such adversity, participants in the first instance drew upon social and religious discourses, such as "thou shall not kill", which related to their feelings of deep regret, guilt and responsibility. These discourses were also used to reason with their internal world about the value of their own life.

If you think that feeling responsible for killing somebody it makes your own perception of your own life value fall away to nothing progressively over time, because it really affects your thinking.....you end up with that crude,

simplistic 'an eye for an eye' thing, "Well I've killed, so therefore I shouldn't be here either." (Ben)

Most participants feared public condemnation, which is likely to have increased their guilt and hindered their coping ability (Feockler *et al.*, 1978). Others also spoke about their worries of being judged by others as “*bad*” or “*murderous*” people.

...being evil, that I was wicked, that's how I felt... At the time I thought I just wanted to be invisible... just thought they must think, "She's that stupid woman.....stupid to do what she did, or vindictive, or wicked."...I just felt such dreadful shame, and guilt....I felt like a murderess, and in my heart that's what I was telling myself, that I was a murderer and I shouldn't be there. (Jane)

These global negative self-attributions relate to Wallbott and Scherber (1995) and Tangney's (1997) conceptualisation of shame and its complex relationship with guilt. All participants experienced a heightened and chronic sense of guilt and shame. This finding supports Lowinger and Zoloman's (2004) who propose that for drivers who kill, the lack of legitimacy to externalise their feelings can be displaced into strong feelings of guilt (Lowinger & Zoloman, 2003). Furthermore, Hickling and Blanchard (2006) suggest that without such legitimisation processes, there is a potential for self-recrimination, which in turn can hinder the re-establishing of an adaptive self following trauma (MacNair, 2002).

Implications for clinical practice

The struggle to cope with the psychological aftermath of causing an AD was evident in all participants, with suicidal ideation featuring as a recurrent theme. In relation to the UK Government's initiative (DoH, 1999; DoH, 2002) to reduce suicide rates by 20% by 2010, this group of people appear to be at a high risk of suicide particularly in the first year following the accident. Alcohol misuse, an inability to function in the work place and at home, and the recurrence of the

deep feeling of guilt and shame appear to instigate thoughts of suicide and attempts to seek help. Not seeking professional help when suicidal may have tragic consequences and is reflected in our current suicide statistics. This study demonstrates how challenging it is for this group of people to access professional support and when they do, it is often at crisis point, after many years of suffering. This highlights a need for greater awareness amongst GPs of the detrimental psychological affects of causing an AD. This in turn may facilitate earlier and timelier referrals to appropriate secondary mental health services.

The findings illuminate some interesting potential clinical needs for drivers who have accidentally killed. It appears that drivers may benefit from early intervention support, or crisis intervention. This may serve as a preventative strategy against the development of more serious trauma responses and complicated grief reactions. The findings suggest that such provisions might include: empathic emotional support, information provision about potential trauma symptoms, how to recognise more serious PTSD symptomology and where to access mental health services. The absence of such knowledge contributed to the participants' distress and uncertainty. The findings also suggest a need for signposting practical assistance, e.g. informing people about the criminal justice system and procedures. The task may normalise and help to bring some order to the lives of those who have accidentally killed. Self-help leaflets may facilitate recognition of their experiences and encourage timely uptake of appropriate services.

Early intervention support as suggested already exists and is provided by charitable organisations such as BRAKE and Road-Peace. However, they only serve the interests of the bereaved family members. There is no such support for drivers who have caused an AD. As a society, we appear to turn away from these drivers' pain and needs and therefore maintain their experiences of disenfranchised trauma and grief.

When those who have accidentally killed do come to the attention of clinical services, clinicians need to consider the complexity of their difficulties. For example, NICE guidance for the treatment of PTSD symptoms do not fully capture the struggle to understand the nature of responsibility and acceptance of their role in a person's death, nor does it find a measure of redemption or meaning. Each of these areas needs further investigation. Clinicians should be mindful of legal legacies when working with this client group, consider the impact of such experiences in relation to confidentiality and therapeutic trust, and discuss this openly with their clients.

Methodological considerations

The study's findings are based on the experiences of a small group of people. Thus, the study is modest in its claims, acknowledging that the findings may or may not resonate with the wider population of drivers who have caused an AD. The self selected sample and their retrospective accounts may not be representative of drivers who have accidentally killed. Furthermore, the limitations of a cross-sectional design must be considered.

Conclusion

The experience of accidentally killing represented a distinct life-changing moment for drivers in this study. The incident created a wave of destruction and uncertainty that seeped into all domains of the participants' lives. It is hoped that this study will serve as a catalyst and inspire discussion in the development of further research examining the experiences of people who have accidentally killed another person.

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