Finding meaning in caregiving, well-being, and spousal caregivers of people with dementia

Volume I

by

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(Clinical Psychology)

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I would like to express my heartfelt thanks to Dr Sue Thorpe my Research Supervisor, for her continuous support, enthusiasm, encouragement and belief in me that kept me going, especially during times of difficulty.

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Finally I would like to thank my parents Valerie & Tony Richards. They have made many sacrifices to help me achieve things in life, particularly during the course of training when the demands on my time meant I could not be with them as much as they might have hoped for during a time my mother’s health was not good. Sadly, my mother passed away before she was able to see me fulfil the dream she had for me in achieving my doctorate. This portfolio of work is dedicated in honour of her memory.

IN MEMORIAM

Valerie Ann Corinne Richards

(1936 – 2009)
This portfolio represents the work I have completed and the experiences I have gained over my three years as a Trainee Clinical Psychologist. It is comprised of three dossiers which are split across two volumes. Volume I (the Public Portfolio) contains those documents which can be placed into the public domain, and Volume II (the Confidential Portfolio) contains those documents which contain information of a more sensitive nature and therefore cannot be made publicly available to protect the confidentiality of those involved.

The three dossiers are:

**Academic Dossier** – this is comprised of essays written on topics of adult mental health and professional issues, as well as accounts of Problem Based Learning Tasks. Process accounts of case discussion groups were also written, but only abstracts are included in Volume I, with the full accounts appearing in Volume II.

**Clinical Dossier** – this is comprised of case reports of clinical activity, along with documents relating to my placement experience and evaluation. For confidentiality reasons the full documents appear in Volume II, however an overview of my clinical experiences gained on placement along with abstracts of the case reports are presented in Volume I.

**Research Dossier** – this is comprised of my Major Research Project, a smaller Service Related Research Project, and the abstract for a small scale Qualitative Research (group) project undertaken. My research experiences gained over the last three years are summarised in a Research Log. All of these documents are located in Volume I.
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Volume 1

(Public Portfolio)
Section 1

Academic Dossier

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1.3 Personal & Professional Learning Group (formerly case Discussion Group) Process Accounts (Abstracts Only)
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1.12 Professional Issues Essay
March 2008
Year 1

'Critically discuss one model for the assessment and treatment of people given a diagnosis of Personality Disorder. Make specific reference to the perspectives of service users.'
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1. Introduction

As a first year trainee clinical psychologist, one of the main models of therapy I will be working with is CBT (cognitive-behavioural therapy), although more specifically with people who have clinical disorders such as depression, anxiety etc. for which CBT is a recommended therapy (Dept. of Health 2001). However, Judith Beck (1998) indicates that CBT can also be used to good effect with people who have a diagnosis of personality disorder (PD), but cautions us that its use with this client group is not so straightforward. Also of interest is her suggestion that up to 50% of people presenting for treatment for clinical disorders, may in fact have a previously undiagnosed PD or PD traits, which could then impact on the efficacy of treatment for their clinical disorder, if not then taken into account. Thus in reflecting on my own clinical practice (and learning needs) when considering this essay, it seems pertinent not only to think about CBT for PD in a 'stand alone' context, but also in relation to recognising and managing PD within the context of CBT for a clinical disorder, should a PD come to light in the course of therapy.

Thus I have taken CBT as the model of focus.

This essay will consider what having a diagnosis of PD means, and how it is understood in cognitive terms. After briefly reflecting on the standard approach to CBT, the discussion will focus on its application regarding PD diagnosis, assessment, treatment and the therapeutic milieu, to take account of the distinctive traits that make psychological intervention with people with PD more challenging. This will then be
grounded in the evidence for CBT as an effective intervention for PD. In conclusion I will reflect on the relative merits of CBT as a model for treating PD.

2. Understanding personality disorder as a mental health condition

2.1 Relationship of personality disorder within Mental Health Services

Before considering any psychological intervention for PD, it is worth reminding ourselves, that there are certain aspects within mental health culture that may also impact on any work done with this client group. Whilst many clients within mental health services may often feel themselves to be in a powerless position, people with PD have often felt even more stigmatised by their 'label'. Ramon et al (2001) note that this is often due to staff (and other peoples') attitudes to them, as evidenced in service user comments about being made to feel 'bad as well as mad' and 'service lepers'. Historically, PD has been constructed around notions of being 'untreatable', although NIHME’s (2003) report - ‘Personality Disorder: no longer a diagnosis of exclusion’, has tried to redress this.

However attitudes can be slow to change as I know from my own experience working in a CMHT, and as clinical psychologists, BPS (2006) suggest that we have a certain responsibility towards promoting an improved understanding of PD amongst our colleagues regarding this client group. Despite NIHME's (2003) report, research on service
user perceptions by Horn et al (2007) and Horton (2003) still notes service users as reporting commonly held negative thoughts and feelings regarding; unwillingness of professionals to inform/discuss diagnosis; diagnosis as a rejection, and basis for exclusion from support; notion of untreatability as killing hope for future; feeling blamed/ashamed of their condition; difficulty forming and maintaining relationships with professionals. More positively however, these authors also note that in the context of a psychological intervention where the diagnosis had been properly explained it was viewed less negatively, and indeed some people found it helpful to have a name by which to validate their difficulties and experiences. Against this background, it is perhaps not surprising that people with PD entering psychological therapy may be feeling wary and/or sceptical about both therapy and the therapist, which will have implications for engagement and the therapeutic alliance. However the collaborative nature of CBT and its formulation approach to understanding and treating people, should, if managed sensitively, help overcome this.

2.2 Defining personality disorder – the medical model

Whilst personality itself is an area that has been well studied in psychology, it remains a complex construct to define. This is perhaps equally reflected in the difficulty that clinicians have had in defining (or constructing) what constitutes 'abnormal' personality or personality disorder. Diagnostic discourse within Mental Health Services, is still largely driven by the medical model of 'illness' espoused in the two
taxonomies in use, namely DSM-IV-TR (Diagnostic and Statistical Manual – American Psychiatric Association 2000), and ICD-10 (International Classification of Diseases – World Health Organisation 1992), and their definition and diagnostic categories predominate, particularly DSM which is the most widely used for research purposes. Despite the grounding of PD in this medical model of 'illness', people with PD have not always been afforded the benefits or sympathy concordant with this viewpoint by many professionals or indeed others, (at least from the service user perspective as previously illustrated).

Before referral to psychology for intervention, people will typically have been defined as having PD if they meet the following broad medical definition:

' an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture. The pattern is manifest in two or more of the following areas: (1) cognition; (2) affectivity; (3) interpersonal functioning and (4) impulse control. '  

(DSM-IV-TR 2000)

They will probably also have been given a specific type of PD diagnosis, according to the particular personality traits they display e.g. borderline PD. Whilst a detailed critique of the contested nature of these medical models in respect of PD is beyond the scope of this essay, notable criticisms exist regarding: their validity and reliability (e.g. Pilgrim 2001, Widiger et al 2007); as well as the distinction made by
DSM-III onwards, of separating the clinical and personality disorders onto separate axes (I & II) (Krueger 2005). Indeed, he notes that these disorders have more similarities than differences and suggests it would be a better endeavour to understand how personality connects them together, which in many ways the CBT use of formulation attempts to do, as will be discussed later. In fact Pilgrim (2000) challenges clinical psychology to overcome its ambivalence to psychiatry, and expose the shortcomings of the diagnostic approach suggesting that formulation is a more compelling approach, and offers a genuine alternative for explaining peoples’ presenting problems.

Meeting the criteria for a PD does not necessarily mean you need treatment for it. Indeed, epidemiological studies suggest that around 12% of the general population could meet the criteria for PD (Emmelkamp & Kamphuis 2007), i.e. 1 in 8 people, yet services are not inundated with referrals for PD treatment. Beck (1998) notes that having a PD is only problematic for people insofar as it: (a) produces suffering in the individual concerned; or (b) leads to difficulties in relation to others or society. Furthermore several authors (e.g. Segal et al (2006),) note that whereas clinicians view symptoms of PD as ego-dystonic (outside of the self, and in need of change) people with PD typically view their symptoms as ego-syntonic (being congruent with their self-image). They often see the problem as residing in others not themselves (Beck et al 2004), and consequently do not tend to seek
treatment for these symptoms, but rather for the symptoms of other clinical disorders which their PD may make them more vulnerable to (Segal et al 2006). Thus for CBT, working on a collaborative formulation for PD with someone who does not feel (at least initially) that they need to change anything, will make engaging them in the assessment process itself particularly challenging, before even considering any treatment.

Effective treatments are required however, since compared to the general population PD is over-represented within mental health services, with up to 50% of clients having PD as noted earlier. Many will have presented in the context of a crisis due to experiencing depression, anxiety etc. for which they have been referred, with the notable exception of Cluster B PD's e.g. borderline PD (Roth & Fonagy 2005). This suggests that having an effective therapy like CBT with the potential to treat both PD, and clinical disorders in the presence of PD, would be beneficial.

3. The cognitive approach to understanding personality disorder

3.1 Assumptions of CBT model

The CBT approach itself is premised on an assumption that a person's behaviours and feelings are intimately connected to their thought patterns. It is not the particular situation per se that provokes the
emotional response or behaviour exhibited, but the perception or interpretation (cognitions) that a person has about it that does so. As a therapeutic intervention, CBT presupposes that it is possible to monitor and change thinking patterns, and that by changing how a person thinks about a situation, it is possible to change how they feel or behave towards it (Segal et al 2006).

3.2 Aetiology of PD from a cognitive perspective

Beck et al (2004) suggest that the behavioural strategies witnessed in people with PD are the overt expression of underlying thoughts and feelings. They take an evolutionary approach to explaining behaviour in PD, whereby it represents the use of 'primeval strategies', e.g. attacking behaviour in antisocial PD as a strategy against predation. Behaviour is viewed not as good or bad, but as more or less adaptive when used in today's contemporary environment, according to the appropriateness of the response to the situation.

In describing the development of PD, Beck et al (2004) view it as stemming from the interaction between genetic predispositions and exposure during childhood to undesirable influences from other people or specific traumatic events, which then creates dysfunctional schemas that go on to form the basis for adult personality, as in Figure 1 below.
Childhood experiences may act to reinforce an inappropriate situational response e.g. a shy child having overprotective parents, may lead them to feel a need to depend on others, and lead to overdevelopment of this schema and its behavioural strategy, and underdevelopment of a self-efficacy schema for instance. Beck et al suggest that in PD, the maladaptive schema become hypervalent, and have a compulsive tendency to being invoked in preference to more adaptive ones. They also tend to be over-generalised, inflexible, imperative and change resistant. Beck et al note, that we all possess both adaptive and maladaptive schema, however it is the interpretational bias towards expression of the maladaptive schema, often inappropriately,
particularly when personal loss or threat is involved, that result in the
dysfunctional response observed as personality disorder.

Beck et al suggest that whereas in the case of the clinical disorders the
shift towards biased processing and interpretation of information has
resulted in the temporary loss of a person's ability to reality-test their
dysfunctional beliefs and attitudes, in PD this has been, and still is an enduring problem. The aim of CBT, is for the therapist to act as a substitute reality-tester for the client, and help the person re-activate their own reality testing system.

4. Assessing personality disorder

4.1 Meaningfulness of a prior diagnosis of personality disorder within the CBT approach

Although a prior diagnosis of PD may have been given by a referring clinician, this diagnosis may not be wholly useful in the context of a CBT perspective. Whilst Beck (2005) notes that it is possible to identify particular beliefs about the self and others etc. that are commonly shared by people with a particular type of PD, e.g. for dependent PD: I need others to survive; others are strong and capable; no assumptions can be made about their manifestation in an individual client. As Dudley & Kuyken (2006 – as cited in Johnstone & Dallos eds.) note, diagnosis is descriptive, atheoretical and nosological, and as such has a limited bearing on CBT formulation. Furthermore, depending on the source from which the diagnosis was made (e.g. psychiatrist), this may or may
not reflect an accurate judgement, since many of the diagnostic criteria in DSM/ICD are subjective, and may not have been derived using a standardised assessment tool, e.g. SCID-II (Structured Clinical Interview for DSM-IV Axis II Personality Disorders – First et al 1997), MCMI-III (Millon Clinical Multiaxial Inventory-III, Millon et al 1994). Again however the diagnostic validity of these is equally contentious due to their poor convergent validity, susceptibility to mood states etc. (Widiger 2002).

Due to the challenging nature of PD, Beck (1998) suggests that ideally both assessment and treatment should be carried out by an experienced clinician, and that where this is not the case, conducting an assessment using a well structured format is essential. However the aforementioned tools are not wholly compatible with a CBT approach, since they can be both tiring, and as Western & Shedler (1999 – as cited in Widiger 2002) note they can appear to be a long, mindless, superficial, symptom counting exercise. In a client group who already hold negative perceptions of clinicians, this is only likely to increase such beliefs, and unlikely to help foster a good therapeutic alliance. Johnstone (2006) notes that in contrast to the shortcomings of psychiatric diagnosis, formulation - such as provided by CBT - can provide a more personally meaningful and mutually collaborative stance in mental health work.
4.2 CBT and formulation – a more meaningful approach for assessing and understanding PD

In taking a formulation approach, CBT uses a generic model such as that shown in Figure 2, to structure the process, but applies it in an idiosyncratic way to a client’s particular problems, to produce an understanding that is personally meaningful.

![Figure 2 Showing cognitive therapy model (carr & McNulty (2006))](image)

the client's difficulties as possible. Dudley & Kuyken (2006) suggest the five P’s approach to CBT formulation. The presenting issue(s) need to be defined clearly and specifically, including cognitive, behavioural and emotion aspects, as well as some understanding of the psychosocial context. This is important on two levels: firstly because this information
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will be used to develop the goals for therapy; and secondly, by allowing
the client to talk about their problems it enables them to feel understood
and gain a sense that these might be solvable, especially if the therapist
responds with sensitivity.

Consideration should then be given to the precipitating factors (what
triggers the problem) and the perpetuating factors (what maintains the
analysis structure to elucidate the thoughts, feelings, behaviour and
physiological components, which can be used to demonstrate the often
circular connection between them to the client, and why it is in some
ways only natural, that they should be experiencing the difficulties they
are. For people with PD, the predisposing factors are particularly
pertinent, both the quality and quantity of stressors especially from
childhood. It is these which have lead to the development of the core
beliefs and assumptions that are forming the basis of the client’s current
dysfunctional coping strategies. Unlike a more psychoanalytic
approach, childhood/developmental history is only required insofar as it
relates to the clients current difficulties. Protective factors are also
important, since these will be strengths and resources that therapy can
build on.

Davidson (2006 – as cited in Tarrier ed.) emphasizes the assessment
process as having a crucial role in developing the therapeutic
relationship. It is therefore important not to rush this, or pursue
information and fail to attend to the client. Forgetting to ask a question
is likely to be overlooked, but lacking warmth etc. won’t be. People with PD may be especially sensitive to this, since they often feel they have not been listened to by other clinicians, and may possibly be feeling a sense of failure at having been passed around from one clinician to another without having felt helped or wanted. This point by Davidson seems very much in accord with the sentiments discussed earlier regarding the perspectives of service users.

Carr & McNulty (2006) describe CBT formulation as an endeavour of ‘collaborative empiricism’, based on the shared exploration and understanding that is developed between client and therapist. This should, if implemented sensitively to reflect warmth, empathy and unconditional positive regard, help to address the negative feelings that people may be entering therapy holding, and enhance their willingness to engage in the therapy process. Whilst many people may enter therapy with benign expectations thus making it relatively easy to develop a therapeutic alliance with them, Beck (1998) notes that this is generally not the case with people with PD and this an especially challenging part of therapy. If insufficient attention is paid to the therapeutic relationship, then therapy is unlikely to be helpful to the client. As Horton (2003) notes, a service user with PD who found her therapist to be unempathic felt she gained no benefit from their sessions, despite the therapist being an ‘expert in her field’. 
However, as Beck (2005) notes, even this formulation approach can leave clients open to the same ‘abuse’ and problems regarding the power of the therapist as expert, if the therapist misuses it. It is clearly important for the therapist not to make assumptions about the behaviour or any intentions that may or may not exist behind it on the part of the client or others (Westbrook et al 2006). Indeed the diagnostic definition reminds us that PD is diagnosed in relation to the person’s difference from their own culture, not the therapist’s. Beck (2005) states that therapists should be aware of diversity issues especially in relation to self and client, since misinterpretations can have disastrous consequences for therapy, and cites the case of a white American therapist who thought that an Asian girl with exam stress prior to returning to her own country to get married, was showing a dependent PD and encouraged her to practice severing her ties to her family. A more appropriate cultural interpretation would probably not have led to a PD diagnosis.

Whilst the assessment phase of therapy will result in an initial formulation which then acts as the rationale for treatment, formulations are not a fixed picture of the client’s cognitive and behavioural processes, but continually evolve as new information comes to light (Westbrook et al 2006). They suggest that typically adjustments are fairly minor (as shown in their formulation process diagram in Figure 3 below), however should something major come to light e.g. a previously unnoticed PD, then a complete reassessment may well be required.
Figure 3. - Showing process of assessment and formulation (Westbrook et al 2006)
Formulations can be particularly helpful when presented in a diagrammatic format to a client, and provides a coherent framework for the client’s difficulties, which can make them appear less daunting since many of the underlying patterns for different situations may in fact be similar (Davidson 2006). Figure 4 illustrates how recurrent themes in thoughts and behaviour in PD may be linked:

Diagram 2. Showing sample cognitive formulation for PD. (Taken from Davidson 2006 as cited in Tarrier ed. 2006)
By ensuring that the client feels the formulation makes sense and conveys their understanding of their difficulties, it can be used to identify the areas of greatest need on which treatment can be focused. If a good working alliance has not been established, and the client has not engaged with the process so far, moving on into the treatment phase is likely to be unprofitable. A good working relationship can be forged by attending to three key components: agreement on the task, agreement on therapy goals; and a positive therapist-client bond (Borodin 1979, cited in Westbrook et al 2006).

5. Treating personality disorder using CBT

Developing a good therapeutic relationship is central to CBT (although it is not alone in this), however Roth & Fonagy (2005) note that a good therapeutic relationship is a necessary but not sufficient part of the beneficial effect of CBT. Westbrook et al (2006) suggest that whilst the therapeutic relationship may not in itself be curative, a key part of its function is its role as the vehicle of change within CBT. Indeed they view the therapeutic relationship as representing a laboratory for working on problems and testing new skills that can be transferred to the real world. Unlike the psychoanalytic approach which focuses on the ‘transference’ that occurs in the therapist-client relationship, CBT focuses on the relationship itself, and its potential for modelling to the client, other possible ways of relating to people e.g. others don’t desert you just because things get difficult (Westbrook et al 2006). This is especially valuable in therapy for people with PD, for whom
interpersonal relationships have typically been a source of much difficulty (Beck 2005).

Davidson (2006) suggests that CBT lends itself well to working with clients with complex problems, although she notes this only works in the context of the formulation framework. As the needs of people with PD are more complex than the clinical disorders, this suggests that CBT could offer much to this client group, however Beck (1998) notes several key modifications may be necessary when applying CBT to PD. When working on negative automatic thoughts, and beliefs, people with clinical disorders tend to view their cognitions as truths rather than ideas. The ego-syntonic nature of PD means some people may have difficulty accepting the cognitive model of their experiences and can easily feel invalidated when asked to try and understand them from a different perspective. Thus with PD, therapists usually need to spend a lot of time enabling people to understand how their life experience has led to them developing some extreme beliefs and negatively skewed patterns of thinking, resulting in some currently dysfunctional ways of behaving, and using the cross-sectional analysis provided by the ABC model can be especially useful. Working on automatic thoughts and especially core beliefs is particularly challenging as they take longer to modify, and hence CBT therapy will tend to be more long-term than usual. Interventions which engage the client and provide evidence of their worth to the client are the most likely to have a lasting effect on changing meanings. (Carr & McNulty 2006).
Greater emphasis is placed on needing a strong therapeutic alliance with PD, since the clients may activate dysfunctional beliefs within a therapy session regarding themselves, the therapist or the therapy, which the therapist needs to be sensitive to so they can be worked on immediately, and it can be helpful to do a separate formulation for this. The therapist may also need to consider the role of their own beliefs that arise in the course of interaction e.g. frustration, and apply CBT techniques to themselves to resolve these. Such therapeutic aspects are perhaps more reminiscent of a psychodynamic approach.

Goal setting and problem-solving can also present difficulties in PD, since the person with PD may want to set goals for others, or set vague/unrealistic goals for themselves e.g. I want to be better. Due to their life experiences however many people with PD may also lack effective problem solving skills. The therapist needs to be mindful of this, and teach these first where necessary to enable client to then be able to tackle their goals. Equally important is the need to teach relapse prevention techniques especially as negative core beliefs are never completely modified in PD and are at risk of reactivation.

Some people with PD may also struggle with the structured nature of CBT therapy e.g. agenda setting, what goes on it etc., due to the beliefs they hold about this e.g. my therapist is trying to control me. The therapist needs to be alert for clues regarding this so they can vary the structure accordingly until a strong enough therapeutic alliance has
been built. Equally the therapists own personal style may need to be adapted to be more compatible with the client’s PD traits, until the therapeutic relationship has been forged strongly enough. However as Westbrook et al (2006) note, the therapeutic relationship is not a fixed entity, but can easily break down if not attended to. The therapist should always bear in mind that they are a guide/mentor in a collaborative process, not an instructor.

It is possible that whilst using CBT with a client with a clinical disorder, personality traits which may or may not be sufficient for a diagnosis of PD may become apparent. Beck et al (2004) suggests indicators of this might be: non-compliance with therapy; therapy feels blocked; client talking about change but not making it; inability to focus on their behaviour as source of dysfunction; amongst others. However one needs to be mindful, not to misinterpret such reasons with an assumption of PD. If it is PD, then these traits need to have preceded the clinical disorder, and stemmed from childhood. Difficulty engaging with therapy may be about not understanding what is required of them, not feeling engaged with the therapist, or lack of motivation etc. Even if such PD traits are apparent the person may not want these addressed. However research shows they could still gain some benefit for their clinical disorder from continuing with therapy (Beck et al 2004), although some reformulation and restructuring of therapy as noted above may be required. In such circumstances as a trainee, discussion would need to take place both with a supervisor and the client as to
whether therapy should continue, or be passed over to a more experienced colleague (as noted by Beck 1998)

6. Evidence base for using CBT for personality disorder

From the point of view of service users, psychological interventions seem welcomed as long as the therapeutic relationship pays attention to their needs (Horton 2003). Indeed the BPS (2006) guidelines on PD note that it is the therapeutic alliance that is the strongest predictor of outcome in psychotherapy for PD.

Whilst guidelines such as Dept of Health (2001) show there is much evidence to recommend CBT for clinical disorders, particularly using the ‘gold standard’ of randomised control trials, my own findings (supported by Beck et al 2004) is that there appears to be a dearth of this type of evidence in the literature regarding CBT for PD. Studies that exist have tended to focus on borderline, antisocial and avoidant PD, and often focused on efficacy for clinical disorders in the presence of PD rather the focusing specifically on the efficacy for PD itself (Beck et al 2004). They comment on the results as having been mixed, with the presence of PD often seen as reducing the efficacy of CBT in the clinical disorder, although some benefit was still gained. However given the critique regarding the discreteness (or possible lack of) regarding PD and clinical disorders, it is questionable whether it is possible in such combination studies to single out what the results mean. Since Beck (1998) also notes that ‘standard CBT’ needs to be modified to
accommodate more effectively the specific needs presented by people with PD, perhaps these mixed results are not surprising with standard CBT. However studies of CBT with PD that have used open or series case design methods, have shown positive trends (Davidson 2006, Beck 1998, Roth & Fonagy 2005).

One problem with measuring outcome efficacy is rating it against no longer meeting the criteria for a diagnosis of PD according to DSM criteria. Grilo et al (2004) note in their two year stability study, that the expression of severity of PD can change naturally over time according to life circumstances. Thus can therapeutic changes over the same period necessarily be attributed to the therapy if this measure used. Clearly some agreement over how to measure therapy outcome for PD needs to be reached, for the evidence to carry more weight.

Meta-analysis of studies has proved difficult as evidenced by Leichsenring & Leibing (2003), who compared effectiveness of psychodynamic therapy against CBT. They found them to be equally effective in treating PD, however comparison was difficult since there is a lack of standardisation across assessment and outcome measures for PD. This is partly due to the lack of convergent validity across measures used, where an outcome on one measure may not be equivalent to another (Widiger 2002).
Unfortunately, in terms of assessing CBT in respect of process-outcome, Dudley & Kuyken (2006) note there is still only limited research to date, and almost none in respect of case formulation. Thus the value of CBT when assessed from this perspective is currently resting on 'established good practice'.

7. Conclusion

Whilst one needs to take care not to simply advocate CBT as the panacea for all mental health difficulties, it seems to me that the basic principles of CBT with its emphasis on developing a shared understanding and the focus on the therapeutic alliance as a vehicle for change, suggests it has the potential to provide a therapeutic milieu that can meet the needs of people with PD. It would certainly seem to represent a more meaningful way for them to engage with clinicians in exploring and understanding their difficulties through the collaborative process of formulation.

Given the apparent high co-morbidity of PD with other clinical disorders, it is likely that many people presenting for CBT treatment may have some PD traits. Specialist services for PD are somewhat limited, and if, as suggested here, CBT can be modified to accommodate the needs of at least some of this client group, this may open up more therapeutic options for them, and make services feel as though they are more inclusive of their needs. As a trainee, this essay has certainly made me more aware of my own CBT practice with people with clinical disorders.
as well as gaining an understanding of how I might be more sensitive to
the needs of people with PD should this arise in the course of my
practice.

The evidence base for using CBT with PD is still developing. However
despite the problem that PD as a diagnosis presents regarding validity
and measurement issues, CBT would seem to be at least as effective
as other forms of therapy available, despite mixed results when
considering it in relation to clinical disorders. It would be interesting to
see if in time it is possible to evaluate CBT efficacy based on the use of
formulation rather than psychiatric diagnosis, although ‘good practice’
would suggest formulation is a good therapeutic tool if used well.
8. References


‘What are the differences and similarities in the process and content of supervision and consultation practices in clinical teams? How might we evaluate the effectiveness of supervision and consultation in our NHS work?’
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1. Introduction

In offering supervision and consultation, it is important that we as clinicians are aware of the differences between them, what we are offering as supervisors or consultants, and whether we have developed appropriate and effective skills to deliver them. In the first part of this account, I will discuss the distinction between these two roles, noting the key difference regarding accountability and responsibility. However both activities share many features in common especially in respect of the processes by which they accomplish their aims, and the more subtle differences apparent in this will be highlighted as they emerge within the narrative. In the second half of this account I will consider our positioning as scientist-practitioners, which makes it incumbent on us to ground our work in an evidence-base that demonstrates it as effective. Many authors have been critical of the current literature, and a key problem in evaluating effectiveness has been in deciding what actually constitutes an effective outcome for supervision and consultation, and how to deal with the complexity involved in measuring outcomes. The merits of using both formal and informal, means of evaluation will be reflected on.
2. Assessing the similarities and differences between supervision and consultation

2.1 Defining supervision and consultation

There are no agreed standard definitions in the literature for supervision as applied in clinical practice, which has changed over time as the profession evolves. Fleming & Steen (2004) note, that even the BPS (British Psychological Society) do not subscribe to any one definition or model of supervision, although they view supervision as an essential activity of clinical practice at all levels. Several authors (e.g. Scaife 2001, Fleming & Steen 2004) support the utility of Bernard & Goodyear's (1998) definition:

'An intervention provided by a more senior member of a profession to a more junior member or members of that same profession. This relationship is evaluative, extends over time, and has the simultaneous purposes of enhancing the quality of professional services offered to the client(s) she, he or they see(s), and serving as a gatekeeper of those who are to enter the particular profession.'

Whilst this definition is by no means inclusive or wholly representative of the complexity involved, it perhaps represents a reasonable attempt at conceptualisation, and a contrast to consultation which can be defined as:
'a voluntary, non-hierarchical relationship between two professionals who are often of two different occupational groups, which is initiated by the consultee for the purpose of solving a work-related problem.'

Caplan (1970)

Brown et al (2006), suggest that there are no right or wrong definitions of consultation, but contest the restricted term of 'professionals'. A consultee could for instance a family, group or community. Equally, a psychologist could take the part of consultee, in seeking to understand the needs of service user groups in developing services. Brown et al (2006) proposes that consultation may be better thought of as a simply a problem-solving process.

From these definitions, supervision and consultation might appear to represent quite different clinical activities. Even at this level, there are some clear differences emerging in the relationship between the participants in each process, particularly on issues such as power, evaluation, learning and safeguarding.

2.2 Purpose, Function and Participants

Supervision is a mandatory requirement of the BPS (2008), both for trainees and qualified staff. The purpose of supervision is cited as being twofold (Bernard & Goodyear 2004):
• to facilitate the supervisee’s professional development
• to safeguard client welfare

This suggests supervision performs several functions: education, support and ensuring adherence to professional standards, and can create a context in which theory-practice links can be made. For trainees however, Cushway & Knibbs (2004) state that the primary purpose of supervision is actually to safeguard the client. Inskipp and Procter (1993) suggested a tripartite model of supervision functions which might be implicitly or explicitly covered in a session:

• formative: focusing on the supervisee’s learning and development
• normative: focusing on the supervisor’s managerial and ethical responsibilities
• restorative: focusing on the emotional effects of the work on the supervisee

Consultation when made available by psychologists is an activity that is provided at the consultee's request. The purposes of consultation (Brown et al 2006) are:

• to improve a consultee’s functioning with a client
• to facilitate the development of the consultee’s skills so that they can cope with a similar problem independently in future
• to enhance the service that a client receives
There would seem to be some elements of commonality with supervision functions, regarding facilitating learning and development of skills, but for the consultee, these are directed at problem-solving as opposed to therapy skills, although both supervisees and consultees are encouraged to develop reflective skills about their work. Unlike the supervisor, the consultant does not engage in the normative and restorative functions i.e. evaluate or emotionally support the consultee (although they may help them to reflect on whether their feelings towards a client are getting in the way of the work).

This highlights where a key difference between these two activities lies, namely that whereas a supervisor retains a degree of accountability and responsibility for the work done by their supervisee, a consultee remains solely responsible for the decisions they make and the work that they do. Brown et al (2006) suggest there are good ethical reasons for this, especially as consultation is typically a cross-professional interaction. Consultants, like all professionals should not exceed the boundaries of their competence. As psychologists may lack sufficient knowledge about the professional norms, codes and culture of another professional, they could exceed the bounds of their competence if they were to take responsibility for the other clinicians work (Scaife 2001). For this reason supervisors only take on supervisees of a similar profession i.e. other psychologists or therapists, as it is specifically part of their role to set clear and safe boundaries around the supervisees practice. In offering consultation to other professionals, this does help
psychologists to gain an insight and increased understanding of the work done by their fellow professionals, both within their own teams or in external teams (Jones 2005). Both supervisors and consultants do need to be mindful of the duty to preserve client confidentiality, but with the usual cautions regarding the limits to this.

Supervision is very much an ongoing relationship that takes place at agreed regular intervals of time. Consultation meetings are very often time limited depending on who the consultee is. Meetings with individuals in your own team to discuss a particular client typically may involve only one session. Brown et al (2006) notes, this has the advantage of prevent any dependency on the consultant from developing in the consultee, and in combination with them retaining ownership of the work promotes their self-efficacy in managing their client work.

Consultees can also be a group, within your own team or an external organisation (which may provide a liaison or bridging role between the psychologists team and an outside agency - Southall & Steinberg 2004). Regularity of meetings is at the consultee’s behest and although you may have an ongoing agreement to meet with them, this should always be subject to regular reviews to ensure it is meeting the consultees needs (Jones 2005). Indeed whereas one-to-one is the more preferable mode for supervision given its focus on teaching and evaluation, confidentiality and a safe space in which the supervisee can
talk about their work and feelings about it, consultation is very often done on a group basis (which works well as long as the team is cohesive – Jones 2005), as it offers the economies of scale that Caplan (1970) was keen to achieve in maximising the limited resource that psychologists are.

Fleming & Steen (2004) note that supervision can be done on a group basis, where there can be gains from the process of the group, but this needs careful facilitation to ensure people feel comfortable about sharing their work in front of others. If they don’t this could have implications on issues such as clients safety, and probably should not replace individual supervision completely. A less threatening version is peer supervision, where all participants have the same status and meet with the intention of sharing good practice or gaining non-judgemental advice on their work, which is similar to co-consultation except this represents a multidisciplinary meeting with the same objective. Such group endeavours may take the form of a reflective practice group, or may involve discussing particular cases that individuals have requested for the group to discuss. Just as with supervision, this allows for the opportunity to take a step back from the work and think about what is going on for the client and the worker. As such, both supervision and consultation represent evidence of good practice as part of clinical governance (Fleming & Steen 2004).
In thinking about the wider systems that consultation encompasses, Heller (1985) notes that used appropriately, it can also be a means to empower disenfranchised groups. Wedgbury et al (2005) describes how the service user and carer movement has taken up the mantle of acting as consultants to the organisations and clinicians who provide them with services. In this instance, the consultants are utilising their experiences as receivers of services, from which to offer thoughts on service development. Where service providers have been prepared to give up the power typically inherent in their more usual relationships with service users and carers and accept the role of being the consultee, this has permitted service users/carers to have a voice and partnership role in the development and provision of services, which after all should be aiming to meet their needs.

2.3 Engaging in the process

Supervision is mandatory, not only for trainees, but is also seen as an essential part of continuing professional development by the BPS. This is in contrast to consultation which is recommended as a service that qualified clinicians ought to be offering (BPS 2008). Thus there is little choice about being a supervisee, and indeed you may not have much choice on who your supervisor is depending on factors such as the size of the psychology team. Similarly supervisors may not get to choose who they supervise. Consultants are somewhat freer to make choices about what they offer and to whom.
Both supervision and consultation are interpersonal processes, and as both Alderfer & Lynch (1987) and Brown et al (2006) note, nothing has a greater impact on the success of these processes than the relationship that develops between the participants. Whilst both processes adopt a collaborative stance where mutual trust and empathy are key to building a good relationship, they differ in the extent to which democracy can prevail. Supervisors have a teaching and evaluative role to play, whereas consultants do not, and it is important to their stance that they are non-judgemental (Brown et al 2006). Proctor (1997) suggests a key first step to establishing a good working relationship is to go through a process of contracting, as this provides a container for the work and sets out markers which can guide and prioritise the direction for both parties. This helps to keep the process safe, by ensuring clarity about the sessions and providing clear lines of accountability (Jones 2005, Wheeler 2004). It should also detail how differences of opinion might be dealt with, and establish the negotiability of the relationship (Scaife 2001). In respect of supervision, Lawton (2000) notes that there is a strong link between the rigour of the contracting process and the quality of the working alliance that develops.

Osborn & Davies (1996) highlight the importance of having written supervision contracts which address five key principles:

- goals and expectations of supervision
- mutuality of the relationship
- ethical principles
- practical service issues
- ally supervision with counselling and consultation

Conversely, since the consultant is invited into the process by the consultee, Brown et al (2006) note that it is important to ask yourself ‘why me?’ and ‘why now?’, before entering into a contract, as this can help avoid later dilemmas or hidden agendas. A clear, mutually agreed contract such as suggested by Lake et al (2008) can then be devised about:
  - what you are going to offer
  - what you are offering it for
  - how you are going to offer it

They note that it is important to make this as explicit as possible, especially for the internal consultant where the team may make assumptions about the 'expertise' the psychologist is offering in this role.

Scaife (2001) notes that the most helpful relationships are those based on mutual trust and respect, and that the working alliance should be the place where differential status can be explored and a collaborative relationship developed. This is more easily achieved in the consultancy relationship. Although the consultant is trying to promote consultee functioning, they work on the assumption that the consultee is already
competent in their own profession/area of practice, enabling them to create a non-hierarchical relationship were both can be positioned as experts in their own right,

In a supervisory relationship, although a collaborative stance is the aim, the supervisor is unavoidably positioned as the expert, due to their evaluative role over the supervisee which places them in a position of power. Fleming & Steen (2004) acknowledge that as supervisees move from being trainees to experienced practitioners there is a shift away from a master-apprentice to a more collegial relationship, although if supervisor retains a line management role this can still create tension.

In order to provide the best service to clients, supervisees and consultees need to be able to disclose their intimate thoughts and experiences about their work. The evaluative nature of supervision makes it harder for a supervisor to facilitate this in a non-threatening way (Scaife 2001). Webb & Wheeler (1998) identified a positive correlation between quality of the working alliance and disclosure. A poorer rapport leads to lower self-disclosure which for supervisees has potential implications regarding safety and ethics in their clinical practice. Ladany et al (2001) found that the supervisory relationship can be enhanced when the supervisor is prepared to shares their own experiences and their supervisory style is interpersonal, sensitive and task oriented. McNeill & Worthen (1989) found this allows for tacit re-labelling of mistakes as learning experiences. Negative reactions of supervisors to supervisees performance is the most cited reason for
non-disclosure (Ladany & Melincoff 1999), especially if there is a poor working alliance. Inskipp & Procter (1995) suggest the central role should be one of understanding not supervision.

Both supervisors and consultants need to pay attention to diversity factors if they are to facilitate the development of culturally competent supervisees and consultees. Smith (1981) noted that a myth of 'sameness' can often prevail, whereby an assumption is made that the skills of helpers are generic and can apply equally to a person irrespective of their background. Supervisors and consultants must be aware of their own values and assumptions, whilst encouraging their supervisees/consultees to reflect on theirs, as well as giving consideration to those of the client, and the impact that each person's cultural values and assumptions will have on the work. Bernard & Goodyear (2004) note that supervisor's awareness of diversity issues often lags behind that of their supervisees, however Gatmon et al (2001) found that when supervision included a discussion of diversity issues, supervisees reported increased satisfaction with supervision which enhanced the working alliance. Pinto (1981) noted that for a consultant to be effective they needed to be culturally empathic. In fact Bernard & Goodyear (2004) suggest that all interactions are multicultural, and we need to constantly check out our assumptions to prevent awkwardness and avoid incompetence.
2.4 Structuring the process - Frameworks/models

By using drawing on the available models of supervision, this can provide a reference point and a structure that gives the work coherence and helps to make sense of any difficulties encountered (Wheeler 2004). Such models may also provide a frame of reference by which an evaluation of supervisor and supervisee competence can be judged. The embeddedness of psychologists as therapists, led to the initial development of both supervision and consultation models that were adaptations of the models that were used in therapy (Matthews & Treacher 2004, Brown et al 2006). Thus supervision and consultation were guided by the same processes as the therapy itself subscribes to, e.g. psychodynamic, systemic, behavioural.

Whilst Putney et al (1992) observe that the congruence of theoretical orientation between supervisor and supervisee enhances the supervision alliance, Bernard & Goodyear (1998) argue that therapy based supervision models do not capture the complexity of the supervision interaction and restrict the evidence base by offering few avenues of for research and practice. Neither supervision nor consultation are therapeutic processes, but are an important process in their own right. It should not be forgotten that both of these activities involve a triad, where the client is receiving a direct service form the supervisee/consultee and an indirect service from supervisors and consultants. Indeed Roth & Pilling (n.d.) note that supervision is an
implicit part of therapeutic treatment that is often not acknowledged in therapy efficacy research.

Beinhart (2004) notes that more recently, several models that reflect the processes involved in supervision have been developed, such as Stoltenberg et al's (1998) Integrated Development Model, the Discrimination Model of Bernard (1997) and Hawkins & Shohet's (2000) Process Model. These enable the supervisor to structure supervisor according to the needs and level of development of the supervisee irrespective of any therapy model the supervisee may be using. This allows for the use of formulation not just about the client's situation, but also about the supervisee in relation to the work, by enabling them to take roles as both participant and observer of the process (Scaife 2001).

Lake (2008), notes that few models have been developed for use in psychological consultation specifically. He suggests that the aim of consultation should be to help the consultee develop a formulation of their client, which might enable new insights and ways forward to be uncovered. He sets forth a cyclical model which the consultant can guide the consultee through in order to work towards this, in a similar way to how psychologists themselves would do so with supervisors. Activities such as role plays can also be utilised in session to think through how possible future interventions might play out. For both
supervision and consultation processes, such models help to ensure the development of meta-cognitive processes (Scaife 2001).

3. Evaluating the effectiveness of our work

The need for our practice to be seen as effective is becoming more important than ever in the current NHS climate. With increasing scrutiny being given to clinical practice via clinical governance, services and commissioners want to be able to see that they are employing competent staff who have the skills and knowledge to collaborate in providing both clinically and financially effective services for clients. As clinicians who subscribe to a scientist-practitioner model, it falls to us to ensure that we both work in accordance with and attempt to generate the evidence that supports our work.

3.1 Are we using evidence-based practice?

In my search of the literature, I was interested to read the experiences of supervision described by Matthews & Treacher (2004) who are both now course clinical tutors. They discuss how although as clinical psychologists we subscribe to the scientist-practitioner model of working, in practice it is not always apparent that we adhere to it. They describe how as trainees they were exposed to different supervisors with different styles, but there was no discussion of the model used, its theoretical base, or the evidence for using it. In turn as they became supervisors themselves, they chose a model to use based on the
appeal of the theoretical aspects of its approach rather than making a choice through evaluating the evidence-base in a manner more akin to the scientist-practitioner method. As justification for using their chosen mode of supervision they utilised anecdotal evidence from their own practice as confirmation of the value of the approach taken. It was only when they became involved in the training of supervisors and engaged with a more in depth analysis of the supervision literature that they became aware of some of the weaknesses inherent in their own approach as supervisors. In reflecting on my own experience of supervision as a trainee, I can see many parallels with that of Matthews & Treacher, and I wonder how typical this still is of (trainee) supervision experiences generally. As clinicians we are very good at ensuring we provide effective evidence-based therapy for our clients, but do we always apply these same standards to our other areas of practice?

Sloan (1999) notes that we often use our own supervisors as role models, and given their seniority and the trust which we endow them with through the supervisory relationship, it might be easy to fall into the trap of assuming their practice represents good practice. However Wheeler (2002) notes there are no recognisable standards set for supervisory practice, and Fleming & Steen (2004) have commented that there tends to be an assumption that supervision is effective. But as Roth & Pilling (n.d.) comment, the ubiquity of supervision does not prove its worth. Clearly trainees progress to become competent therapists, however according to Hess (1987), being a good therapist
does not necessarily make you a good supervisor since the focus of each endeavour is different, i.e. providing therapy to a client directly versus facilitating the learning in another to do so. This would apply equally to consultation skills. Amongst the competing pressures of our roles, it is perhaps easy to overlook supervision practice and evaluation as part of continuing professional development. It might be interesting to see whether supervisees rate supervisors who have attended training as being more effective. Writing this assignment has certainly increased my own awareness of these issues, prompting me to be mindful both in how I should be using supervision for effective self-development, and in thinking about how to develop the appropriate skills to become an effective supervisor myself.

3.2 Does the current evidence-base offer support for effective practices of supervision and consultation

The gold standard in evidence based research is represented by peer-reviewed efficacy studies. With respect to supervision and consultation research, such evidence would be hard to come by especially for supervision, since the ‘no supervision group’ required for comparison purposes would be unethical. Supervision is ordinarily a part of any therapy package that is evaluated, however few studies ever assess the impact of supervision on the outcome of therapy as a part of therapy efficacy research (except a few highlighted in Milne & James (2000) review of CBT).
A key issue in evaluating supervision and consultation is they are not manualised approaches. If a systematic or structured approach is not taken, and one is not explicit about what is trying to be achieved, it makes it hard to determine whether an activity has been effective i.e. achieved its purpose. Thus what is effectiveness being judged against? As Wampold & Holloway (1997) ask, 'what is a successful outcome?'

If we were able to ground our approach in the evidence base, then this would provide criteria against which we can evaluate our own practice – are we achieving similar outcomes. This would provide the standards against which we could audit our work for instance. The original research is also likely to have validated any measures used, which we could then use to help rate our own performance.

One major drawback in the supervision literature noted by Wheeler's (2002) review was that although she found over four hundred articles related to supervision, only eleven were written by UK based authors with the rest being North American in origin – an ongoing issue. As most of this literature refers to counselling and psychotherapy trainees, this presents a difficulty regarding the generalisability of such studies to UK based clinical psychologists. Lawton & Feltham (2000) note that whereas counselling supervision is more process-oriented, clinical psychology supervision is more goal-oriented. A key criticism of the literature is it is very limited with respect to outcomes of supervision, either in relation to supervisee competence or client benefit – the
ultimate test of efficacy (Ellis & Ladany 1997). This gap in the literature is perhaps more reflective of the greater interest that exists on the process of supervision, and the assumed virtue of supervision in spite of the weak evidence-base (Cape & Barkham 2002). Thus caution should be exercised when considering the relevance of the work, or any evaluation measures in guiding one's own practice.

With regard to consultation, Lake (2008) notes that it has been hard to produce an evidence-base as yet, since much of the process of consultation is flexible and integrative in approach which does not fit well with the tradition of randomised control trials. He suggests further development on the models is required in order to help inform thinking and practice and so start to establish an evidence-base for their effectiveness. A key question might be whether it is okay for consultation to benefit only the consultée, or must the also be a benefit to the client as well in order to deem the process as effective – a methodological nightmare to try and establish. Blumenthal & Lavender (1997) note that CMHT staff rate consultation as a key role for team psychologists, but does the high value they place on it mean it is viewed as effective by staff?

As part of my adult mental health clinical placement I undertook a service evaluation of the consultation services offered by the team psychologists. It was not possible to audit it, since there were no standards against which to do this. Neither were there any validated
measures. As a tentative first step in evaluating consultation, a self-report measure was devised to see whether the consultation achieved its purpose of facilitating increased understanding of the client in the consultee. The result was significant, although an attempt to see if the session gains had a generalisable effect across practice was not successful. Discussion of the results with the consultees enabled them to feel they now have the evidence to justify maintaining this service from the team psychologists which they value. For the psychologists, although it was felt to demonstrate an effective use of their time, service managers did not necessarily see the consultation as a 'unique' activity for psychologists. Perhaps we need to be careful in how we present ourselves as a 'non-expert' in the psychological consultation role, whilst still selling our expertise at it.

Self-report measures have similarly been used in much of the supervisor research, which Fleming & Steen (2004) observe focuses mainly on the supervisees reaction to the supervisor, e.g. Supervisor Rating Form (Heppner & Handley 1981), Supervisor Working Alliance Inventory (Efstation et al 1990). However they report that there has been no demonstrated relationship between supervisee perception and supervision outcomes. The issue of the impact of supervisor behaviour on the supervisee has not generally been assessed. Indeed Lambert & Ogles (1997) comment that the elements of supervision that actually contribute to the development of the supervisee as an effective practitioner have yet to be identified. Wampold & Holloway (1997)
suggested that outcomes of supervision are likely to be found in changes in supervisees characteristics. If the goal of supervision is to facilitate learning to produce a competent therapist then this ought in turn to produce a positive change for the client. Milne & James (2000) observe that such studies as have been done in this area have insufficient focus on therapeutic efficacy. In general, Ellis & Ladany (1997) report that little attention has been given to testing any existing supervision theory, with few replication studies, resulting in a dearth of viable measures of clinical supervision. Furthermore Ellis et al (1996) produce a critique which suggested that most of the supervision literature lacked methodological rigour, which makes it difficult to know what can be reliably concluded from the existing evidence-base. They suggest that there is little evidence to support supervisors as enhancing skills in supervisees, and few relate to client change. Given the number of variables (including inter-personal, social, and cultural) that would need to be controlled for, they suggest that any investigation is unlikely to detect true effects.

When considering using quantitative methods as a means for establishing effectiveness, Holloway & Hosford (1983) suggested a conceptual stage model for understanding supervision research:

1. provide descriptive observation of the observed phenomenon
2. identify important variables and the relationships between them
3. develop theory base on empirically devised evidence
I wonder whether we are still exploring stage 2 in this respect for both supervision and consultation.

3.3 Evaluating personal effectiveness

Although it is imperative to try and develop an evidence-base through research based on effectiveness, this should not detract us from seeking out effectiveness on a more personal level. Through using more informal measures we can obtain direct feedback from supervisees/consultees on whether they found a session useful/helpful, in much the same way as we would do in therapy with a client. Using brief rating scales such as the 0-10 scales used in Solution Focused Therapy can be equally useful in helping to identify where we are at now, and what it might take to move up the scale, and thus be viewed as working more effectively by those with whom we are working. It is of course necessary to be mindful of the power in supervisory relationships, but if a good working alliance has been established, then hopeful an honest response can be obtained.

4. Conclusion

Supervision and consultation are essentially activities which we engage in to help facilitate skill development in others. Both use a combination of reflection and formulation to help deepen the understanding of clients. The process is more collegial for consultants, who are freed by not having to take responsibility for the work of the consultee, nor need to evaluate them. Whether we are effective practitioners in these roles
has been hard to establish so far, due to the triadic nature of the process and the complexity in teasing out the key factors and relationships involved in making the process effective and overcoming the methodological problems this causes. In utilising models in practice that allow for a more standardised and consistent approach, this may enable factor identification and research on efficacy. At present, perhaps the best we can do is share good practice from receiving direct feedback from supervisees/consultees, over what they do and don't find useful in what we do.
5. References


Heller, K. (1985) Issues to consultations in community groups: Some useful distinctions between social regulations and indigenous citizen groups, Counseling Psychologist, 15, 403-409


1.2 Problem Based Learning Reflective Accounts

1.21 Year 1
1.22 Year 2
1.23 Year 3
1.21 Problem Based Learning

Reflective Account

March 2008

Year 1

'The relationship to change'
Having never written a reflective account before, I started by thinking about how reflection is conceptualised, and found that of Chinn (2007) to help guide my thoughts. She distinguishes between the thought processes of: reflection – to gain greater insight about self and/or client; and, reflexivity - how your own experiences, position and preferences, impact on client work. I see both these elements as important for developing my practice as a reflective practitioner, and hope that within this account I have addressed them.

The PBL task itself, was to explore the theme of ‘relationship to change’, and put together a presentation on it to be given in six weeks time. On a personal level this topic felt quite poignant to me, through having experienced some significant life changing events myself. Similarly, from the group perspective, we are all embarking on a period of personal and professional change as we begin clinical training, and as Leiper & Maltby (2004) note, ‘the idea of change is fundamental to all the psychotherapies’.

As a group, we approach the PBL based on the principles set out by Wood (2003). She notes that the aim is not to solve problems per se, but to develop the following generic skills and attitudes:

- Teamwork
- Listening
- Co-operation
- Respect for colleagues' views
• Critical evaluation of the literature
• Self directed learning and use of resources
• Chairing a group
• Recording
• Presentation skills

These are skills that are clearly synonymous with those a clinical psychologist should possess, both for working with clients, and in professional multi-disciplinary teams, and this task certainly helped in my continued development of these.

When the group first met, it felt like we gelled well together, united perhaps by joint enthusiasm for the course, anxiety over the task and its apparent vagueness etc. At some point however, when working in a team, there will be differences of opinion which need to be managed. This occurred (significantly for me) during discussions about how to approach the topic of change. My personal preference had been to consider therapeutic change, since this felt particularly meaningful to me, both as someone who has received therapy, and someone who is now learning to become a therapist. Unfortunately my idea was not met with much enthusiasm by some of the group who suggested it was too boring (which felt quite dismissive), and although the other suggestion of ‘lets just see how we change as a group over the next five weeks’ and write about it felt quite vague to me, this seemed to be decided on as our approach.
I respected the fact that clearly I would have to go with the majority view, and determined to make my contribution to the team effort, however it was a big change for me to find myself in a situation of working towards a personal goal that I did not feel was of my own choosing. I was finding it difficult to grasp where the group were going with the approach selected, or to find any meaningfulness in it towards my own PBL goals around therapeutic change. I found this situation very anxiety provoking, as I felt I was giving up ‘academic control’ to others, and in terms of the transitional curve which we subsequently used to map change in the group, I felt my own curve went very much out of sync with the rest of the group at this point, dipping steeply into the area of distress/despair.

In reflecting now on why I felt this way, I realise that my experiences of life do not predispose me to relying so completely on others to direct my life. I was an independent learner with the OU, am an only child and have had to rely on myself in making some major life changing decisions. When I have really needed people to support me in the past, e.g. parents, I have typically been let down. On the positive side, however, my reflective journal shows me that I utilised some of the principles of ACT (Acceptance and Commitment Therapy) to deal with how I felt, e.g. needing to accept the situation and ‘go with the flow’. Also to trust the group as ‘they are intelligent people as well who know what they are doing’ was another recurring theme. I feel this has
enabled me as a therapist, to understand some of the anxieties that a client might have about the process of therapy, and that even though I take care to explain this to them, ultimately they have to trust in my expertise to take them through it. In putting this experience in context now, I think I have gained more confidence in trusting others to be in control should the need arise in future, despite feeling a sense of powerlessness within the group at the time.

To work effectively as a team, we agreed to structure our sessions using the seven step model suggested by Wood (2003), appointing a chair (to facilitate the session) and a scribe (to record the session). These roles were rotated each week to give everyone a chance, and I chaired our second session. Chairing meetings is not a new experience for me, and I was mindful of being the only man in the group, and also of not using my position as chair to pursue my own needs, especially in view of my discord with the group about our approach to the PBL.

In feeling vulnerable already, diversity issues such gender that arose seemed to increase the negative affect I felt, causing me to feel distanced within the group. As yet I have not had the confidence to share my feelings about this with the group, in part because I worry about hurting their feelings and our relationship as it stands. As I prepare to facilitate a therapeutic group soon in my clinical work, this experience has been a stark reminder to me of how group dynamics operate, and how easy it is for marginalisation to occur albeit
unwittingly, and thus to be careful in ensuring everyone feels valued and the group feels meaningful to them.

To give a sense of coherence to the process of what we were doing, and plan towards pulling everything together for the presentation, we started each session by agreeing an agenda. This would typically consist of:

- Presentation of homework (i.e. information tasked to research previous week)
- Critical discussion regarding the merits of theories/literature presented
- Consideration of relevance of this knowledge to groups objectives, and the need to fill gaps in knowledge or re-evaluate objectives in light of it
- Decide on actions required before next session to move task forward and allocate these.
- Scribe to circulate record of session to keep people informed of discussions

As a group, this structure enabled us to work collaboratively, and use individual member's particular expertise/skills e.g. creativity as appropriate, with tasks being shared out within the group. Similarly, I have been able to transfer my experience of using such a structure to my clinical practice, not only in terms of preparing and evaluating work
done with my clients, but particularly within a CBT session, to keep discussion relevant to the client’s needs through collaborating with them on agenda setting. This also ensures we are working towards the goals that are important to the client, and using assessment letters etc. keep them informed of the plan for therapy.

In examining change from a theoretical point of view, we researched several models, of both individual and group changes. The small scale nature of the tasks required us to be selective (as is the case in research), and we chose to focus on the two that felt most relevant and meaningful to the groups experience. In the therapeutic setting, I have had to collaborate with clients to make similar decisions where they present with multiple difficulties e.g. depression, anxiety and OCD. Even if time is not a constraining factor, you can only address difficulties individually (although improvements in one area can help in others), and the salience of each to the client will be the determining factor for the work you do.

We wanted to consider both planned and unplanned change, which we felt were both features of our group’s experience. For us the PDSA model (Plan, Do Study, Act – Langley et al 1996) represented planned change within the group, as the cyclical nature of it very much mirrored the planned work we did in sessions. Similarly, in considering its relevance to the therapeutic environment, it seemed to have useful parallels for the process of change within a CBT model, both for
individual sessions, and the course of therapy as a whole. The example of how we did this is shown in Appendix 1. I have found that in clinical practice, it is a nice simple guide to hold in mind for planning therapy.

In respect of unplanned change, we felt that Transitional Theories e.g. Adams & Hopson (1976) explained the underlying processes happen as change occurs. Appendix 2 shows the cycle for both positively and negatively precipitated change, which meet at the point of crisis. As a group, we reached this point as we tried to make coherent sense of what we had learnt. It was only as we collaborated in completing and giving a successful presentation that enabled the group could move on with new confidence. For me personally, I feel it is only in writing this reflective account and understanding my experience better that I have reached this point.

In terms of clinical practice, this cycle provides a good visual representation for me of where my client is at. They may have experienced an event or series of events e.g. car accident as one of my clients has, which has triggered cognitive change. Unable to deal with the impact of change, she has got stuck in crisis (which is typically where a lot of clients who come to therapy are at). As a therapist I see my role as helping enable them to move forward towards recovery, whilst being aware that as therapeutic change occurs the cycle could just as easily slip backwards as move forwards. In thinking systemically about client change, this could have implications for unplanned change
in their carer/family which both the client and I need to be mindful of. This was brought to my mind when thinking with a client about the impact on her family of overcoming her lifelong phobia.

As I reflect back on the PBL exercise, I realise that it is only in re-reading the journal I kept at the time and thinking about my subsequent placement experience in order to write this reflective account, that I have been able to fully appreciate the value and meaning it has had for me and my clinical practice. Having to write this reflective account has made me re-examine in detail an experience that I might otherwise have felt reluctant to reconsider, due to my memory of its negative affect. It strikes me, that as therapists we expect our clients to follow a similar process in keeping thought records for instance, and my own experience in re-examining the PBL enables me to understand, and keep in mind, that nothing in therapy is just a paper exercise but requires sensitivity in acknowledging how difficult/distressing it might be, and why a client might feel reluctant to engage with it. Through this reflection, I feel I have gained a more balanced view of events (and a better understanding of the process of reflection), and realise now that I have ultimately been able to attain the original goals I wanted to achieve from the PBL. For me this has had parallels to CBT work on exploring clients' negative automatic thoughts, to look for other possible (including positive) meanings and explanations, beyond those that one's negative affect has made dominant. I have been reminded that change is often difficult, but as a therapist, good self-awareness and
understanding within the therapeutic relationship is a key part of helping clients manage change.
REFERENCES


Appendix 1 – PDSA model (Langley et al 1996)
Appendix 2 – Transitional Theory model (Adams et al 1976)
1.22 Problem Based Learning

Reflective Account

March 2009
Year 2

‘Working with people in later life, their families, and the professional network’
For this exercise, we were given a case referral vignette, and the group's initial task was to think about our response to it as practicing clinicians, and then give a short presentation to the rest of the cohort regarding the approach we had taken and some of the key themes and understandings that had emerged from our work. Through writing this reflective account of the PBL exercise some months later, I will now be aiming to be both reflective and reflexive (Chinn 2007) about the experiences, learning and development that took place both within the group and for me personally. Interwoven with this I will consider the links between theory and practice, and how I believe my clinical practice has developed in relation to the PBL exercise, by reference to my placement experiences.

The task 'problem'

A copy of the case vignette is attached in Appendix 1, and sets the scene of a referral made to a clinical psychologist in an Older People's Mental Health Service regarding a 69 year old man with suspected memory problems and care needs. A psychological opinion was being sought by Social Services as part of their overall assessment of this client's needs and care planning.

The aim of this exercise was not to problem solve the case per se, but to explore our approach to it. Experiential Learning Theory (Kolb & Kolb 2005) emphasizes the role of the 'learning space' as a means of constructing and enhancing knowledge, through drawing on Vygotsky's
(1978) notion of the 'zone of proximal development' whereby learning and development is facilitated through a transaction between the person and the social environment i.e. social experience. Through working as a group and drawing on our respective experiences (personal and professional), as well as investigating relevant literature, we aimed to socialise ourselves to a wider range of knowledge and practices that might: inform our approach to, and understanding of the client and his family; highlight key issues for critical evaluation; enable us to think about our role and relationships within the multi-disciplinary professional network; and reflect on how this our new knowledge might guide (or constrain) our clinical work and our developing clinical practice.

The task group and our approach

To form this year's PBL groups, the course team elected to combine the second and third year CDG groups half and half. For me, this lead to a very different learning experience. Last year as new trainees, none of our group knew each other, giving rise to anxieties over interpersonal issues such as trust, knowledge base, and task competency. One year on, we have the advantage of knowing each other better and have accumulated additional clinical experience and skills, allowing us to have more confidence in ourselves and each other. This year, although we were again working with some trainees who were not well known to us, this did not seem to cause the previously experienced interpersonal anxieties. For my own part I was able to appreciate the additional
knowledge and experience the third year trainees brought to the process, enabling me to feel confident in trusting them to play their part in the process, as well as having more self-confidence this year in my own role. I had a sense of the group perhaps experiencing me similarly, through their reciprocation of trust and confidence in me.

Our approach to the PBL was also structured differently this year. There was no course tutor to facilitate the process, and in being left to our own devices, the group did not consciously express a need to guide/organise our work using an overt learning and development model such as that of Wood (2003) as we did last year. On reflection however, I note this did not lead us to be disorganised in our approach, but rather we seemed to draw on our prior learning experiences to generate an implicit shared understanding of what was required and how to engage with it.

This enabled the rapid development of teamwork through mutual cooperation and respect between group members. Everyone was listened to, and given the opportunity to put forward their thoughts and suggestions, and mutual agreement about what merited further discussion and critical analysis determined which ideas were taken further. We assumed our own responsibility for making notes relevant to our own learning needs and the tasks we agreed to undertake towards the groups objectives. These generic skills and attitudes which both the group and myself demonstrated our development of through engaging
with the PBL task, equate to those Wood (2003) notes a PBL should be helping to foster. Such skills are important in our continuing development as clinical psychologists whether working as therapists, colleagues in teams, or taking on leadership and consultation roles.

In reflecting on using and developing these skills and attitudes on placement, in addition to therapeutic work, there are several parallels that stand out for me, both in intra-disciplinary situations e.g. peer supervision, and working with the wider multi-disciplinary team e.g. referral/case discussion meetings. Through feeling comfortable in one's own role, experience and knowledge, and being able to value this in others, mutual trust can be created, and collaborative partnerships formed enabling conversations that allow us to explore our different perspectives and understandings regarding clients/carers and care practices. I believe this has and will continue to help myself as an individual clinician and the teams I work in, to enhance the services we subsequently provide to our clients and their families and to remain client-centred in our approach. This accords with recent good practice policy initiatives such as the Dept. of Health's 'Ten Essential Shared Capabilities' (2004).

**Developing our understanding of the ‘problem’**

As a group we felt that thinking systemically about this case might prove fruitful on two counts. Firstly in holding and managing the multiple and conflicting perspectives within the family and professional network
regarding how they saw the ‘problem’; and secondly, in dealing similarly with our own thoughts, ideas and interpretations about the case given our varied personal and professional experiences, and the need to hold a multiple perspective position even amongst a group of clinical psychologists.

In our initial discussions about the case, and our assessment of the client, we had a sense of potentially overwhelming ourselves with suppositions or assumptions, but in the absence of insufficient information about the family involved. Just as we would in clinical practice, we decided to gather more information about them. As our family was fictitious, each trainee took a character role (family member or professional) and in drawing on their experiences of real people wrote a short history relating to the character and the client, to generate the background information and family story from which we would work.

We had wanted to avoid pathologising the client, and to understand the family and the complexity of the situation through allowing everyone's voice (both in the family and in the group) to be heard such as in family therapy (Dallos & Draper 2005), where the stories told relate to the family's interconnected relationships, values, culture and journey together which are then situated in the wider social and cultural contexts in which they live their lives. In clinical practice however, clients may not always want their family to be involved with us, or their therapy, as one of my CAMHS clients decided. However it is still
possible to work systemically with individual clients (Hedges 2005), and to think with them about the circularity of their behaviour and the transmission of intergenerational values and cultural influences for instance.

In cases such as this PBL, where a client's capacity to appreciate or express their needs might be in question, the ability to hold a systemic perspective is helpful in thinking through the information an informant/carer is telling you, and the meaning and context of it for understanding their position (including the stresses of being a carer) and that of the client. This is important when trying to balance risks, and consider vulnerability and mental capacity in promoting independence as for this client, when others may not be in agreement with their choices. Although I am current on clinical placement in a CAMHS service, in applying this same approach to working with young people who might also find it difficult to express their needs, it has enabled me to stay mindful of ensuring I acknowledge and give weight to their voice and part in the process, in the midst of parental explanations and expectations about their child.

Despite our intentions to be systemic, we became aware that some assumptions were pervading our thinking e.g. dementia rather than depression or family dynamics as underlying the clients difficulties. Ryff (1991) suggests both young and old people hold a stereotype of anticipating increasing decline in wellbeing with age, and I expressed
curiosity in asking the group how we might respond if the client were presenting as twenty years younger. In critically reflecting on this, we realised that in this scenario we might attend more to the client's voice, the impact of divorce and strained family relationships on wellbeing (including the influence of family's cultural and religious beliefs towards divorce), than to the reported memory problems. As our current clinical placements ranged from child to older adult, these two themes of age and divorce seemed to emerge as most salient for us to focus on, both to meet our PBL objectives and provide a focus for the group that would enable everyone to feel they could both contribute to and gain something from the process that would be useful in both their current and future clinical practice.

Focusing towards the presentation

In reviewing the literature, we were struck by the relative dearth of studies on the effects of divorce on children and adults, and although a meta-analysis by Amato & Keith (1991) suggested that divorce does impact on children's wellbeing, effect sizes are generally weak and when other characteristics e.g. parental mental health are controlled for, the effect often disappears, making generalisation difficult. In respect of age, Stirling (2004) notes how a social role valorisation analysis highlights a kind of 'age-apartheid' that exists towards older people in technologically advanced societies where segregation, rejection, discontinuity, invalidation and blame lead to demoralisation of older people and negative discourses and beliefs in society about old age.
Furthermore, with statistics from the Alzheimer's Society website which suggest a dementia prevalence rate of 1:1400 (age 40-64) and 1:100 (age 65-69), this is also likely to factor in our consideration of dementia as a possibility due to age.

In presenting our work to the cohort, we wanted to avoid being too didactic, and instead stimulate thinking and reflection. To enable them to engage with the thought processes we had followed, and reflect how a client's age might influence our response we presented two family therapy sessions, based on the current and twenty years younger scenarios, which we scripted to discuss the same family issues but differing in line with our understanding of how the family dynamics and psychologists response might differ, and whose voice would be heard. We then discussed why dementia was and was not assumed for each scenario, the effects of divorce on children, and the notion of age apartheid, concluding with some reflections on the process and our learning.

Reflecting on my reflections
I note that in writing this account I have maybe preferenced my learning from our group interactions over the case itself. As I have yet to do my Older Adult placement, some of my learning has yet to be put into practice, and I have perhaps focused on those aspects that seem to have had more relevance to my current clinical work, whilst holding in mind those aspects important to my future clinical work and continuing
development. I think both the group and I have been able to challenge our thinking and develop both personally and professionally throughout this PBL task, and the positive feedback we received for our presentation suggests we might have enabled others to share in our new understandings also.
REFERENCES


Hedges, F. (2005) *An Introduction to Systemic Therapy with Individuals: A social constructionist approach*, Basingstoke, Palgrave Macmillan


APPENDIX 1 – The PBL case referral vignette

Title: Working with People in Later Life, their Families, and the Professional Network

Problem Based Learning Exercise

What is the problem? Who has the problem? What might happen?

Mr Nikolas is 69, and has been referred to the psychology department for assessment of his short term memory problems, and his needs for care. The allocated social worker thinks Mr Nikolas is not looking after himself properly – his fridge has out of date food, his clothes are not well washed, and his toilet and bedding are unclean. His GP thinks he is managing well. During the period of assessment, Mr Nikolas' son Alexander, accused Mrs Edwards of financial abuse against his father. Social services invoked the Court of Protection and his divorced wife agreed to manage his financial affairs. Mrs Edwards, his new non-residential partner, was asked by the family not to visit their father/ex-husband any more, in an angry doorstep confrontation at her home by the older son. Mrs Edwards contacted the same psychology service and asked for their help. Mrs Edwards gave her version of events to Mr Nikolas' two older sisters, who both live abroad.

Some Background Information

Mr Nikolas is the son of a Russian Jewish émigré who married a white English east end Londoner. His father left his mother when he was seven and he had no subsequent contact. He was raised within the CofE tradition of Christianity, and holds a faith base. It was not until he was a mature adult that he learned of his father's origins at the time of his mother's death. He had always been told his father was an Englishman.

When he was 33, Mr Nikolas married a white English woman who was 15 years younger than him, from a Catholic background. She is not practising. They divorced at her instigation 6 years ago. She had spent the majority of their marriage in receipt of a diagnosis of major depression, with bouts of counselling, prolonged anti-depressant medication use, and so on. Following the divorce, she was able to cease prescription medication use, took up local employment, and developed a new friendship circle. Her older son called her a 'whore' when he discovered she was seeing another man, romantically.

So, Mr and Mrs Nikolas had two sons, Alexander and James, both now in their thirties. James lives abroad and does not keep much in contact with his father. Alexander is local, runs a small business and is married to a woman who struggles with eating distress and fears of contamination, such that she does not allow their two small children to play in the garden. The family do not discuss these matters.
Mr Nikolas has two older sisters, both of whom live in Australia and are not well enough to travel to the UK, but wish to be involved in decision making about the future care of their brother.

Mr Nikolas was devastated by the divorce and the need to sell the family home for the divorce settlement. He moved to a small property nearer his older son and two grandchildren. He spent a few years on his own, walking miles every day, and shunning company. Eventually a friend persuaded him to join a local history society and he became involved in escorting visitors and tourists around museums. There he met Mrs Edwards, a while English divorced woman, 2 years older than him. She is financially independent and owns her own home. She has PT employment with a stately home in the area, and was a children’s nanny most of her life. She has a chronic debilitating health condition that results in joint pains. She has no children and no living relatives. She has an active friendship group.

Mrs Edwards and Mr Nikolas became friends and then their relationship became romantic and sexually intimate. They have been together for 3 years. They kept their separate houses, and spent time in each other’s home. Mr Nikolas asked Mrs Edwards to marry him at the time the police instigated the removal of his driving licence. He had been struggling with short term memory problems, and when stopped at a police blockade where police were redirecting traffic, he refused their instructions and tried to drive on. The police officer recognised a ‘psychological’ problem and reported his behaviour to social services. The same police officer advised Mrs Edwards that Mr Nikolas needed medical attention. Mrs Edwards was uncertain and informed his older son who contacted social services. This resulted in the withdrawal of his licence and the confiscation of his car by his older son. His ex-wife was observed to drive this vehicle subsequently by Mrs Edwards.

Prompt questions:
Who/what/where is the problem?
How to define the professional network? How might professional roles be defined under these circumstances?
How is leadership shown/to be shown within the professional network, and what might collaborative practice look like under these circumstances?
What is the role of the psychologist with respect to Mr Nikolas, his close family members, Mrs Edwards and the professional network?
What ethical issues need to be considered?
How is financial abuse to be defined?
The relationship between memory and depression?
The role of life events?
Impact of divorce on grown up children?

The Academic Tutor Team, September, 2008
1.23 Problem Based Learning

Reflective Account

February 2010

Year 3

'How do we know if IAPT is working?'
In writing this PBL reflective account as a third year trainee, I am mindful that I have both brought prior skills, knowledge and experiences to the PBL process, yet still need to develop these further as I move towards qualification. Even then my development will remain ongoing, as Cook (2004) notes, reflecting and learning together is a dynamic process - something to be continually engaged in rather than to be seen as achieved. Schon (1983) highlights reflection (both ‘in’ action and ‘on’ action) as essential tools for improving practice, through being a mechanism that can turn experience into knowledge. However McAlpine & Weston (2000) suggest that it is only by extending this model to incorporate reflection ‘for’ action (planning to implement the outcome of reflection), that reflection becomes fully effective in enhancing practice. I have used this model to guide my reflections about this PBL task. Interwoven are considerations of theory-practice links, and examples to illustrate the impact on my current clinical practice or how I might use this learning in the future.

The task ‘problem’

This year’s PBL ‘problem’ scenario was based on the IAPT (Improving Access to Psychological Therapies) programme (see Appendix 1). Our brief was to think about how, if we were commissioned as consultants, we might assess the effectiveness of IAPT, and to present our findings to the cohort and tutors. To undertake this task in the ‘real world’ would undoubtedly require considerable thought, time and resources. We had a six week timescale, but had to fit this in around our other academic and work demands. This necessitated taking a pragmatic and realistic approach about what might be achievable. This in itself was a useful exercise in time management. As a practitioner, projects may arise that are temporary additions to one’s workload e.g. I am currently assisting the OT team set up a group for people with dementia. This has helped me reflect on finding a balance between allocating sufficient time to
make an effective contribution, whilst still maintaining the required commitment to your other work.

In learning from our previous PBL experiences, we were aware that a key objective for the task was not about problem solving per se, but about engaging in an experiential learning opportunity with others in order to promote skill development now and for the future.

The task group and our approach

The course team had again mixed the second and third year trainee cohorts for this PBL task. However this year from our perspective as third year trainees, our experience of the PBL group felt quite different. We all reflected on having a sense that the second years were implicitly looking to us for some leadership and direction, which was not an expectation we were aware of holding ourselves last year.

We were curious about this, especially as a couple of our second year colleagues seemed to possess greater knowledge and interest in IAPT than ourselves, which could have enabled them to provide the group’s leadership and direction. Effective leadership does not require seniority, but is about having the skills and knowledge to understand what needs to be done and facilitating individual and collective efforts to achieve shared objectives (Yukl 2001). One explanation for what could be characterised as the second years’ uncertainty, was revealed when, a couple of weeks into the task, the second years said they had noticed that we (as third years) appeared confident in working together. It transpired that whereas we were part of an existing functional group (same PPD Group), the second years were not. Jones & George (1998) note that a key component for effective group working comes from having developed mutual trust and co-operation in other group members, gained through having knowledge of and confidence in their
abilities. Thus last year this was present as two functional year groups merged, but this was not the case this year.

Festinger (1954) suggests that where people in groups are uncertain of their capabilities or standing, they will engage in social comparisons with similar others to assess their functioning. In teams, Molleman et al (2007) note that social comparisons can hardly be avoided as people are continually confronted with the attributes, abilities, performance and personalities of others. However Buunk et al (2007) found that this can produce positive outcomes for learning in the areas of self-evaluation, self-enhancement and self-improvement. As long as people engage in upward identifications towards others they perceive as performing slightly better than themselves, this provides models for learning, through enabling people to recognise their own skill levels and inspiring them to set similar goals for themselves. However, engaging in downward comparisons and identification can lead to negative effects regarding self-perception and interpersonal trust, and produces poorer outcomes. Therefore in a new group situation, the challenge for generating effective team-working is to create the conditions that foster positive social comparisons (upward identification). As third years we tried to achieve this through modelling aspects such as leadership to the second years, whilst also encouraging them to collaborate in the process and feel their skills were valued. As the task progressed, group confidence grew and levels of uncertainty decreased, suggesting we had risen to this challenge.

I have subsequently tried to develop these ideas within my clinical practice. My supervisor, as an advocate of the person-centred approach for dementia (Brooker 2007), was keen for me to model this approach in my work so other staff might observe it and recognise its value for their own practice. As I work on in-patient wards staff have many opportunities to observe me in this way. This has led me to think about
and be more aware of monitoring my own behaviour towards others, and how I communicate with staff about clients. My aim is to model more helpful ways of constructing and understanding the client and their needs. For instance in contributing in this way to ward rounds, I have been able to engage staff in thinking about care planning from the client's perspective of their needs.

Developing our understanding of the task 'problem'

When this year's PBL was handed out, both myself and other group members felt some initial lack of enthusiasm regarding the theme. Whilst clearly we all subscribe to being evidence-based practitioners, not everyone relishes being a researcher. However as Pilgrim (2008) reminds us, clinical psychologists have always had many skills to offer services beyond just being therapists, and New Ways of Working for Applied Psychologists (BPS 2007), simply recognises that our skills in areas such as consultation and leadership, are roles we should now be engaging in as part of our contribution to multi-disciplinary team-working. As third year trainees nearing qualification I reflected to the group that this task offered us an experiential opportunity to think about developing our skills in this direction.

As the task brief had suggested the preparation of a consultancy report, we tried to explore the task from the perspective of being a consultant and thinking about what steps they might take to assess effectiveness. Although we had some knowledge of IAPT, it emerged that much of this was second hand (i.e. via lectures) and clearly incomplete. We decided that our first objective was to engage in a literature search, so that we could build a clearer picture of IAPT, its history, aims, provision and effectiveness so far. As a group, we all had our own perspective on IAPT, and in trying to evaluate the information gathered we became aware of often falling into the trap of debating the merits of IAPT rather than attending to our objective of evaluating efficacy. Although
stimulating, these discussions wasted time and detracted from the group achieving its objectives. Thus we appointed someone to monitor our discussions and bring the group back on track if we strayed. In reflecting on this point and meetings I have attended on placement, successful groups have typically been those who had good leadership that helped them stay focused. I hope that this experience will serve as a salutary lesson in how to ensure things get done when I take on leadership roles myself in the future.

In considering the issue of efficacy, we began by considering how outcome measures are used. IAPT already has these built into its delivery programme, however efficacy in a clinical context is not just about results being statistically significant, but also about whether they represent reliable change and clinically significant change. We also identified how the subjective ratings inherent in these measures can also be influenced by the effect of external factors on responders, e.g. social desirability, and how accurately they reflect a person's experience of therapy. They also fail to capture qualitative information such as the process factors of therapy e.g. quality of therapeutic alliance, which Llewelyn & Hardy (2001) note are equally important when trying to understanding improved client outcomes. Whilst it is important for our work to be evidence-based, as a therapist I often find myself questioning whose benefit I am really serving when I ask a client to complete a measure – the service's, mine or theirs. Indeed when design my MRP regarding well-being in carers of people with dementia, I took care to consult with carers regarding the study design and appropriateness of measures I am using.

**Focusing towards the presentation**

In discussing these issues, this led us to think about how effectiveness might mean different things to different people depending on their perspective as a stakeholder in IAPT. We felt that before we could
begin to assess effectiveness, we needed to try and understand these multiple perspectives. We also needed to start thinking about how we might present our task findings to the cohort. Since we were acting as consultants, I suggested to the group, that perhaps we could role play how a consultant might conduct a focus group with stakeholders to explore their perspective on the issues involved. This would provide a more experiential way of conveying our PBL thought processes to the cohort, and better mechanism for reflection than a dyadic PowerPoint presentation, which the group agreed with.

As IAPT is still in the roll-out phase we decide to have two parts to the role play: (1) looking at setting up the service; and (2) reviewing the service. We split into year groups to each write a script, which made the task more manageable and enabled everyone to contribute to it. Having identified who we thought the key stakeholders might be (e.g. commissioners, therapists, service users), and as we wrote the scripts tried envisage ourselves as the person and think about what might be most important from their perspective, and whether this might change over time. Some the key issues which came out for us were: how commissioners may be more focused on numbers and value for money; therapists feeling concerned about erosion of their skills and the quality of the therapeutic relationship; and service users wanting to feel valued and having some real choice over the nature and quality of the therapeutic experience. We also tried to reflect how the service user's voice can often get lost in the power relationships inherent in these situations, and that one of the consultant's roles is to help ensure their voice is heard, as are those of other diverse and marginalised groups.

Final reflections

Whilst conducting research seemed to be an underpinning theme for the PBL, for me one of the main experiential learning points at the time of the task was about group processes and how our experiences might
mirror those I might encounter on placement. In reflecting on the account I have written here, in light of my subsequent placement experiences, I notice that this salience has remained, but not just in how I might use this experience to be a more productive group member, but to think about how as a future group leader or consultant I might enable groups to achieve their objectives. In this way I feel I have begun to develop my skill base beyond just being a therapist and towards meeting the challenges that newly qualified clinical psychologists have to meet.
References


Appendix 1 – The PBL scenario

Year 2/3 PBL

'The Problem'

How do we know if IAPT is working?

The Improving Access to Psychological Therapies (IAPT) programme was commissioned in response to the economic arguments of Lord Layard. The Department of Health have committed funding rising to £173 million to the programme which has one principal aim: to support Primary Care Trusts in implementing National Institute for Health and Clinical Excellence (NICE) guidelines for people suffering from depression and anxiety disorders. At present, only a quarter of the 6 million people in the UK with these conditions are in treatment, with debilitating effects on society.

The programme began in 2006 with Demonstration sites in Doncaster and Newham focusing on improving access to psychological therapies services for adults of working age. In 2007, 11 IAPT Pathfinders began to explore the specific benefits of services to vulnerable groups. These pilot services, through routine collection of outcome measures, showed the following benefits for people receiving services:

- Better health and wellbeing
- High levels of satisfaction with the service received
- More choice and better accessibility to clinically effective evidence-based services
- Helping people stay employed and able to participate in the activities of daily living

On World Mental Health Day 2007, Health Secretary Alan Johnson announced substantial new funding to increase services over the next three years:

- £33 million for 2008/9
- A further £70 million to a total of £103 million in 2009/10
- A further £70 million to a total of £173 million in 2010/11

This funding will allow:

- In 2008/09 34 Primary Care Trusts to implement IAPT services, with more to follow in the next two years
- Regional training programmes to deliver 3,600 newly trained therapists with an appropriate skill mix and supervision arrangements by 2010/11
• 900,000 more people to access treatment, with half of them moving to recovery and 25,000 fewer on sick pay and benefits, by 2010/11.

Adapted from the NHS IAPT webpages - [http://www.iapt.nhs.uk/](http://www.iapt.nhs.uk/)

You have been asked to prepare a consultancy report on how the effectiveness of IAPT can be assessed.

You might want to consider:

...something about the questions that need to be asked about IAPT

...something about the designs, methodologies and analyses that could be utilised to address these questions

...something about the training and competencies of the IAPT workforce

...something about the outcomes that will be valued by different stakeholders

...something about the translation of findings into policy and practice
1.3 Personal and Professional Learning Group (formerly Case Discussion Group) Process Accounts (Abstracts Only)

1.31 Year 1

1.32 Year 2
Abstract

This is a reflective account, which looks at the personal and professional development achieved through the use of the Case Discussion (CDG) group process. It is a journey that is only just beginning, and will continue not only for the next two years of the course, but throughout the rest of my professional career, even though the context may be different. It has been a challenging year, in which I have learnt much about myself and my ability to cope with the demands of the course as well as in developing my professional skills. Having a peer supervisory style group as this, is a reminder that we all have fears and worries, but that we all have something we can bring in order to learn from each other. Whilst it has taken some while (certainly on my part) to begin to feel safer in discussing both personal and professional issues, I feel that this reflection has enabled me to think about how I might use the space offered by the group more effectively in future, and so enhance my development.
1.32 Personal and Professional Learning Group Process Account

July 2009
Year 2

Abstract

This account continues the journey of our personal and professional development through the second year of training. It draws on some aspects of our experiences in the first year to illustrate how we have developed our skills, and uses group development models including Tuckman (1965) to explain the group processes. It reflects on how we dealt with the difficulties that had arisen in the group dynamics during the first year, and how in acknowledging these and renegotiating the ground rules we were able to move on and become a more productive group. It has again been a year of challenges for us all as the two placements we were on during the year were not areas in which many of us had any experience. The fact that this year we were more able to share our experiences as well as our knowledge made it a much improved learning experience for us all. As we headed towards the end of the year, we were able to feel more confidence in our skills and knowledge and start to envisage ourselves as becoming qualified
psychologists. This enabled us to begin thinking more about the
development of skills beyond just being therapists and what we needed
to achieve, so that by the end of training we will have the skill and
knowledge base to fulfil what is required of us as qualified clinical
psychologists.
Section 2

Clinical Dossier

2.1 Overview of Clinical Experience gained on Placement

2.2 Case Reports (Abstracts only)
2.1 Overview of Clinical Placement Experience

**Year 1**
October 2007 – September 2008
Adult Mental Health

**Year 2**
October 2008 – March 2009
Child & Adolescent Mental Health

April 2009 – September 2009
People with Learning Disabilities

**Year 3**
October 2009 – March 2010
Older People’s Mental Health

April 2010 – September 2010
Neuropsychology Service
Adult Mental Health (Additional Placement)
Throughout my clinical placements I have worked with a range of clients who have differed in terms of their age, gender, educational and intellectual level, socioeconomic background, and ethnicity. They have also presented with a variety of mental health difficulties, and some have also had physical disabilities. Each placement has offered me unique opportunities to learn new skills and develop my competence as a Trainee Clinical psychologist. Each placement this has included observing the work of my supervisor and other psychologists in the team, as well as meeting with staff from other disciplines to discuss their roles and liaise with them regarding my work with our mutual clients. Below is a brief outline of my experiences, for which more detailed reports can be found in Volume 2 of this portfolio.

**Adult Mental Health**

This placement was primarily split between working in a CMHT (Community Mental health Team and an SPT (Specialist Psychological Therapies) team. Clients were seen on an out-patient basis although some home visits were made. It also included two short pieces of work on an inpatient ward and with the Assertive Outreach Team. I saw 24 clients in total for a combination of assessment and intervention work, including two neuropsychological assessments. Clients had a range of mental health difficulties, including: anxiety, phobia, depression, psychosis, OCD, PTSD, eating disorders and personality disorder. The primary model used was CBT which included both 1:1 and group based therapy, and I also had the opportunity to gain experience in using systemic and narrative models of therapy as well. I used a variety of outcomes measures the CORE-OM, BDI-II, BAI, & YSQ. I attended psychology and other team meetings, as well as local workshops on Narrative Therapy, Emotional Regulation and Schema Therapy. I undertook my SRRP on the consultation service offered by the team psychologists to the MDT, and presented the results back to the team. I also did a presentation to the Psychology Team on Gender Dysphoria, and took part in the Service User/Advisor Placement Project.
**Child & Adolescent Mental Health**

This placement was based in a community CAMHS Team, seeing clients on an outpatient basis and included a school visit. I saw 14 clients in total for a combination of assessment and intervention work, including two neuropsychological assessments. Clients had a range of mental health difficulties, including: anxiety, phobia, depression, OCD, anger issues, and developmental difficulties including ASD & ADHD. I worked with clients both individually and with their families using a range of approaches, including CBT, Systemic and Narrative models. I also gained experience of Child Protection issues, through a piece of joint work with a CAMHS Social Worker. Outcome measures used included the SDQ & BYI. I attended the fortnightly psychology team meeting, and monthly multidisciplinary peer group case and psychodynamic discussion groups. I gave a presentation to the monthly neuropsychology group meeting on the use of WISC-IV clinical clusters. I also allowed a GP trainee to observe an intervention session and discussed the role of a psychologist with her.

**People with Learning Disabilities**

This placement was based in a Community Team for People with a Learning Disability. Clients were primarily seen at home, the Day Centre, or Residential Home. I saw 11 clients in total for a combination of assessment and intervention work, including neuropsychometric, functional and sexual knowledge assessments. Clients had a range of learning disabilities from mild to severe, and some mental health difficulties including: autism, anxiety, phobia, anger and other behavioural & cognitive difficulties. I worked with clients both individually and in conjunction with their families and/or Day Centre/Home staff using a range of approaches including CBT, Behavioural and Systemic models. I also did some indirect client work through offering consultation to staff. I attended team meeting and their ‘Away Day’, as well as a Safeguarding Adults meeting, and a ‘Best Interests’ meeting. I jointly ran a training session on Autism with my
supervisor, and gave presentations to the Service User and Carer
groups about the work/help that a CTPLD Clinical Psychologist can
offer.

**Older People's Mental Health**
This placement was primarily based on an inpatient ward, with some
outpatient work at the Neuropsychology Service base, and occasional
home visits. I saw 12 clients for a combination of assessment and
intervention work including neuropsychological and suicidality
assessments. Clients had a range of mental health difficulties,
including: anxiety, depression, psychosis and dementia/cognitive
difficulties. I worked with clients both individually and in conjunction with
their families and/or Ward Staff with a particular emphasis taking a
person-centred approach. Within this I used a range of therapeutic
models including CBT and Systemic models, as well as thinking with my
supervisor about how a psychodynamic perspective might contribute
towards our formulation of a client’s difficulties. I attended and
contributed to the weekly ward round, and undertook indirect client work
through offering consultation to the staff team. I also attended the
OPMH and joint LD/OPMH psychologists meetings. I did a joint training
session to staff on the use and interpretation of the ACE-R, and
attended training on the HONoS 65+, and personality disorders in older
people. I looked at the possible use of adapting Leenaars Thematic
Guide for Suicide Prediction in Psychotherapy for use as part of the
suicide assessment process by psychologists on the ward.

**Neuropsychology Service**
This placement was based in a community Neuropsychology base, with
all clients seen on an outpatient basis. I saw 12 clients aged 19-81 and
did a combination of neuropsychological assessment and therapy work.
Clients and a range of neuropsychological and associated mental
health difficulties, including: Multiple Sclerosis, Parkinson's Disease,
Brain Injury, Epilepsy, memory Problems, anger issues, anxiety and
depression. I worked with clients both individually and in conjunction with their families and other professionals involved in their care. In my therapeutic work I primarily used CBT, although also drew on Systemic and Narrative approaches. I used outcome measures such as the DAS & TOMS, and neuropsychological assessment tools including: WAIS-III; WTAR; BMIPB; NAB; DKEFS; RIST & VOSP. I did an evaluation on the use of two neuropsychological tools (RIST & WTAR), use case study evidence from clients assessed to consider there relative usefulness as assessment instruments. I visited a Social Services run ABI group, and provided feedback on my observations of their work.

**Additional Adult Mental Health Placement**

This placement was based in a CMHT (Community Mental Health) team. Clients were seen as outpatients both at base and in their own home. I saw 2 clients who I assessed and provided an intervention to. Mental health difficulties included: anxiety, depression and OCD. This placement was done to specifically focus on 1:1 CBT skills, as an adjunct to the year 1 AMH placement, but was shorter than planned due to trainee ill-health.
2.2 Case Reports

(Abstracts only)

2.11 Case Report 1
  – Adult Mental Health

2.12 Case Report 2
  – Adult Mental Health

2.13 Case Report 3
  – Child & Adolescent Mental Health

2.14 Case Report 4 – Oral
  Presentation of Clinical Activity
  - People with Learning Disabilities

2.15 Case Report 5
  – Older People
2.11 Case Report 1

Adult Mental Health

April 2008

Year 1

‘Cognitive Behaviour Therapy with a woman in her fifties, presenting with a specific phobia of birds’
Abstract

Presenting problem: This client was referred for help with her self-reported long-standing phobia of birds. She had been managing by avoiding situations where birds might be present, restricting the activities she could engage in or enjoy. Recently it had caused her difficulties at work, prompting her to re-evaluate its effect on her life and to seek help once again to try and overcome it.

Goal of therapy: the client wanted to be able to walk down the road without having to worry about scanning for birds.

Assessment & Formulation: It was not possible to identify a specific predisposing factor/trigger for the phobia. However going somewhere new or where she knew birds would be present created an anticipatory fear before she even got there. Her main fear, was that a bird would fly into her face, and that she would lose control and look silly. By running away the moment a bird appeared, she was perpetuating her anxiety by failing to stay and learn that her fear might be unfounded.

Therapy/Intervention/Outcome: eight sessions of CBT were offered. This included socialising the client to the model, psycho-education about anxiety and discussion of the formulation. In collaboration with the client a graded exposure hierarchy was devised to help her conquer her anxiety and gain the opportunity to change her thinking. She successfully completed this, and achieved her therapy goal, as evidenced through her self-report and decreased scores on the Fear Questionnaire (Marks & Matthews 1979).
2.12 Case Report 2
Adult Mental Health

September 2008
Year 1

Cognitive Behaviour
Therapy with a man in his forties, presenting with depression’
**Abstract**

**Presenting problem:** The client was referred for help for depression (to which he was occasionally prone), as well as social anxiety. He had recently changed his job, and reported having difficulty learning what to do which had triggered feelings of incompetence and was fearful of the consequences of looking 'silly' if he made a mistake.

**Goal of therapy:** to help the client improve his self-confidence at work by eliminating his avoidant behaviours, and look at relapse prevention.

**Assessment & Formulation:** exploration of the client's childhood revealed he had critical parents, and experienced some humiliating incidents at school, possibly predisposing him to low self-esteem. Now, in new or unsure situations he lacked confidence to act, because of fears that he would make a mistake and that others would laugh at him, and not like him. He thus avoided performing actions in front of work colleagues that he was unsure of getting right, thereby perpetuating his anticipatory fears about their response to him. This also prevented him from learning his job properly leading to a decreased sense of self-competence, and depressed thoughts and feelings.

**Therapy/Intervention/Outcome:** eight sessions of CBT were offered. This included socialising the client to the model, psycho-education about anxiety and discussion of the formulation. The client completed some thought records about incidents at work, and we explored what a more balanced thought might be. Behavioural experiments were devised for him to test these out, which he completed with some self-reported success, and achieved some increased confidence at work.
2.13 Case Report 3
Child & Adolescent Mental Health

April 2009
Year 2

‘An extended assessment using psychometric measures with a six year old boy exhibiting social and cognitive difficulties’
Abstract

Presenting problem: The client was referred for a neuropsychological assessment to help contribute to the team's overall assessment regarding the possibility of him having an Autistic Spectrum Condition.

Assessment: His mother described him as struggling with social interaction, having some educational difficulties and lacking emotional expression which made it hard to interpret what he might be thinking or feeling. A literature review suggested that neuropsychological testing might help highlight the client's strengths and weakness, and whether these were evidential of those typically seen in children with an ASC. The WISC-IV, WIAT-II, TEA-Ch and Happe stories were administered, and the client engaged well with this.

Interpretation/Formulation: Result analysis indicated that the client was of low average ability. Ipsative analysis indicated verbal skills were a strength (but not for abstract concepts such as feelings), but lacked spontaneity. Numeracy and perceptual reasoning were weaknesses. Whilst such results are atypical for ASC, the problems he displayed with theory of mind and cognitive inflexibility are more typical of ASC.

Recommendations: the assessment was not intended to be diagnostic in itself, however the pros/cons of obtaining one were discussed with the parents especially with regard to obtaining help at school. The use of 'Social Stories' was discussed to help the client learn appropriate social skills, build his self-confidence and help him improve his social interactions. His cog inflexibility makes managing change hard, and routines preferable. By exploiting his verbal skills through carefully planning and explaining any changes could help alleviate his anxiety of this.
2.14 Case Report 4
Oral Presentation of Clinical Activity
People with Learning Disabilities

September 2009
Year 2

‘Working collaboratively with a man in his twenties who has Autism and a Learning Disability, referred for ‘challenging behaviour’”
Abstract

Presenting problem: This client was referred by staff at the Day Centre he attends who reported his behaviour as being 'challenging'. He was said to be acting in a disruptive way including 'bullying' other clients, and was observed on occasions to have behaved in a sexualised and inappropriate manner towards women. Many of these behaviours had been present for a long time, but had recently occurred with staff outside of the Day Centre environment which was of particular concern and precipitated the referral.

Goal of therapy: As psychological therapy was being provided at the request of others rather than by the client himself, a key aim was to try and engage with the client and build a therapeutic relationship. From this both direct and indirect intervention work was offered to him, his family and the centre staff. This included reflecting on the formulation developed about the reasons for his behaviour, and interventions aimed at helping him to improve his social skills.

Assessment & Formulation: It was already known that the client had mild learning disabilities as well as autism. Information about his current behaviour and difficulties was gathered via unstructured interviews with both Day Centre Staff, the client and his family, as well as through using structured assessment tools for Challenging Behaviour, Functional Analysis, Social Reasoning and Sexual Knowledge. This enabled a formulation to be developed, which suggested that as is typical of people with an autistic spectrum condition (ASC), the client had some difficulties in reading and interpreting the responses of others. He had a very narrow range of topics that he would talk about repetitively, resulting in non-reciprocal social interactions where others became bored and ignored him. Whereas many people with ASC prefer their own company, for this client it was an important part of his cultural values to be friendly and sociable, so it upset him when people did not respond to him. It was when this happened that he would engage in
behaviours to attract their attention, e.g. staring, cornering them, but was unable to recognise these were inappropriate and only resulted in people wanting to avoid him more.

A sexual knowledge assessment was also completed. This indicated the client had some knowledge of the mechanics of body parts and sex. He did not recognise concepts such as contraception. He showed interest in having a relationship with a woman, but did not know how to begin a conversation with someone you liked, or realise how some of his comments and actions might be interpreted as sexually suggestive.

**Therapy/Intervention/Outcome:** the client had good language skills and friendly personality that enabled him to socialise. I did some 1:1 work with him on helping him understand the 'rules of conversation and friendship, including practicing reciprocal conversations on a wider range of topics. To support this we develop a pocket book of topics that he knew he could talk about, that his family and Day Centre Staff were encouraged to use with him to change topic if he became repetitive.
'A neuropsychological assessment of a lady in her seventies presenting with mood and cognitive difficulties'
Abstract

Presenting problem: The client was referred to the Older People’s Neuropsychology Service as there was uncertainty about whether she had depression that was resulting in memory problems or vice versa. The aim was to see if this could be differentiated.

Assessment: The client and her husband were interviewed about her difficulties, and also provided me with diaries in which she recorded her experiences. They both reported noticing a decline in memory skills and episodes of low mood and tearfulness, including fears about having Alzheimer’s Disease. A recent CT scan reported evidence of a ‘mini-stroke’, but the client had not experienced any symptoms. Neuropsychological testing was done covering the cognitive domains of memory, attention, language, visuospatial skills and executive functioning for both verbal and non-verbal skills. The neuropsychological profile obtained indicated that the client generally performed as expected, but had specific deficits in attention, executive functioning and especially memory.

Interpretation/Formulation: The appearance of specific deficits would point away from depression as the primary cause of her difficulties but would be in keeping with having had a stroke, possibly in the left temporal lobe. Her episodes of tearfulness could be accounted for as a consequence of the stroke and adjusting to the subsequent memory and functional losses.

Recommendations: I provided three additional (CBT based) sessions to help the client and her husband understand the links between her memory and distress, and to think about useful strategies to support her memory. Ongoing support and monitoring was advised in case of further decline.
Section 3
Research Dossier

3.1 Research Log

3.2 Qualitative Research
   Project (Abstract only)

3.3 Service Related Research
   Project

3.4 Major Research Project
### 3.1 Research Log

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<th>Description</th>
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<td>Formulating and testing hypotheses and research questions.</td>
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<td>Carrying out a structured literature search using information technology and literature search tools.</td>
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<td>3</td>
<td>Critically reviewing literature and evaluating research methods</td>
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<td>4</td>
<td>Formulating specific research questions</td>
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<td>5</td>
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<td>6</td>
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<td>7</td>
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3.2 Qualitative Research Project

June 2008
Year 1

'What influence do people think their birth order has had on them? Towards a Grounded Theory'

(This was a small scale research project which was jointly conducted and written up between myself and a group of trainee colleagues, so is only presented here as an abstract)
Aims: This study explored people's perceptions of the influence of birth order on their lives.

Background: Birth order in families has received a great deal of research attention, yet currently there does not appear to be any theoretical framework to explain birth order from a social constructionist perspective.

Method: A grounded theory approach was used to explore the influence people think birth order has had on them.

Data collection and analysis: Data was collected from tape-recorded, semi-structured interviews with four participants, which included one round of theoretical sampling. Data analysis and analysis occurred concurrently.

Results/Analysis: The findings identified a main category of 'roles and functions in families', which was further characterised by three key components: what the roles are; change in roles over time, and factors that mediate the process of roles and functions within families.

Conclusion: This study suggests that people's experience of their birth order can be explained by an emerging theory of 'roles and functions in families'.

Relevance to clinical practice: It may be helpful for therapists to be aware of the perceived importance of birth order and explore people's perceptions and experiences during therapeutic work in order to enhance meaning-making.
3.3 - Service Related Research Project
Adult Mental Health

July 2008
Year 1

'Evaluating the existing provision of psychological consultation to staff in a Community Mental Health Team'
Abstract

The aim of this study was to evaluate the consultancy work offered to CMHT staff by the Clinical Psychologists based within the team. The provision of consultancy work to teams has been highlighted by Pilgrim (2001) as being part of the unique contribution that Clinical Psychologists can make to their teams and is supported by the BPS (2007, 2008). Currently, there is a paucity of research in this area, and little evidence-base against which to evaluate this service. A questionnaire was devised to gather both quantitative and qualitative data from the staff attending consultancy sessions. Statistical analysis showed a significant difference between pre and post consultation scores, with a substantial effect size was also observed, suggesting that staff experienced a beneficial effect on their thinking from receiving psychological input to their work with a client via the consultation process. Content analysis indicated that staff aims for seeking consultation such as wanting 'direction' were being met by achieving 'clarity' from the sessions. Key benefits from the process were seen as having time to reflect, gaining a better insight on client, support, and thoughts/feelings of now having more direction in their work. This suggests that the consultancy work the psychologist can contribute to the team is valued, as previously reported by Blumenthal & Lavender (1997). However, this evaluation only represents the views of one team and thus not generalisable, but it may offer a stepping stone towards the development of research in this area.
Introduction

The role of the Clinical Psychologist within Mental Health Services is an evolving one, with many more now working alongside their colleagues from other Mental Health disciplines in integrated multi-disciplinary Community Mental Health Teams (CMHTs). This has seen a move towards greater emphasis on partnership working as iterated in recent practice guidelines such as the 'Ten Essential Shared Capabilities' issued by the Dept. of Health (2004). Similarly the British Psychological Society (BPS) (2007) also supports this integration, whilst stressing the need for psychologists to also retain their own unique identity through the contribution they make, e.g. by offering a counterbalance to the medical model.

Clinical Psychologists have skills and knowledge beyond being therapists, which they can bring to the team. Their knowledge of psychological principles and theory can help with the identification of strengths and needs (both staff and clients), and contribute to the provision of user centred care. As reflective-scientist practitioners, psychologists can draw on evidence-based and value-based, knowledge and interventions, in order to facilitate this and meet the needs and aspirations of service users and those involved in their care (BPS Practice Guidelines 2008).

Pilgrim (2008) notes that back in 1989, the Mowbray Report highlighted such skills in Clinical Psychologists, specifically their unique expertise in
being able to construct individual and contextualised formulations about clients. The Report suggested that psychologists should focus less on the provision of therapy and more on utilising these skills in the context of providing consultancy (and training) work to other staff as part of their routine clinical practice. However, Pilgrim indicates that during the intervening 20 years the profession has been slow to adopt this component into their practice. This aspect of the psychologist's role appears to still be in its infancy, as suggested by the recent articles by Lake (2008a, 2008b and Preedy 2008), regarding the up-skilling and training of Clinical Psychologists, and models for how to structure consultation sessions are only just beginning to emerge in the literature such as Lake (2008b). It is perhaps little wonder that there is a paucity of research on this role for psychologists in the literature.

Consultancy in this context is not about providing case supervision, as the consultee retains responsibility for decisions about their clinical work with the client. It is focused on providing a supportive and protected space for staff to think and reflect psychologically about their client, and the work that they are doing or could do with them to enhance the care/service provided (Lake 2008b, Lake et al 2008).

From the perspective of CMHT staff, Blumenthal & Lavender (1997) conducted a study on staff perceptions of the role of clinical psychologists working in a CMHT. This highlighted that the availability of the psychologist to consult on clinical difficulties was viewed as
second in importance only to assessment of a client's suitability for psychological treatment. Whilst it is the only study of its kind, this would suggest that CMHT staff see consultation as a key part of the contribution that psychologist's can make to the team.

The CMHT participating in this project currently provides consultancy work (both on an individual and group basis), and the Clinical Psychologists involved were keen to evaluate it. This was ethically difficult for them to do for themselves for reasons of anonymity and confidentiality, but by being mindful of this, as a trainee on placement I could help eliminate some of the dilemmas involved.

The aim of this project was twofold. Firstly, to attempt to measure quantitatively via a survey questionnaire whether the consultation sessions offered were proving to be effective and beneficial for staff. Secondly to gather some qualitative data about staff views of the sessions and explore it for any emerging themes that might offer further insight about the consultation process.

**Method**

**Design**

A within participants design was used, in order to assess whether the consultation session effected any changes in participants thinking about their client using a short questionnaire scored using a Likert Scale. Scores on the questionnaire for before and after sessions could then be
compared statistically for any significant differences. An increase in scores post-consultation would indicate a beneficial effect. It was also planned to administer the Post-Consultation questionnaire again four weeks later to evaluate whether reflection over time had any further impact on staff thinking. Several free-response questions were included to enable participants to comment on particular aspects of the sessions, which would then be examined using content analysis.

Participants & Sampling
The project was undertaken with the clinical staff at a CMHT based in a large town (population 100,000 client base 1500 – approx). The team personnel involved, comprised the two psychologists who offered the consultations sessions, and 21 other clinical staff on the team (6 Psychiatrists, 11 CPN's, 2 Social Workers, 2 OT's) to whom the consultation sessions were available. The actual participants were a self-selected sample, from those who volunteer to participate amongst the staff who requested a consultation session during the 16 week study period (March–June 2008). In all, the participant group was represented by 12 clinical staff who took part at least once (5 Psychiatrists, 6 CPN's, 1 OT – i.e. 57% of staff), with some providing data on more than one occasion, since each consultation session was counted as a separate instance for measurement.
Materials

The questionnaire used was adapted (with permission) from that designed by a clinical psychology colleague who is also undertaking a similar evaluation in another Trust. The questionnaire has yet to be validated as a measurement tool for this purpose, however the lack of published work in this area means there were no other existing tools to use. The questionnaire was thus used based on its face validity, that the statements used to represent the four factors of: understanding; psychological mindedness; support and stuckness/frustration; constituted those which the session could be instrumental in bringing about change in, and thus would appropriately capture the process under evaluation.

The questionnaires were administered on three separate occasions and differed in the following ways:

- Pre-Consultation questionnaire (Appendix 1) – 10 statements measured on a Likert Scale (scored: ‘not very much’ =1 up to ‘a lot’ =4, with items 7 & 8 reverse scored).
- Post-Consultation questionnaire (Appendix 2) – the same 10 statements, plus a further 5 statements (items 11-15) about the session itself. (scored: as above, but items 13, 14 & 15 reverse scored).
- Post(+4)-Consultation questionnaire (Appendix 3) – repeat of Post-Consultation questionnaire.
Each questionnaire contained a different set of free-response questions, and had instructions regarding completion and participation on the reverse.

A sealed post-box was provided, and sited in the staff room so that completed questionnaires could be returned anonymously to the researcher.

**Procedure**

The project was introduced and explained to staff at their staff meeting prior to the start of the study period. They were informed about the project rationale, the voluntary nature of participation, and how anonymity and confidentiality would be preserved, and had an opportunity to ask questions about the project.

The researcher liaised with the two psychologists involved to ascertain dates for when consultation sessions would be taking place and with whom, maintaining a diary of these. Pre-Consultation and Post-Consultation questionnaires were issued to all consultees prior to the day of their session, and if they participated by returning both questionnaires, the Post(+4)-Consultation questionnaire would be issued four weeks later. Questionnaire were individually numbered before being issued, and annotated a, b or c, so that returned questionnaires relating to the same participant could be matched, i.e.
Participant 1 would return questionnaires 1a, 1b and 1c. Only the researcher kept a note of, and had access to the list of which questionnaires were issued and to whom, and whether they were returned. Identifying details written on the questionnaires for administration purposes were done so in pencil, for later erasure to preserve anonymity.

Following the data collection period, questionnaires were sorted into their matched sets, with any single unmatched questionnaires being removed from the study, under assumed withdrawal. The questionnaires were then scored by applying the Likert Scale scores accordingly, and this data was then entered into SPSS for analysis. Answers to the qualitative questions were then subject to content analysis.

Results

Quantitative Data

In total, 50 sets of Pre-consultation and Post-consultation questionnaires were issued, of which 22 sets (44%) were completed and returned. Of these, 14/22 (64%) represented individual consultations, and 8/22 (36%) were for group consultations. It should be noted that for group consultations, all attendees were issued questionnaires in advance as necessitated by the study, however not all may have brought a client to the group for discussion. Thus some will
have been issued for non-measurable instances, which will have adversely affected the return rates calculated. Only 3/19 (16%) Post(+4)-Consultation questionnaires were returned, providing insufficient data for the evaluation of longer-term changes or maintenance of change. Thus the planned statistical analysis regarding these questions could not be performed.

Analysis was therefore focused on a comparison of the pre-consultation and post-consultation questionnaire scores only, with a view to evaluating whether scores had changed significantly following the consultation process, and could be indicative of a change in thinking having occurred.

Table 1. Showing a summary of the mean, median, range, and standard deviation obtained from the questionnaire data.

<table>
<thead>
<tr>
<th>Consultation type</th>
<th>Pre-Consultation score Q1-Q10</th>
<th>Post-Consultation score Q1-Q10</th>
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<tbody>
<tr>
<td>Individual consultation sessions</td>
<td>Mean 22.36, Median 22, Range 10 (18-28), Standard deviation 2.468</td>
<td>Mean 24.93, Median 25.5, Range 11 (20-31), Standard deviation 2.947</td>
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<tr>
<td>Group consultation sessions</td>
<td>Mean 22.38, Median 24, Range 7 (19-25), Standard deviation 2.669</td>
<td>Mean 24.13, Median 24.5, Range 9 (20-29), Standard deviation 2.642</td>
</tr>
<tr>
<td>Individual and group session data combined</td>
<td>Mean 22.36, Median 22.5, Range 10 (18-28), Standard deviation 2.479</td>
<td>Mean 24.64, Median 25, Range 11 (20-31), Standard deviation 2.804</td>
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</table>
When considering how to analyse the data statistically, it was observed that the median and mean scores for the pre and post data sets were quite close, with a relatively small range - most scores lay within 2 standard deviations of the mean (see Table 1). This suggested the possibility that the data might be normally distributed, and thus the Kolmogorov-Smirnov Test was used to test this. The result confirmed all data sets as normally distributed, with the exception of the Group Pre-Consultation data. Thus the Dependent t-test was used to for all comparative analyses, except where the Group Pre-Consultation data was involved when the Wilcoxon Signed Ranks Test was used.

Three comparisons were made between the Pre-Consultation and Post-Consultation data sets, all of which were shown to be statistically significant:

- With regard to individual consultations, participants showed a significant change in their thinking after the session ($M=24.93, SE=0.788$) compared to before ($M=22.36, SE=0.660$), $t(13)=-3.994, p<0.01, r=0.742$
- With regard to group consultations, participants showed a significant change in their thinking after the session ($Md=24.5$) compared to before ($Md=24$), $z=-2.047, p<0.05, r=0.55$
- Overall, irrespective of whether a consultation was individual or group based participants showed a significant change in their
thinking after the session \( (M=24.64, SE=0.598) \) compared to before \( (M=22.36, S =0.529) \), \( t(22)=-4.828, p<0.001, r=0.725 \)

Effect sizes were also calculated for each of the data sets: individual sessions \( r=0.742 \), group sessions \( r=0.55 \), overall data \( r=0.725 \). These represent large effect sizes (accounting for 25% or more of the variance) and an apparently substantial finding regarding the effect of consultancy sessions on participants' thinking.

**Qualitative data**

Many participants opted to provide responses to the free-response questions on the questionnaires. 15 participants (68%), cited their aims on the Pre-Consultation questionnaire, and of these 14/15 (93%) participants stated on the Post-Consultation that their aims had been met, with one not stated. A further 5/7 participants who had not originally stated their aims for the consultation, did say they felt their aims had been met. Thus overall, 19/22 participants (86%) stated their aims had been met, with the remaining 3/22 (14%) not expressing an opinion.

On the Post-Consultation Questionnaire, 17/22 participants (77%) commented on what they thought were the most beneficial aspects of using the consultation process, none of the participants commented on there being anything they found unhelpful about it.
The qualitative data was analysed using content analysis, and the following key themes were viewed as emerging (Appendix 4):

Staff aims from seeking consultation:

- Opportunity for reflection
- Direction
- Interventions
- To think more psychologically

Were staff aims met:

- Clarity (or client or purpose)
- New ideas
- Validation/reassurance
- Contribution of others (group context)

What was the most beneficial thing consultation provided:

- Time to reflect
- Think about alternatives
- Direction/Guidance/Focus
- Interventions/Strategies
- Better insight on client
- Support
There were insufficient Post(+4)-Consultation questionnaires for any themes to be drawn out.

Discussion

Whilst the time constraints inherent in this project may not have permitted all staff who wanted to, to participate, and indeed some may have chosen not to, the 12 staff (57%) who did take part represent a cross-section of the multi-disciplinary team, with the exception of the Social Workers. It is hoped therefore that the data obtained may be considered reasonably representative of the views held by the team as a whole. As this project represented a service evaluation of a single CMHT, caution must be exercised regarding generalising the results beyond this team.

Whilst the Pre-Consultation and Post-Consultation questionnaires had a return rate commensurate with survey style studies, the Post(+4)-Consultation questionnaire return rate was poor (16%), thus analysis of changes over time following the session was not possible. People may have felt they had nothing further to add, or could not remember the details about it, so any future studies should bear this potential problem in mind.

Consultation sessions were viewed as taking two forms. Individual sessions involved the psychologist and member of staff, thus variation in scores should be an effect of the consultancy session as the
independent variable. Since these results were statistically significant, with scores increasing post-consultation this is suggestive of improvements in understanding having occurred, and the potential for increased effectiveness in working with clients. Group consultations (case reflection or CBT reflection sessions) involved the psychologist and several members of staff. Whilst this may have added additional variables to the situation of the consultancy session, the group result still showed a significant difference between pre and post scores. Therefore a similar conclusion as for the individual sessions might also be drawn. When the data was combined to provide a bigger sample for analysis, again a significant difference was still found suggestive of a positive change in thinking following the consultation session. Whilst raw score differences appeared small, this evaluation has perhaps benefited from the statistical strength inherent in using a related design.

Factor analysis was not carried out, as the sample size was too small (Field 2005 p639), so the relative contribution of the factors measured by the questionnaire (understanding – Q1 & Q10, psychological mindedness - Q6 & Q9, support – Q3 & Q8 and stuckness/frustration – Q2, Q5 & Q7) could not be analysed, or the questionnaire validated by this method. However the beneficial effects seen in the quantitative data would also appear to be borne out in the qualitative data collected, through the emergent themes.
All participants had indicated via Q4 that they thought the session would be helpful to some degree, which might suggest a bias towards anticipating a positive outcome. Participant’s responses post-consultation indicated that they did not subsequently feel disappointed by the session, and their comments about whether their aims were met supported this. It was beyond the scope of this project to seek the views of those staff who did not participate, however it might be interesting in future research to gain an understanding of why staff do not take up the opportunity to have a consultation session with the team psychologist.

In reflecting on the themes that emerged from the content analysis of the questionnaires, there are several links between what participants see as being beneficial factors of seeking a consultation, and what they aim to get from it. Having the space and opportunity to reflect in itself was seen as an important aspect. Participants indicated they could use this space to think more psychologically, gain direction, as well as knowledge about interventions. In considering whether their aims had been met, gaining greater clarity in all these areas was the overriding theme amongst participants, as well as gaining some new ideas, and feeling validated or reassured about the work with their client. With regard to their perception of the benefits of the consultation sessions, these same themes emerged, including being able to gain a better insight into their client.
These themes would also appear to have concordance with the factors measured in the quantitative instrument used. The factor of understanding relates to insight of client, support is the same, as is thinking psychologically, and gaining direction or knowledge of other interventions can address participants feelings of stuckness/frustration. This would also support the face validity of the questionnaire as a measure of changes in participants thinking as a consequence of the consultation session.

The unique expertise of psychologists in providing formulations of clients (as suggested by Mowbray 1989), is perhaps at the heart of enabling staff to gain a better insight into their client. Through this, a new direction may be found for client work to proceed, along with knowledge of appropriate interventions or strategies to try. This may account for why Blumenthal & Lavender’s (1997) study had consultation work so high up the scale of importance for the roles of psychologists. Interestingly, the majority of staff participating – psychiatrists and CPN’s – come from a medical model background, and are perhaps interested in seeking the formulation approach as a counter-balance their own diagnostic approach, which the BPS(2007) emphasizes as a unique part of the contribution psychologists can make to the multi-disciplinary team.

This project has attempted to take a first step in evaluating what is quite a complex feature of the Clinical Psychologist’s role, that is still in its
infancy. The significance of the findings suggests staff are benefiting from the opportunity to seek a consultation session with the psychologist, and analysis of their comments suggest that subjective staff feel their aims are being met and the process is beneficial. This role reflects part of the way a psychologist can work in partnership within the CMHT to contribute to the quality of care for clients, and provide an element of psychological input that a client might otherwise not have access to.

At the time of writing, there had not been an opportunity to present the results of this project to the whole team, however this has been discussed with the team manager and will take place shortly.

Acknowledgements

I would like to acknowledge the support given to this project by the staff at the CMHT involved and thank them for their participation. I would also like to thank my field supervisor for her support in helping me undertake this project.
References


Appendices

i) Appendix 1: Pre-Consultation Questionnaire

ii) Appendix 2: Post-Consultation Questionnaire

iii) Appendix 3: Post(+4)-Consultation Questionnaire

iv) Appendix 4: Summary of content analysis of all questionnaires

v) Appendix 5: e-mail from supervisor confirming feedback of SRRP results to service
Appendix 1: Pre-Consultation Questionnaire

Psychology Consultation Service Evaluation Project
As you may be aware, during March, April, May and June of 2008, I am undertaking an evaluation of the psychology thinking space that is offered to all team members. I am doing this as part of my research module for my clinical psychology training course, which has the full support of the team psychologists (whose work in this respect is being evaluated), as well as my research tutor at Surrey University. As reflective-scientific practitioners, it is important to us to undertake evaluations such as this, to ensure our work is grounded in evidence-based practice, and your help with this project would be much appreciated by all of us.

As you have requested a meeting with .................................. on ..........................................., I would very much appreciate it if you would volunteer to take part in this project, by taking the time to complete the questionnaire overleaf. You should be aware however, that you are NOT UNDER ANY OBLIGATION to complete this questionnaire, and it WILL NOT AFFECT the consultation that you have with the psychologist. The information provided in this questionnaire will not be made available to the psychologist prior to the meeting, nor will it form part of the thinking process or reflections regarding your client. I am very aware, that I am asking you to evaluate a service provided by a fellow colleague, and want to reassure you that I have taken the utmost care to try and ensure that your confidentiality and anonymity is preserved, should you choose to participate. If you have any queries in this regard, please do not hesitate to ask me. You need add no other details to the form beyond those asked for.

The outcome of the evaluation will be reported back to the team via a short presentation summarising the results. The full report will be submitted to the university, and anyone will be welcome to view/have a copy of this when available, should they so wish.

Completing the questionnaire
It is anticipated that it should take no more than 5-10 minutes of your time to complete the questionnaire. Instructions on how to complete it can be found overleaf.

Please complete the questionnaire prior to the consultation date noted above. Completed forms should be returned to me via the box marked ‘XX’s Questionnaires’, located in the staff room.
Thank you for taking the time to read this information sheet, and I hope you will feel able to participate. Should you have any questions, please do not hesitate to speak to me.

Trainee Clinical Psychologist

e-mail:
Supervised by: XXXXX (XX CMHT) & Laura Simonds (Dept. of Psychology, Surrey University)
Pre-consultation questionnaire to be completed by consultee

There are several statements below, which ask you to reflect on your thoughts and feelings about the client for whom you have requested this consultation. Please read each statement carefully, and tick the box which best describes your current position in relation to this client. Your initial thoughts are likely to be fairly accurate, so you should not worry about reflecting too deeply. It is not expected that you will spend more than 5-10 minutes on completing it. Yours comments on the final question would be helpful, but it can be left blank if you wish. Please ensure however, that you have ticked a box in answer to all of the 10 statements.

Please indicate the extent to which you would agree with the following statements:

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<thead>
<tr>
<th>Statement</th>
<th>Not very much</th>
<th>A little</th>
<th>Quite a lot</th>
<th>A lot</th>
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<tr>
<td>1. I understand this person at the moment</td>
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<td>2. I feel confident about where I am going with this client</td>
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<td>3. My colleagues in the team are supporting my work with this person</td>
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<td>4. I anticipate that the consultation will be helpful</td>
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<td>5. This client makes me feel uncomfortable</td>
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<td>6. This person can evoke strong emotions in me</td>
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<td>7. I feel this person no longer requires the support of this service</td>
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<td>8. Other team members do not know about or understand my work with</td>
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<td>9. My emotions have impacted on my work with this client</td>
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<td>10. I cannot understand how work with this person does not seem to be</td>
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What would you like to gain from this consultation?

Thank you for taking the time to complete this questionnaire
Appendix 2: Post-Consultation Questionnaire

Psychology Consultation Service Evaluation Project
This is the second questionnaire in the series, issued as part of the information gathering process for the above project, which is taking place during March, April, May and June of 2008, and your continued help with this project is much appreciated. This questionnaire has been given to you following your meeting with .................................. on ................................, to think about your client, and should be completed with this person in mind. To preserve confidentiality and anonymity, everyone is being given a copy of this questionnaire following their consultation, whether they elected to participate or not by completing the Pre-Consultation Questionnaire.

If you have chosen to participate and completed the Pre-Consultation Questionnaire, then your continued participation in completing this second questionnaire would be much appreciated. If you chose not to participate in respect of this client consultation because you have not completed the Pre-Consultation Questionnaire, then please do not complete this one either, as we need both questionnaires completed for the subsequent data analysis. I would emphasize that your continued participation is still entirely voluntary, and you have the right to withdraw at any time and have any information provided removed from the study. Even if you completed the Pre-Consultation Questionnaire, you can still change your mind about participation and need not complete this questionnaire. If you return this questionnaire uncompleted I will take this as indicating your wish to opt out at this time, and the information you provided on your first questionnaire will automatically be removed from the study.

Completing the questionnaire
It is anticipated that it should take no more than 5-10 minutes of your time to complete the questionnaire. Instructions on how to complete it can be found overleaf. You need add no other details to the form beyond those asked for. Please complete the questionnaire as soon as possible after the consultation date noted above. Completed and uncompleted forms should be returned to me via the box marked ‘XX’s Questionnaires’, located in the staff room. Thank you for taking the time to read this information sheet, and supporting this project. Should you have any questions, please do not hesitate to speak to me.

Trainee Clinical Psychologist

e-mail:
Supervised by: XX (XX CMHT) & Laura Simonds (Dept. of Psychology, Surrey University)
Questionnaire No.

**Post-consultation questionnaire to be completed by consultee**

There are several statements below, which ask you to reflect on your thoughts and feelings about the client for whom you have requested this consultation. Please read each statement carefully and tick the box which best describes your position in relation to this client following the psychological input you have just received. Please ensure you have marked a box for every statement. Your comments on the additional questions would be helpful, but they can be left blank if you wish.

Please indicate the extent to which you would agree with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not very</th>
<th>A little</th>
<th>Quite a lot</th>
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<td>2. I feel confident about where I am going</td>
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<td>3. My colleagues in the team are supporting</td>
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<td>4. I feel the consultation has been helpful</td>
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<td>5. This client makes me feel uncomfortable</td>
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<td>9. My emotions have impacted on my work</td>
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<td>10. I cannot understand how work with this person does not seem to be progressing</td>
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<td>11. I can use some of these ideas with other</td>
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<td>12. This session has made me think about how professional issues might impact on this</td>
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<td>13. This session helped me identify solutions</td>
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<td>14. This session has no bearing on my work</td>
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<td>15. I cannot see any alternative perspectives to the work I am doing</td>
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It would also be helpful, if you could make some comments in answer to the following questions:

Were your aims in requesting this consultation met?

..........................................................................................................................................

Briefly, what would you say was the most beneficial thing that the consultation provided?

..........................................................................................................................................

Was there anything about the consultation that was not particularly helpful?

..........................................................................................................................................

**Thank you for taking the time to complete this questionnaire**

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Appendix 3: Post(+4)-Consultation Questionnaire

Psychology Consultation Service Evaluation Project

This is the third questionnaire in the series, issued as part of the information gathering process for the above project, which is taking place during March, April, May and June of 2008, and your continued help with this project is much appreciated.

This questionnaire has been given to you to complete in respect of the client you discussed with ....................... at the meeting held on .................................. It is asking you to reflect on how you now think about and understand this client, and whether the passage of time or work you may have subsequently done with this client has in anyway changed the understanding you had gained from the meeting. You are only being given a copy of this questionnaire, if you have already completed the Post-Consultation Questionnaire.

I would reiterate that you are under no obligation to complete this questionnaire.

If you choose not to complete this questionnaire, it will not invalidate the information already collected from the previous questionnaires, which can stand alone, however your continued participation in completing this questionnaire is much appreciated. Non-completion will not be taken as signifying your withdrawal from the study, but that you have simply chosen just to participate to the point of completing the first two questionnaires. You do however still have the right to withdraw any previous information provided for the study, and can contact me at any time to let me know if this is your wish. So that I am aware if you have chosen not to complete this questionnaire, please post the blank form back in the ‘XX’s questionnaires’ box

Completing the questionnaire

It is anticipated that it should take no more than 5-10 minutes of your time to complete the questionnaire. Instructions on how to complete it can be found overleaf. You need add no other details to the form beyond those asked for.

Please complete the questionnaire as soon as possible following receipt, and return it to me via the box marked ‘XX’s Questionnaires’, located in the staff room.

Thank you for taking the time to read this information sheet, and supporting this project. Should you have any questions, please do not hesitate to speak to me.

Trainee Clinical Psychologist

e-mail:
Supervised by: XX (XX CMHT) & Laura Simonds(Dept. of Psychology, Surrey University)
Questionnaire No.

**Post (+4)-consultation questionnaire to be completed by consultee**

There are several statements below, which ask you to reflect on your thoughts and feelings about the client for whom you requested this consultation. Please read each statement carefully and tick the box which best describes your position in relation to this client following the psychological input you received on the date mentioned on the front of this form. Please ensure you have marked a box for every statement. Your comments on the additional questions would be helpful, but they can be left blank if you wish.

**Please indicate the extent to which you would agree with the following statements**

<table>
<thead>
<tr>
<th></th>
<th>Not very</th>
<th>A little</th>
<th>Quite a lot</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I understand this person at the moment</td>
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<tr>
<td>2. I feel confident about where I am going with</td>
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<tr>
<td>3. My colleagues in the team are supporting</td>
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<td>4. I feel the consultation has been helpful</td>
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<td>5. This client makes me feel uncomfortable</td>
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<td>6. This person can evoke strong emotions in</td>
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<td>7. I feel this person no longer requires the</td>
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<td>8. Other team members do not know about or understand my work with this person</td>
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<td>9. My emotions have impacted on my work</td>
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<tr>
<td>10. I cannot understand how work with this person does not seem to be progressing</td>
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<td>11. I can use some of these ideas with other</td>
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<td>12. This session has made me think about how professional issues might impact on this</td>
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<td>13. This session helped me identify solutions</td>
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<td>14. This session has no bearing on my work</td>
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<td>15. I cannot see any alternative perspectives to the work I am doing</td>
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It would also be helpful, if you could make some comments in answer to the following questions:

Have you been able to do anything differently with your client based on any new understanding gained from this consultation, if so, what?

Has anything in the way you think about this client changed further (positive or negative) since the meeting, as a consequence of having had the opportunity to discuss this client with a team psychologist?

Has this consultation had any impact on your thinking in regard to your clinical practice in general?

**Thank you for taking the time to complete this questionnaire**
Appendix 4: Summary of the content analysis of all questionnaires

1. Pre-Consultation Questionnaire

| Question: What would you like to gain from this consultation? |
|-----------------|-------------------------------------------------|
| Theme                        | Comments on questionnaire supporting the theme |
| Opportunity for reflection (on client or self) | - A bigger picture  
- Ways to discuss diagnosis with client  
- to reconcile feelings of what do I do now  
- how can I offer the most support  
- to know how client might be helped  
- greater understanding of this person's presentation  
- opportunity to reflect  
- to gain a clearer formulation |
| Direction (in working with this client) | - Sequence of treatment for best effect.  
- Some direction  
- clear plan of action  
- how to take things further in spite of chaos  
- clearer plan  
- to know the way forward  
- a clearer picture of my role |
| Interventions | - direction/guidance on using CBT techniques  
- practical ideas about phobias/eating  
- learn about other psychological interventions which could be offered to client.  
- reflect on future interventions. |
| Thinking more psychologically (about work with client) | - Using motivational interviewing in relation to assessing and moving forward a care plan.  
- Clearer idea of how to progress psychologically with this client.  
- how my work might dovetail with psychology  
- to obtain psychological input towards client's recovery  
- consider potential therapeutic outcome for client. |
2. Post-Consultation Questionnaire

<table>
<thead>
<tr>
<th>Question: Were your aims in requesting this consultation met?</th>
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<tbody>
<tr>
<td><strong>Clarity</strong></td>
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<tr>
<td><strong>New Ideas</strong></td>
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<tr>
<td><strong>Validation/Reassurance</strong> (for staff)</td>
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<tr>
<td></td>
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<tr>
<td><strong>Contribution of others</strong> (in group context)</td>
</tr>
</tbody>
</table>

Question: Briefly, what would you say was the most beneficial thing that the consultation provided?

| Time to reflect | - time to discuss approaches/care plan  |
| | - it enabled me to stand back from the clients usual manner of responding  |
| | - clarification of assessment of the ‘problem’  |
| | - time for reflection and clarity about where things connect  |
| Think about alternatives | - a discussion of a variety of options  |
| | - exploring alternatives  |
| | - different mindset  |
| Direction/Guidance/Focus | - planned action outcome (from session)  |
| | - a constructive plan  |
| | - joint assessment offered  |
| | - having an action plan  |
| | - direction, guidance  |
### Interventions/strategies
- structure to intervention
- practical solutions and things to try
- practical guidance on phobias
- introduced me to a different style of formulating which I will try to use with other clients
- exploring other coping strategies

### Better insight on client
- to notice that client is not psychologically minded
- to look at underlying significance of events & relationships that led to patients core beliefs
- look at progression of patients illness
- greater clarity of relevant issues in client's life and how these influenced or led to her current beliefs
- helped me to know what areas of patients 'complaints' I need to focus on
- it gave me a better insight into how her problems could be solved
- recognising why client may 'rubbish' the therapist, and why they tend to respond in this manner
- the formulation was excellent

### Support
- I felt supported by the team
- personal support
- feeling confident in being understood by the psychologist
- confirmation that my approach was correct

### Usefulness of session notes
- written notes helped to retain focus

### Question: Was there anything about the consultation that was not particularly helpful?

**No**
- all respondents said no or made no comment
3. Post(+4)-Consultation Questionnaire

Due to only 3 questionnaires being returned, it was not possible to establish particular themes. However questions and responses are listed below:

Question: Have you been able to do anything differently with your client based on any new understanding gained from this consultation, if so, what?
- Use the planned action from session
- Feel confident that I was following a set procedure which was research-based and effective

Question: Has anything in the way you think about this client changed further (positive or negative) since the meeting?
- No

Question: Has this consultation had any impact on your thinking in regard to your clinical practice in general?
- It is useful to have a psychological perspective, this can give a broader perspective
- Space/time is very helpful, which is not available in the normal course of a day or sector meeting
- I can use the information with other clients
Appendix 5 – E-mail from supervisor confirming feedback of SRRP results to service

RE: SRRP 2008

Sent: 21 May 2010 16:38
To: Richards AJS Mr (PG/R - Psychology)

Dear Aaron,
I confirm that you presented the results and process of your SRRP back to the [redacted] CMHT during a team meeting at the end of your placement.
Regards
Katherine

Dr Katherine Preedy
Chartered Clinical Psychologist, Professional Lead for Psychology and Psychological Therapies, West Brighton Access Team
Sussex Partnership NHS Foundation Trust

This e-mail is confidential and privileged. If you are not the intended recipient please accept our apologies; and please do not disclose, copy or distribute information in this e-mail or take any action in reliance on its contents: to do so is strictly prohibited and may be unlawful. Please inform us that this message has gone astray before deleting it. Thank you for your co-operation.

Remember that details of this e-mail may need to be disclosed under the Freedom of Information Act.
3.4 Major Research Project

July 2011

Year 3

‘Finding meaning in caregiving, well-being and spousal caregivers of people with dementia’
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• Implications for clinical practice
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2. Participant Invite Letter
3. Study Questionnaires
4. Ethical Approval Documents
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6. Statistical Data for Preliminary Analysis
7. Statistical data for correlational analysis
8. Statistical data for regression analysis
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10. List of abbreviations used
Abstract

Aims & Objectives: Previous research into factors involved in emotional responses to caregiving has often focussed on its dysfunctional aspect, resulting in a well documented association between negative aspects e.g. burden, and negative health outcomes e.g. depression. Less understanding exists regarding the role of positive aspects, and caregivers' ability to cope well despite difficult circumstances. This study sought to explore how finding meaning in caregiving, considered in relation to the Hopelessness Theory of Depression (HTD) (Abramson et al., 1989), might aid our understanding of this, and the possible moderating role of positive factors.

Methods: A cross-sectional survey method was used, which invited caregivers of people with dementia from two Memory Clinics to participate. Five questionnaires were completed by 55 participants providing measures of depression, hopelessness, finding meaning, coping skills and demographic information.

Results: Significant associations were found between: hopelessness and depression; finding meaning and depression; and finding meaning and hopelessness. Regression analysis provided an explanatory model for depression outcome where hopelessness and finding meaning were the only unique contributors to the model variance.

Discussion: positive and negative factors are indicated as having independent effects on depression in caregivers. Drawing on HTD theory's framework regarding the simultaneous but independent mechanisms of cognitive attributional processes for positive and negative events, and facilitation of recovery/resilience via positive attributional styles, this is posited as one possible explanation for how and why caregivers may cope despite role stresses and difficulties, and for positive events as functionally adaptive. Limitations and ideas for further research are discussed.
Introduction

Historically, informal caregivers have been suggested by Pot (2004) as being the 'hidden victims' of health conditions, observing that the impact and experiences of the families of people with dementia (PwD) did not appear on the research agenda until the early 1980's. Zarit et al. (1980) were one of the first to begin highlighting carer issues, when they introduced the notion of 'burden' as a negative consequence for caregivers of PwD.

Since then, there has been an 'explosive growth' in carer research (Pot, 2004). Many authors (e.g. Ekwall & Hallberg, 2007) have noted how this has largely focused on the negative aspects of caring, with the relationship between caregiving and its negative consequences having become well documented (Schulz et al. 1995). In contrast to this, Kramer (1997a) highlighted how relatively little attention had been paid to the presence and role of positive factors in the caregiving process. Rapp & Chao (2000) suggested that exploring what caregivers saw as positive about their role might prove useful in increasing our understanding of how carers adapt to chronically stressfully situations, and help inform the development of interventions to help stressed carers. Positive psychologists (e.g. Snyder & Lopez, 2005) observed that the positive approach to understanding wellbeing is often more illuminating.
Caregiving is acknowledged as a stressful role (Peacock et al., 2009). However carers may experience both strains and gains in their role and even hold these feelings simultaneously suggesting they are not mutually exclusive, and thus positive and negative aspects of caregiving may represent different dimensions (Kramer, 1997a). Therefore if healthcare professionals are to obtain a more complete understanding of a caregiver’s experience and their needs, Peacock et al. (2009) stated they should not neglect to incorporate positive aspects of caregiving in their assessments.

Caregiver depression is a negative consequence that has been shown to be highly associated with the stress/burden of caring (Pinquart & Sorensen, 2004), and is a significant clinical issue given its deleterious affect on the carer’s ability to sustain their role (Gallagher et al., 1989). However although depression is often cited as a negative outcome in caregiving, studies linking the development of depression in caregivers to theories of depression appear to be absent in the literature. This study sought to explore how one such theory, the Hopelessness Theory of Depression (HTD) (Abramson et al., 1989), might act as an explanatory framework for caregiver vulnerability to depression including the potential moderating role of positive aspects of caregiving, and the possible clinical implications of this.
Overview

The aim of this introduction is to provide the reader with a structured summary of the relevant literature pertaining to informal caregiving, dementia and well-being, which provides a rationale for the current study. It defines informal caregivers and the impact of the caregiving role, with reference to dementia and its unique demands, situating it within the current social and political context. The concept of wellbeing will be discussed including the role of cognitive appraisal and coping as explanatory factors in wellbeing outcomes. The Hopelessness Theory of Depression (HTD) will be considered as a mechanism for explaining depression vulnerability and recovery. The role of positive aspects in caregiving will be discussed, with reference to the existential perspective and finding meaning in caregiving as representing a particular way of conceptualising the positive aspects of caregiving. This will lead to the generation of the study hypotheses.

Defining carers

Within society there are two distinct categories of carers: healthcare professionals who choose the role and informal carers who are ascribed/take up the role in the context of family and friendship. This study focuses only on the informal carer group. For simplicity's sake the terms carer/caregiver are used, but refer only to informal carers.

So how does someone become a carer? Pearlin et al. (1990) suggested that carers emerge from existing family relationships, where caregiving
may be seen as an extension of these in adapting to changing life circumstances. Thus some people may not view themselves as a 'carer' and reject this label, even though they accept its roles and responsibilities. Whilst some may accept the mantel of carer with apparent ease, for others family and societal pressures may be operating with people feeling compelled to adopt the role out of a sense of obligation, or due to the pressure of social norms (Innes, 2009).

The Department of Health (DoH, 2008), define carers as:

'someone who spends a significant part of their life providing unpaid support to family and potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance abuse problems.'

(DoH, 2008, pp.19)

Thus anyone could potentially become a carer depending on circumstances. Carers are not an homogenous group, and the role does not respect boundaries such as gender, age, health, competency, or indeed preserve itself only for those who might choose or desire it. Indeed the role of carer may also be automatically ascribed to people, by health and social service professionals who simply assume that family members, especially spouses, will automatically accept the responsibilities and challenges of the caring role (Braithwaite, 1990), or will always want to continue with it (Innes, 2009).
Prevalence and Incidence

Many people are likely to experience providing care for someone else at some point in their lives. Data about carer numbers was collected for the first time as part of the 2001 Census which revealed that 5.2 million people were providing care to family or friends, and of these carers 1.5 million were age 60 and over (Office of National Statistics, 2003). The government's subsequent Carer Strategy (DoH, 2008) estimates that 1 in 10 people in the UK are acting as carers (9% of men and 11% of women) at any given time, with around 6,000 people a day taking on new caring responsibilities. Thus informal caregiving represents a substantial component of the care provided to meet the needs of the sick, disabled and elderly members of society.

Impact of caregiving

Pearlin et al. (1990) postulated that caregiving is not a separate role in itself but is embedded in the ordinary exchanges of assistance that occur in the context of established close relationships. They distinguished between caring as the affective component of a person's commitment to the welfare of another, and caregiving as how this is expressed behaviourally. They suggest that whereas caregiving is typically only a small component of a relationship, the demands and challenges posed when one party to the relationship becomes impaired through illness or disability, means caregiving may come to dominate it. Help, assistance and affection may become unidirectional, with this imbalance resulting in the traumatic and involuntary transformation of a
cherished relationship into a source of stress itself (Pearlin et al., 1983), where loss of reciprocity and mutuality are key factors (Adams et al., 2008).

Indeed, Hirschfeld (1983) found that mutuality (a caregivers ability to find gratification in the relationship and meaning in the caregiving situation) was a major determining factor in whether carers sought institutionalisation for the PwD. Maintaining the ability to care for someone at home is important in two respects: research suggests that PwD have a better experience of living with dementia when cared for at home (Hoe et al., 2007); and institutionalisation does not necessarily solve a carer’s difficulties since many often suffer from guilt or a sense of failure at letting their relative down (Buijsse, 2005).

There is a well documented association between caregiving and its negative impact on caregivers’ lives. The main conceptualisations include: burden, (Zarit et al., 1980), stress (Donaldson et al., 1997, 1998) and emotional strain (Almberg et al., 1997). These have been suggested as detrimental to quality of life through association with: poorer physical & psychological health (Henwood 1998); an increased risk of mortality (Schulz & Beach, 1999 - although this has been disputed by Brown et al., 2009); decreased emotional wellbeing (Morris et al., 1988), limits to social life and isolation (Smith et al. 2011), and financial strains (Innes, 2009). Kim & Schulz (2008) in a comparative analysis of caregiving strains found that these difficulties are present for
most older caregivers, with levels appearing especially elevated amongst caregivers of people with dementia and cancer.

Some demographic factors have been found to be associated with experiences of caregiving. Gender differences were noted by Ekwall & Hallberg (2007) who found female caregivers experienced a greater sense of burden than men, with men viewing caregiving as more rewarding. Age differences were found by Broe et al. (1999) with carers aged 75+ having a lower level of life satisfaction and a higher level of psychiatric symptoms. Possible cultural differences in the experience of the caregiving burden were reported by Martin (2000), who compared Caucasian and African-American older caregivers. The report of lower burden by female African-American carers was explained as possibly due to their perception of caregiving as part of normal family exchanges performed by women rather than the provision of extraordinary help, but added that gender and cultural role identities may simply add to the complexity in understanding perceived burden. Innes (2009) cautioned that non-reporting of burden by members of different ethnic groups, especially those perceived as having high family care values, does not mean they are not finding their role equally stressful and may still need support.

Dementia and caregiving

Providing care for someone with a condition that is progressive and where carers feel they have little control over easing or changing the
suffering of the person can bring added stress (Kim & Schulz, 2008). Dementia has been described as especially demanding and stressful, as caregivers not only observe the person they love declining functionally and mentally, but also see their personhood being slowly eroded (Pot, 2000).

Dementia is a condition that typically affects people in later life, becoming much more prevalent from age 65 after which the incidence approximately doubles every five years (Woods, 2002). A recent UK study by Knapp et al. (2007) supports this exponential growth rate, citing 1.3% at age 65, 12% at age 80 and 28% at age 90. In real terms, this means some 682,500 people in the UK have dementia (1 in 88 people or 1.1% of the population). Given the forecast for an increase in the size of the older population Knapp et al. predict some 940,000 people will be estimated to have dementia by 2021.

Dementia itself does not have a specific aetiology, as it is a collective term used to represent a neuro-behavioural syndrome of medical conditions that share many similarities. The main diagnostic categories are Alzheimer's Disease, Vascular Dementia, Dementia with Lewy Bodies and Parkinson's Disease Dementia, which may occur singly or co-morbidly and together account for approximately 80% of referrals to Memory Clinics (Wilcock et al., 1999).
Buijsen (2005) provides a useful conceptualisation of dementia. He states that whilst the dementias may have different underlying pathologies, the commonly observed effect on the brain is to produce memory loss. Other cognitive domains such as attention, language perception and executive function are also variously affected, resulting in the characteristic patterns of observed difficulties that lead to a differential diagnosis of a ‘probable’ dementia type. They all give rise to a progressive (steady or stepwise) decline in cognitive and social functioning, with associated behavioural changes and a gradual loss of personhood.

Dementia can also result in other mental health difficulties, due to organic changes in the brain as well as the psychological difficulties incurred due to the experience of living with dementia itself (Woods, 2002). These are often referred to as the non-cognitive features (NCF’s) of dementia, and can include: anxiety, depression, apathy, hallucinations, paranoia, aggression, and sleep problems. Donaldson et al. (1997, 1998) found that it is often these difficulties that families find hardest to cope with.

As a progressive condition, this means PwD require increasing levels of support and care as their symptoms worsen. Dementia may be considered to be a life-limiting illness (Miesen, 2004), but it can take many years to run its course. A longitudinal study by Wolfson et al. (2001) found that the median survival time from diagnosis declines with
age, from 6 years at age 65 to 3 years at age 85+. However 58% and 21% of people in these age groups were still alive at least five years after diagnosis. This suggests a substantial investment is required from carers and society, if PwD are to be supported to maintain their independence and quality of life, especially given the predicted increase in the number of PwD.

Social and political context

At one time it was thought that there was little that could be done for people with dementia, and Kitwood (1997) talked about the 'malignant social psychology' that arose regarding PwD even when people acted from the best of intentions. He noted that being in relationships with others was crucial to the quality of life of a PwD, especially maintaining one with their carer. Clare et al. (2003) subsequently reported how research has now increased our understanding of dementia and how to provide positive interventions to improve the quality of life for PwD and their carers. However despite the abundance of services that have emerged, Innes (2009) notes there is still a lack of consensus about what does and does not work for carers, with usage not necessarily reflecting that which researchers suggest might be useful.

Knapp et al. (2007) noted that policy makers tend to assume that family members will provide care, especially women. O'Shea & Reilly (2000) observe that family care is often viewed as 'free', however O'Shea (2004) reports that the health of carers typically suffers when
governments do not invest sufficiently in community care services. Pointon & Keady (2005) found that insufficient support for families to meet their desire and needs in caring for their relative, resulted in institutionalisation becoming a necessity rather than a choice.

A lack of political will in European countries to treat AD as the serious condition it is was observed by Bond et al. (2005). Innes (2009) suggests dementia may suffer by association, from the negative views and stigma observed in social discourses related to old age and mental health. The UK government attempted to address this with the recent launch of their National Dementia Strategy (DoH, 2009), which guarantees PwD and their carers receive appropriate assessments and services tailored to meet their individual needs. Knapp et al. (2007) estimated that around two-thirds of PwD live in the community, with informal care providing approximately half the care input required by older people generally. Data from the 2001 UK Census assesses the cost of replacing unpaid family care at around £87.01 billion pounds per year (Buckner & Yeandle 2007). The UK government has recently prioritised the needs of carers by outlining a support framework 'Carers at the heart of 21st century families and communities' (DoH, 2008). This recognises the physical and emotional impact of caring, and is aimed at early identification and intervention for carer difficulties, including offering psychological support.
This highlights the costs and tensions of dementia, namely the humanitarian costs of the disease process on PwD and their carers, and the financial costs of caring on the family and society.

**Caregiving and wellbeing**

As Barrow & Harrison (2005) note, the wellbeing of carers has become a major public health concern. Cuijpers (2005) stated that it has been well-established that caregivers of PwD can suffer disproportionately from role stress, with Pinquart & Sorensen (2003) finding mental health difficulties e.g. depression and anxiety, are significantly associated with this.

People in later life generally, have been found to be more vulnerable to developing depression (Beekman et al., 1999; Roberts et al., 1997), which Wattis (2001) attributes to factors such as declining health and social isolation. In Cuijpers’ (2005) review of depression studies in older caregivers of PwD, he found that they exhibited considerably higher prevalence rates (up to 32%) compared to their peers (up to 20%), concluding that caregiving stress added to depression vulnerability. Gender differences were also apparent, however Cuijpers cautioned that this disparity often disappears when prevalence rates of depression in the general population are controlled for. The symptoms expressed in ‘carer depression’ do not appear to be qualitatively different from those observed more generally amongst non-caregiving depressed people (Coope et al., 1995).
Research evidence suggests that depressive symptoms can be adequately treated both using pharmacological (Anderson, 2001; Thase, 2003) and psychological (Churchill et al., 2001) interventions, however Phillips et al. (2009) suggested that caregiver burden tends to stabilise over time and thus any related psychological morbidity may become long lasting under continued stress. As the somatic and psychological symptoms of depression impinge on daily functioning, this may compromise a caregivers ability to adequately look after themselves and/or the PwD which is of concern (Gallagher et al., 1989). Identification and treatment of depression in caregivers is therefore important, where perhaps prediction and prevention in those identified as vulnerable might prove more advantageous than working reactively to restore wellbeing.

Mental health and wellbeing, as Kramer (1997a) states, is about more than just the absence of pathology. The World Health Organisation now takes a more positive stance on mental health defining it as:

‘...a state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community’

(WHO, 2001)

Huppert (2008) comments that sustainable wellbeing is not just about feeling good all the time, since life contains a mixture of emotions
(including pain, disappointment, loss, failure). She stated that it is the
negative emotions of everyday functioning that compromise wellbeing
and that need to be coped with for long term wellbeing to be
maintained.

Keyes et al. (2002) stated that whilst people live in objectively defined
environments, it is how they subjectively define (individually interpret)
the world that determines their response. Keyes et al. distinguish
between subjective wellbeing (SWB) - with its affective (emotional)
component of balancing life's positive and negative affect e.g.
happiness, and the cognitive component (judgements) people make
relation to this e.g. life satisfaction; and psychological wellbeing (PWB) -
representing the ability to engage with the existential challenges of life.
Ryff (1989) conceived of a six-factor model of PWB which included:
positive relations with others; environmental mastery; autonomy;
personal growth; self-acceptance (feeling good about the self whilst
acknowledging own limitations); and purpose in life (endeavouring to
find meaning in one's efforts and challenges). Maintaining high levels of
purpose (meaning), mastery and growth is suggested by Ryff et al.
(1998) as the possible key to developing resilience.

From a research perspective, Linley et al. (2009) noted that whilst there
appears to be agreement about the conceptualisation and
measurement of SWB via instruments such as Positive and Negative
Affect Scales (Watson et al. 1988) and Satisfaction with Life Scale
(Diener et al., 1985), there is still conceptual and psychometric debate surrounding PWB. There is some evidence that although SWB and PWB are highly correlated, confirmatory factor analysis by Keyes et al. (2002) in a large US population study indicated that they exhibit significant uniqueness to mark them as distinct factors in overall wellbeing. They also found that it was the strongly existential aspects of PWB (life purpose and personal growth) that most clearly separated PWB from the affective and life quality aspects of SWB. They concluded that varying levels of SWB and PWB could lead to multiple types of wellbeing, and that similarity in levels might provide a sense of self-congruency, whilst opposite (high vs low) levels might work in a compensatory way to maintain wellbeing. They did caution that the study may reflect a Western characterisation of what it means to live a satisfactory life, however a more recent cross-cultural (USA, UK & China) replication of the study by Linley et al. (2009) similarly confirmed SWB and PWB as distinct factors, and also indicated this distinction to be invariant across the demographic factors of age, gender and ethnicity.

There has also been much debate on whether SWB or PWB are the antecedents of each other. Kashdan et al. (2008) have argued for SWB as a prerequisite for PWB based on the study by King et al. (2006) which demonstrated that when positive affect was induced in participants they reported a higher level of meaning in life. However Linley et al. (2009) found that positive affect was the lowest loading
variable in their model, suggesting that the core of wellbeing is not simply positive affect.

**Cognitive appraisal and wellbeing**

In line with this position regarding the primacy of subjectivity in determining wellbeing, Morris et al. (1988) suggested that for caregivers, vulnerability to psychiatric morbidity is likely to be influenced by the cognitive appraisal (interpretations) they make about their role and situation stresses. Cognitive appraisal plays a key role in the theories and models that have been developed to explain stress and coping, such as Lazarus & Folkman’s (1984) Cognitive Theory of Stress and Coping (CTSC), which Dawson & Winocur (2008) note is the most widely used framework in health settings. Farran (1997) comments that subsequent models to explain this more specifically in caregivers of PwD (e.g. Lawton et al., 1991; Pearlin et al., 1990; Aneshensel, 1995) represented adapted versions of this.

In CTSC theory, stress is not viewed as a stimulus or a response, but a relationship between the person and their environment that is appraised by the person as exceeding their resources and endangering their wellbeing. This relationship is both dynamic and bidirectional. The significance for wellbeing will depend on the meaning an event has for a person based on their cognitive appraisal of it. A primary appraisal is made regarding the harm/loss, threat or challenge presented by the situation, and a secondary appraisal is made regarding evaluating the
coping resources (physical, psychological, social and material) a person has at their disposal. Coping refers to the cognitive and behavioural efforts made by the person to manage the demands.

If appraisal and coping alter the meaning or distress of a situation, it is hypothesised that resolution will occur (with positive emotions appearing particularly in relation to challenge appraisals). If there is no change and negative emotions result/remain then this indicates non-resolution and the process repeats itself setting up the conditions of chronic stress (Lazarus & Folkman, 1984). Folkman (1984) suggests that cognitive appraisal, controllability (beliefs about one's efforts to influence a situation) and self-efficacy (believing one has the necessary task skills), are important determinants of situation response. For instance she noted that if a stressful encounter is appraised as uncontrollable, it is likely to result in learned-helplessness (Seligman, 1975) and its associated pathology of depression.

**Is the caregiving experience only negative and stressful?**

Kramer (1997a) observes that historically social science research has overly focused on viewing and measuring mental health from the perspective of psychological dysfunction, and similarly caregiver research has suffered a similar fate possibly resulting in a skewed perception of caregiving as being a more negative or deleterious experience than may be the case.
Stress-adaptation models like CTSC have a tendency to focus on distress, which Graber & Nice (1991) observed leads to a preoccupation with the burdens and problems of caregiving that can 'empower the problem and disempower the person'. Peacock et al. (2009) cautioned that professionals should not assume that all caregivers become consumed by negative experiences. Caregivers are often keen to talk about the positive aspects of their experience (Kramer 1997a), and a study by Cohen et al. (2002), found that 73% of carers could identify at least one positive aspect to caregiving, with 70% expressing positive feelings about caregiving. Additionally a significant negative relationship was found between positive feelings and negative outcomes (e.g. burden, depression), suggesting that positive aspects of caring (PAC) may act as a buffer for wellbeing.

Many PAC’s have been identified and conceptualised by researchers, for example: satisfaction (Lawton et al., 1989); uplifts (Kinney & Stephens, 1989); rewards (Hinrichsen et al., 1992); gratifications (Motenko, 1989); and finding meaning through caregiving (Farran et al. 1991). Kramer (1997a) suggested that positive and negative aspects of caregiving reflect separate dimensions of the caregiving experience rather than opposite ends of a continuum, as evidenced in the recent study by Andren & Elmstahl (2005) who found that stress (high burden) and satisfaction could co-exist in caregivers (even after controlling for demographic factors). Positive aspects (gains) and negative aspects (strains) have been found to independently predict negative affect.
(Rapp & Chao, 2000), with a meta-analysis by Pinquart & Sorensen (2003) demonstrating that overall positive aspects are more associated to subjective wellbeing and negative aspects more associated to depression. Thus understanding the gains people can derive from caregiving is an equally important factor for investigation (Kramer, 1997b; Post, 2000).

**Explaining the role of positive aspects**

Folkman (1997) revised the CTSC model based on her studies with caregivers of people with AIDS which indicated positive emotions had a role to play in coping. She noted that caregivers would engage in what she called meaning-focused coping (creation of positive events or infusing every-day/ordinary events with more positive meaning), and suggested that this was used when emotion-focused and problem focused coping failed, amending the model accordingly. Positive emotions were proposed as a buffer to sustain coping in the presence of a stressful experience. However Folkman (2008) acknowledged that the inclusion of generating positive emotions was just that, and it is not grounded in theory nor are positive emotions considered for their own adaptational significance in the same way as negative emotions are e.g. fight/flight response.

Although Kramer (1997a) noted that positive psychological functioning suffers from a lack of attention in the literature, one theory that does offer a more specific insight into positive and negative affect and
outcome, and their position as independent dimensions is the Hopelessness Theory of Depression (HTD) (Abramson et al., 1989). This was developed out of the reformulated model of learned helplessness (RMLH) (Abramson et al., 1978), and is a diathesis-stress model drawing on Attribution Theory (Heider, 1958; Wiener, 1986) for its understanding of the cognitive appraisal people make about themselves and events. This takes account of Heider's proposition that what is psychologically important is the way something appears to the perceiver, and the need for dispositional properties (personal or situational) to be attributed to social acts and their outcomes for the world appear stable, predictable and controllable to the perceiver.

Several dimensions of causal attribution have been suggested, including globality (does cause affect this or all outcomes - Abramson et al., 1978), although Weiner argued for only three dimensions as having theoretical and empirical support, namely: locus (internal/external); stability (temporal variance); and controllability (volitional influence of perceiver); which he said underlay all interpretations people make of situations.

HTD specifies a chain of distal and proximal contributory factors (including attributions) that interact with a negative event and are hypothesised to culminate in the sufficient and proximal cause of hopelessness that leads to symptoms of hopelessness depression (HD) - see Figure 1.
Hopelessness in this context is defined as an expectation not a symptom, whereby highly desirable outcomes are unlikely to occur or highly undesirable outcomes will occur, and that however one responds will make no difference (similar to learned helplessness). HD is suggested as particularly likely to occur when negative consequences of important events are attributed as not remediable, stable (unlikely to change) and global (affecting many areas of life). Furthermore, some people may develop a general tendency towards attributing negative events to stable and global factors and thus exhibit a ‘depressogenic attributional style’ (DAS) (the diathesis). Possession of a DAS may
increase vulnerability to HD, however in the absence of negative events, someone with DAS is no more likely than anyone else to become hopeless or develop HD. Attributional styles are suggested as lying on a continuum, thus the less negative a person's cognitive style is the more negative and salient an event needs to be to produce hopelessness. Additionally, Abramson et al. also proposed that the presence of chronic stressors or 'daily hassles' could trigger the hypothesised DAS leaving this group particularly vulnerable to hopelessness. Research by Bandeira et al. (2007) has found hopelessness to be a significant factor in the psychological distress of the caregivers of PwD.

HTD theory suggests that it is the continuing presence of hopeless expectations related to the trigger event or new events, or inferences derived from the fact that one is depressed that will determine maintenance of HD. Negative events are posited as providing a challenge to positive emotional states and hope endures when people are able to refrain from making depressogenic attributions about them, or returns if people can make stable and global attributions about positive events.

Needles and Abramson (1990) developed this further, defining an 'enhanced attributional style' (EAS) - making stable and global attributions for positive events - with the key to recovery from HD being the restoration of hopefulness. Their study which tested this model
indicated that positive events and an EAS did restore hopefulness and reduce depressive symptoms, and that this operated independently of ongoing negative events and possession of a DAS for these. Tests of the model in clinical settings and with older adults indicated recovery occurred independently of the use of antidepressant medication, with attributional style showing stability over time (Johnson et al., 1996; O'Rourke et al., 1996). Subsequently, Johnson et al. (1998) noted that making internal attributions for positive events further increased the likelihood of restoring hopefulness. More recently, Meyer et al. (2010) found that in older people attributional style explained a significant amount (7%) of the variance in depression symptoms related to life events, and the DAS was also found to interact at a lower level of stress than is apparent in young people, suggesting that a DAS may be a particular vulnerability factor for older people.

Testing of the HTD model in caregivers of PwD has found that stable and global attributions may be made by caregivers both regarding their inability to cope with role demands/stress, and about the behaviour of PwD, and that these are significantly associated with and predict depression (Coppel et al., 1985; Cook et al., 1995). In O'Rourke’s (1995) testing of HTD with caregivers of PwD he found that hopelessness was only related to stable and global attributions for negative aspects of the situation, and not to internal attributions. He argues that theoretically possessing an internal locus of control promotes one’s sense of personal responsibility for outcome,
generating the possibility of personal agency and empowerment for change which is incongruous with an expectation of hopelessness. Following this, Houston (1995) and Houston et al. (2000) suggested that self-efficacy (the belief that one can change/control an outcome) may moderate depression vulnerability of a DAS. When they used a positive intervention with housebound older people, they found that wellbeing was enhanced as predicted by HTD, with the DAS/low self-efficacy group showing greatest benefit, and surprisingly even the EAS/high self-efficacy group showing some benefit from the intervention. They concluded that whilst two people may interpret an event in the same way, it is self-efficacy that may determine impact on wellbeing.

**Finding meaning as a positive concept of caregiving**

One construct which Farran (1997) suggests may function as both a positive resource and positive outcome variable is finding meaning, and that examining this positive approach may predict the presence of positive emotional health (wellbeing). In using meaning as offering a means of understanding why it is that caregivers are often able to do so well under such difficult circumstances, Farran (1997) argued for the existential paradigm, which grounds understanding of human experience in the meanings people make of their lives, as providing a theoretical basis for this.
Existentialism regards human experience as unexplainable, because it views life as having no meanings or guidelines except for those created by individuals themselves. It recognises the phenomenological aspect of experience, as events are viewed as unique and ever-changing, and cannot be considered outside of their context (Yalom, 1980). It also addresses themes such as suffering, meaninglessness/finding meaning and hope, and emphasizes the role of free choice, responsibility and consequences of action (Frankl, 1963). Yalom (1980) observes that the absence of meaning provokes distress, and a study by Zika & Chamberlain (1992) found that meaninglessness was related to psychopathology whereas having a sense of meaning leads to positive mental health outcomes.

Frankl (1963) stated that the ultimate suffering people can endure is to lose the ability to find meaning, and that a fundamental element of suffering is powerlessness (inability to change one’s circumstances). Farran et al. (1991) identified this in caregivers of PwD as being expressed through their lack of choice about becoming a caregiver, which led to feelings of constriction, burden, hopelessness and endlessness. In line with the existential perspective, they suggested that meaning in caregiving occurs when caregivers assume responsibility for making choices about their life and caregiving and value the positive aspects of the caregiving experience, developing provisional meaning (through the transactions of everyday life) and ultimate meaning (by drawing on deeper philosophical and spiritual
beliefs/values). They also noted that the construct of provisional meaning shares much in common with Ryff's (1989) six-factor model of wellbeing.

Frankl (1963) drawing on his personal experience of being in a concentration camp observed that even when everything else has been taken away, you can still choose the attitude you take to life. Levine et al. (1984) have suggested caregivers 'live in a prison, struggle on a battlefield and languish in a concentration camp' (p.222) in what is perhaps a rather bleak view. However Farran et al. (1991) proposed that finding meaning (being able to change the manner in which you experience and respond to an ongoing negative situation) enables recovery from this, as it answers the question 'What can I make of this situation?' As Noonan et al. (1996) noted, whilst carers say they would not have chosen the situation, they are determined to make the best of it, and suggested meaning may have strong connection to why caregivers persevere in their role.

Pennebaker (1997) observed that people need to search for meaning to help them understand traumatic and painful events. In a qualitative study by Ayres (2000) she suggested that the construction of meaning allows caregivers to manage and respond to situations flexibly, as meanings represent the explanations that caregivers construct to integrate their caregiving experience with general meanings of life and that these provide the link between caregiver expectations e.g.
ordinariness or burden of situation and the strategies used to cope with it.

Noonan et al. (1996) acknowledged that the construct of meaning has suffered from a lack of conceptual clarity, which may reflect the complex nature of it. They suggest that it may be a multi-dimensional construct containing at least a cognitive and emotional component as evidenced in Giuliano et al.'s (1990) definition 'positive beliefs one holds about one's self and one's caregiving experience such that some gainful outcomes are construed from it' (p.2). Noonan & Tennstadt (1997) using Guiliano et al.'s (1990) Meaning in Caregiving Scale found that meaning in caregiving was negatively associated with symptoms of depression and positively associated with self-esteem. Additionally, they also found that caregivers could report high burden whilst also gaining meaning from caregiving supporting the notion of these as independent dimensions, and that meaning is not simply a reframe of negative events. Meaning was also not found to be related to objective stressors, and thus rejected by them as a mediator of stress. Interestingly, they found coping response was unrelated to depression, which is at odds with the literature. Noonan et al. (1996) previously observed that coping is the widely cited mediating factor used to explain individual differences in caregiving response to stress and wellbeing outcomes.
Farran (1997) argued that whilst a stress/adaptation perspective tends to focus on identifying discrete stressors, the existential paradigm speaks to the overall effect of the caregiving experience. For instance Farran et al. (1991) found that 77% caregivers chose to develop more positive attitudes towards caregiving and to appreciate the positive aspects of life more. Farran notes the existential perspective assumes that positive and negative aspects have a dialectical relationship which supports their simultaneous existence (e.g. hassles and uplifts - Kinney & Stephens, 1989), and whereas stress/adaptation models view cognitive appraisal as re-interpretation, existentialism views this as being transformational.

Farran et al. (1999) observed that research and understanding of positive aspects of caregiving has been hampered by the lack of theoretically grounded and psychometrically sound measures that would enable systematic assessment. Based on the qualitative reports gathered by Farran et al. (1991), they developed and tested a new instrument - Attitudes Towards Caregiving - to measure meaning in caregiving as grounded in existential theory, as a means of assessing the positive aspects of caregiving. This was found to be valid and reliable. Consistent with previous research, meaning was found to be negatively associated with depression. They therefore suggested that this measure should prove useful for future research which focuses on why or how caregivers do so well in spite of the difficulties they face,
and may have clinical applications regarding identifying caregiver strengths and potential areas for intervention.

**Present Study**

To date, the HTD model does not appear to have been researched in relation to the positive aspects of caregiving, yet it offers a mechanism by which the moderating effect on wellbeing of both positive and negative aspects might be understood. Level of depression symptoms are therefore used as the outcome measure, however the aim is to consider positive psychological functioning due to the absence of these in respect of a positive aspect of caregiving, namely finding meaning. The aim was to build on previous research, and consider the explanatory potential of the HTD model regarding the simultaneous holding of positive and negative feelings about caregiving, and how this might help answer the question of why many caregivers do well despite their stressful circumstances.

Based on HTD theory, it was hypothesised that:

1. Hopelessness, as a measure of negative aspects of caregiving (and a potential indicator of a DAS) would be positively associated with depression symptoms.
2. Finding meaning in caregiving as a measure of positive aspects of caregiving (and a potential indicator of an EAS) would be negatively associated with depression symptoms.

3. Finding meaning and hopelessness will be negatively associated with each other.

4. If finding meaning and hopelessness represent independent responses to positive and negative aspects of caregiving, then they should each account for some of the variance observed in depression symptoms.

5. The ATCFM may have clinical utility for predicting caregiver wellbeing and assessing vulnerability to depression.
Method

Study Design

This study used a quantitative survey method with self-completion questionnaires. This approach was taken, with the aim of testing the theories and hypotheses from previous research, and to consider how the current findings might add to the development of the theoretical framework. Surveys provide a standardized method of administering and collecting data, with postal surveys offering participants time-efficiency and convenience benefits (Sapsford, 2001). This was an important consideration given the demands on caregivers. It was hoped that these benefits, and the ability to reach a larger sample of the target population might result in a more inclusive range of caregiving experiences being collected. Anonymity was also guaranteed to reduce potential influences from the ‘socially desirable’ responses sometimes elicited when researching sensitive issues (Sapsford, 2001).

A within-subjects, cross-sectional, correlation design was used, with participants only being approached once. It was non-experimental, as no variables were manipulated or controlled by the researcher (Yeats, 2004). However as with any quantitative methodology, it relied on the underlying assumptions of variables being observable, identifiable, stable, and measurable (numerically) and thus reportable on (Barker et al., 2002, Marks, 2004). Also implied is the researcher’s position as
detached, impartial and objective (Yeats, 2004), although as Smith (2003) cautions, research is never truly value free.

As with all research, there are inevitably some design limitations. For instance, events in participants' lives may overly influence results, causal inferences will not be deducible, and non-response rates might affect sample representativeness limiting the generalisability of findings (Yeats, 2004). Despite this, Marks (2004) suggests that when measuring psychological states and health status this design represents a good methodology to use. It can still allow for a consensus to be arrived at, which Creswell (2009) noted contributes to existing theory and may extend our understanding and ability to explain and predict the phenomena involved.

**Participants (sample)**

Participants were recruited from two sources: a Memory Clinic covering a town with a large rural area (Site B) and a Memory Clinic located within a city area (Site H). The researcher collaborated with clinic staff to identify caregivers known to the clinics that might represent potential participants. The following criteria were used:

**Inclusion criteria**

All participants were:

- adults aged 60 and over
- the spouse/partner of a person diagnosed as having dementia (any type)
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- permanently living with, and providing unpaid care to their spouse/partner
- in possession of adequate English language skills for the demands of the study

Exclusion criteria

- Caregivers who fulfilled the inclusion criteria but had cognitive problems themselves
- Caregivers who were physically frail
- Caregivers who were not the spouse/partner e.g. other family members.

These criteria were chosen with a view to obtaining a sample group where caregiving was likely to be playing a key role in peoples' lives, with the potential for influencing wellbeing. By using restrictions such as participants being of retirement age and caregiver poor health, it was hoped to limit the presence of additional stressor factors e.g. managing employment, caring for children, that might complicate the picture when considering the caregiving role as an explanatory factor for any observed instances where wellbeing appeared to be low.

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1 As the research was reliant upon self-report measures, this criterion was deemed necessary. The involvement of the researcher or an interpreter would have compromised anonymity/confidentiality, and possibly elicited socially desirable responses. Interpreted (and psychometrically sound) versions of the scales were not available.

2 This was to exclude offspring as carers, as their relationship to the PwD and other competing demands may result in different perspectives and stresses. Confounding or other variables may have arisen which were beyond the scope of the present study to consider.
A total of 220 potential participants were identified and each were sent the study pack and invited to participate. Of these, 55 were returned representing a response rate of 25% (but two were later removed due to incompleteness). Consensus appears lacking regarding what constitutes a good response rate to postal surveys. Sitzia & Wood (1998) stated that even 30% might be viewed as 'reasonable' with 50% being 'quite high'. They cautioned that the key implication to consider is response bias, as non-respondents are typically more likely to be people who have a lower health or socioeconomic status, and/or who are less satisfied with care received. Irrespective of sampling difficulties, Denscombe (2007) recommended 30 as a minimum but sufficient sample size on which statistical analysis could be performed and valid findings produced, but cautions about the generalisability of findings from small samples.

Given the demands on caregivers' time and the largely indirect benefits to them from participating in this study, the response rate of 25% was probably quite reasonable. The number of participants was sufficient to meet Denscombe's criteria. From the participants demographics summary (Appendix 5) it can be observed that these were roughly similar across both sites, and for instance the gender split of approximately two-thirds female, one third male, is in line with that found in other older caregiver research (Innes, 2009, NHSIC, 2010). Some factors did contain low frequency categories, e.g. caregiver
physical and mental health, so potential response bias was born in mind when considering findings.

**Procedure**

The researcher initially contacted a Memory clinic with whom he had previously worked, who were agreeable to sponsoring the study. A second clinic also volunteered to participate on hearing of the study via the Trust Research & Development Manager. When considering study recruitment, one major issue was the infrequency with which potential participants attended the clinics, and the limited number who attended the Carers Support Groups available. Internet use was not typical either. It was determined that writing to caregivers directly might offer the opportunity to participate to the widest range of caregivers and potentially maximize the breadth of experiential data captured.

A Participant Information Sheet (PIS) (Appendix 1) and five questionnaires (Appendix 3) were used. Flesch-Kincaid Readability Scores (Word 2003) were calculated and reading ease scores ranged from 56 to 71 making them understandable to anyone with a general secondary level education, and thus accessible to the study group. The questionnaires (including the Beck Hopelessness Scale (BHS) - Beck *et al.*, 1974) were piloted with some caregivers known to the researcher. Feedback was obtained, with caregivers reporting the questionnaires as feeling relevant, easy to understand and causing them little or no distress to complete. As the pilot group preferred the GHS, which was
specifically developed and validated for use with older people, this was selected as the measure for hopelessness. Feedback was also obtained from some Clinic Staff and an Alzheimer’s Society Support Worker. The pilot group suggested a 35-45 minute completion time for the questionnaires, but given the possible variability amongst caregivers regarding stresses, reading and thinking skills, the one hour guide time provided to participants was anticipated as a more realistic estimate.

Potential participants identified in conjunction with clinic staff, were sent the study pack. This included the invite letter (Appendix 2), which directed them to read the PIS, and to complete and return (in the envelope provided) the five questionnaires if interested in participating. Returning the completed questionnaires was advised as implying informed consent to participate, with anonymity precluding subsequent withdrawal from the study. No caregiver (or patient) information was retained for study purposes by the researcher (or the clinics), so only data disclosed and collected from participants was available for inclusion in the analysis.

**Measures**

There were five questionnaires to complete. The possibility of order effects was considered, with some questionnaires requiring reflection on negative aspects that could potentially lower affective state and influence responses to subsequent questionnaires. To try and control for this, the order in which questionnaires were stapled together was
rotated, (although the PPIQ was always first). Whether participants actually completed them in this order could not be controlled for. Chance also determined which questionnaire orders would be returned, however the final sample did reveal a fairly representative selection of these.

Consideration was also given to the impact that the Questionnaire titles might have on participants. This was both in terms of whether words like 'geriatric' might be interpreted as insulting, especially by the younger participants, and whether words like 'hopelessness' might be upsetting. As these factors had the potential to put people off participating, or possibly introduce a conscious or unconscious response bias in resisting the label suggested by such terms, the main measures had their titles replaced with initials as their heading e.g. GHS Questionnaire to control for this possibility. Each questionnaire was provided with brief on how to complete it.

1. *Participant Personal Information Questionnaire* - PPIQ

*(demographics questionnaire)*

This was a non-standardized questionnaire developed by the researcher to collect demographic information about the participants. The first part asked them questions about themselves e.g. age, gender, the second part about the person they cared for e.g. dementia type and severity, and the third part about their role as a caregiver e.g. time spent caring, help or support received. Answers were indicated by
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circling the relevant option e.g. yes/no, or providing an appropriate number e.g. age. This information enabled subsequent analysis of significant differences in the sample regarding demographic factors.

2. *Attitudes Towards Care-giving Questionnaire (ATCFM)*

This questionnaire was used as a measure of the positive aspects of the care-giving experience. It is a 43-item self-completion questionnaire, consisting of statements about the impact that dementia and caring can have on people's lives, e.g. 'I am sad about losing the person I once knew', 'Care-giving makes me feel that I am helping'. Respondents indicated their level of agreement using the qualitative 5 point scale which ranged from 'strongly disagree' (1) to 'strongly agree' (5). A Total Finding Meaning (TFM) score is then obtained in the range 0-215.

Three sub-scales are also generated:

- **Provisional Meaning (ATCpm)** - 19 items that give a score range of 0-95 for the meaningfulness with which caregivers might view their role.

- **Loss/Powerlessness (ATClp)** - 19 items that give a score range of 0-95 for how they feel about the losses they and their relative have incurred (reverse scored).

- **Ultimate Meaning (UM)** - 5 items that give a score range of 0-25 about the impact of a caregivers' spiritual beliefs.

The ATCFM was developed by Farran *et al.* (1999) to be a psychometrically sound measure for examining the positive aspects of
care-giving. Its purpose was to assist clinicians in identifying caregiver strengths and difficulties, and use this to inform support and interventions based on developing positive aspects. Questionnaire items were derived from qualitative interviews and factor analysis of an initial 135 item measure by Farran et al. (1991). Reliability was established for both ATCFM and the subscales, and internal consistency and Test-retest reliability was found to be good, with Cronbach's alpha and correlation coefficients for each scale as follows: ATCFM ($\alpha=0.91$, $r=0.8$), ATCpm ($\alpha=0.88$, $r=0.85$), ATClp ($\alpha=0.89$, $r=0.85$), UM ($\alpha=0.91$, $r=0.89$). Factor analysis established construct validity with a Goodness of Fit Index of 0.763. Comparison to similar measures and caregiver variables e.g. marital satisfaction suggested convergent validity for each of the subscales, with discriminant validity being demonstrated through finding the hypothesized inverse relationships between the subscales and scores on the other unrelated measures, were significant ($p<0.01$).

Since this study, no other (published) research appears in relation to using the ATCFM. This study aimed to use the ATCFM as a measure of the positive aspects of caregiving in relation to depression theories and outcomes in caregiver wellbeing, and to consider its clinical utility regarding the prediction of caregiver vulnerability to depression. Unfortunately, due to objections raised by the NHS Ethics Committee on the grounds of religious diversity, the UM component had to be removed. As there was psychometric data to support the reliability and
validity of the individual components, removing this was not viewed as problematic for the study aims. Indeed as society becomes more diverse, psychometric measures may need to reflect this better, and this presented the opportunity to consider the validity of a more secular orientated version of ATCFM.

3. Geriatric Hopelessness Scale (GHS)

This measure was used to assess hopelessness. It is a 30 item self-completion questionnaire, consisting of 15 positive and 15 negative self-statements, rated as true or false. Scoring is true=0 and false=1 for positively phrased statements, and reversed for negatively phrased statements. The score range is 0-30, where higher scores indicate increasing levels of hopelessness. Levels of hopelessness are suggested as: 1-10 = Low; 11-19 = Moderate; and 20-30 = High, but with no statistical or theoretical foundation cited for this.

This measure was developed by Fry (1984) as an extension to the BHS scale developed by Beck et al. (1974). This work was based on the notion that hopelessness was a possible correlate of depression, given the negative expectancies towards self and the future implied in this psychological construct. Fry designed the GHS to be more applicable to older people based on Erickson’s life stages model which suggests that older might tend to feel more pessimistic about the future. Structured interviews with 60 older people (age 65+) combined with factor analysis highlighted four major factors, and the 15 items with the highest factor
loadings were used to develop the 30 item scale. This was then administered to a further 78 older people (age 60-80), from a non-clinical population. Reliability was demonstrated with a Cronbach’s alpha of 0.69 (p<0.01), and acceptable internal consistency was indicated by Spearman-Brown’s split-half correlation co-efficient of r=0.73. Comparison to other measures demonstrated good concurrent validity. As expected, scores on the GHS were significantly positive correlated to depression measures (GDS r=0.49, p<0.01; and RBD r=0.29, p<0.05). No statistically significant differences were found based on demographic variables.

A more recent validation study on the GHS by Heisel & Flett (2005), with a sample of 78 older people age range 68-98, again reported it to have acceptable internal consistency (α=0.78). They also performed factor analysis on the GHS, and identified three factors: Fatalistic Hopelessness (FH), Interpersonal Hopelessness (IH) and Spiritual Hopelessness (SH). Construct validity was again demonstrated for the GHS and these factors, and they noted that unlike the BHS, the GHS included the domain of interpersonal hopelessness. They agreed with Fry, that the GHS does not differentiate the presence of a mental health condition, however found that the IH factor can, leading them to suggest a strong link between negative interpersonal cognitions and clinically significant psychological difficulties.
Some limitations are noted regarding use of the GHS. Both studies had relatively small sample sizes that were predominantly female (but perhaps reflective of the gender imbalance in this population group). However given the suggested role of both FH and IH factors in the well-being of older adults (Heisel & Flett, 2005), and the adversity faced by caregivers, this made the GHS a relevant and appropriate measure to use.

4. Patient Health Questionnaire (PHQ)

This measure was used to assess well-being in caregivers, based on the presence/absence of depressive symptoms. The PHQ-8 version used in this study is identical to the PHQ-9 but with the suicidal ideation question removed. Kroenke & Spitzer (2002) reported that for research particularly, where mailed questionnaires are used, suicide risk is low, or depression is a secondary outcome measure, then it is reasonable to remove this item, without significantly affecting the psychometric properties of the questionnaire.

The PHQ-9 is a 9-item self-completion questionnaire, consisting of symptom statements which are directly related to each of the criteria in DSM-IV (APA, 2000) used to diagnose depression. Respondents indicate to what extent they have been bothered by these problems over the last two weeks using a 4 point frequency scale, ranging from 0 (Not at all) up to 4 (nearly every day). Total scores range from 0 to 27. A diagnostic cut-off score of 10 or more indicates major depression.
Other diagnostic thresholds are defined as: 0-4=none; 5-9=mild; 10-14=moderate; 15-19=moderately severe; and 20-27=severe.

This measure was developed by Kroenke et al. (2001) as a quick completion instrument for assessing severity and delivering diagnostic accuracy regarding mental health. It was initially trialed with 3000 primary care patients aged 18+, and analysis of covariance indicated that age or gender did not significantly influence scores. Reliability was assessed, with Cronbach’s alpha of 0.89 suggesting good internal consistency. Test-retest reliability was demonstrated by comparison to a Mental Health Practitioner (MHP) administered PHQ-9 with 48 hours and gave a correlation value of r=0.84. Validity was also assessed against independent diagnosis by a Mental Health Practitioner (MHP) blind to their PHQ-9 score. Criterion validity was established through finding that 88% of patients with a PHQ-9 score of 10 or more (caseness threshold) had been independently diagnosed with major depression. ROC (receiver operating characteristic) analysis, gave a value of 0.95 which Kroenke et al. said indicated both good clinical case discrimination, and that no other measure was likely to perform significantly better than PHQ-9.

With depression as the outcome measure of caregiver wellbeing based on HTD theory, the PHQ was chosen as the means of measuring this as it relates directly to the symptoms of depression, is brief and easily completed. It enabled the measurement of symptom levels in order that
their relationship with other factors could be explored, as well as distinguishing for clinical caseness against which the prediction of depression vulnerability risk on other measures might be considered. It is widely used by clinicians, especially as a screening tool in primary care, and has been demonstrated as an effective assessment tool across all ages, genders, and settings (including non-clinical populations) making it suitable for use here.

5. Coping Skills Inventory (CSI)
This measure was used to assess caregivers' general life coping skills. It is a 45-item self-completion scale consisting of positively and negatively worded statements about personal responses to situations. Qualitative descriptions about response tendency are converted to scores on a 5 point scale, ranging from 0 (almost never) to 4 (most of the time). This gives a total coping score range of 0-100, where higher scores indicate increased coping skills. Additionally it generates seven subscales: reactivity to stress; ability to assess the situation; self-reliance; resourcefulness; adaptability and flexibility; proactive attitude; and ability to relax.

This measure was developed by Jerabek (1996) using an internet recruited sample of 811 people, age range 16-72. Reliability was assessed as good, with a Cronbach's alpha of 0.94, and a Spearman-Brown split-half correlation co-efficient of $r=0.94$ indicating good internal
consistency. The test has not been validated against other measures, but does appear to have face validity.

Coping skills do not just apply to the caregiving situation, but are developed and used in life generally. Caregiving is part of the complexity of life, and this study wanted to take a more holistic approach to measuring the coping skills a caregiver perceives they have at their disposal. Many coping-style measures can narrow the focus to the caregiving situation, which may not reflect the range of coping skills that caregivers apply in everyday life that could also influence wellbeing vulnerability. The CSI appeared to offer a suitable tool for achieving this.
Statistical Analyses

Sample size calculation

Field (2009) noted that sample size will depend on the level of the effect size (strength of relationship) a study hopes to detect. He suggested that effect sizes obtained in previous research may provide a guide to sample size, however the main outcome measure for this study (PHQ) used sample sizes beyond the recruitment ability of this study, as did ATCFM. Field observes that it is possible to calculate the required sample size for a study using estimates of effect size, along with knowledge of two other parameters: alpha (the chance of incorrectly believing an effect has been observed (usually set at 0.05), and beta (the test power and probability that an effect will be correctly detected if it exists). Cohen (1992) recommended a power level of 0.8 (80% chance of detecting an effect) should be aimed for. However as effect size decreases, an increasing sample size is required to retain the same power. Psychological research often involves a balance between constraints on recruitment with the clinical need to explain the variance or relationships, so a medium effect size (r=0.3) represents a common compromise position. In order to determine an appropriate sample size for the statistical analyses proposed in this study, *a-priori* power calculations were conducted using the G-Power 3 software (Faul *et al.* 2007), and are shown in Table 1.
Table 1. *Showing the number of participants predicted to be required to obtain given effect sizes*

<table>
<thead>
<tr>
<th>Effect size</th>
<th>Correlation</th>
<th>Effect size</th>
<th>Regression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>One-tailed</td>
<td>Two-tailed</td>
<td>No. of predictor variables</td>
</tr>
<tr>
<td>Medium</td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>$r=0.3$</td>
<td>64</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>Large</td>
<td>21</td>
<td>26</td>
<td></td>
</tr>
</tbody>
</table>

Regression analysis potentially required the largest sample, however it was anticipated that response rates might be low given carer stresses. Brace *et al.*. (2003) suggested that an absolute minimum number required for multiple regression is five times more participants than predictor variables, although cited a 10:1 ratio as more acceptable. Given the sample size calculations a sample of around 50-90 participants was aimed for, however failing this, 30-40 participants might still represent sufficient size for meaningful analysis to be performed.

*Choosing statistical tests*

Psychological research is most interested in findings that can be commented upon in relation to a particular population, however as we cannot collect data from everyone, if a smaller study sample can be shown to be representative of this population then this may enable findings in them to be generalised. Parametric tests are advisable for
this, and are generally regarded as the more robust and powerful means of analysing sample data and better able to detect real effects and differences if they are there (Field, 2005). However in order for inferences about research to be valid, it is necessary to ensure that the assumptions of parametric tests (normally distributed, homogeneity of variance, interval level of measurement and independence) are met.

Assessing for assumptions of parametric tests

Data were analysed using the Statistical Package for Social Sciences (SPSS, version 18.0). Initial checks were made for errors in data entry, and missing data. The presence of outliers was explored through plotting box-plots, and z scores calculated to see if these were significant. However those found were with normal limits and none were extreme \( (z>3.29) \) so they were retained unchanged. Data distribution was examined for normality including the use of the Kolmogorov-Smirnov test which suggests data are not normally distributed if significant \( (p<0.05) \). Homogeneity of variance was assessed using Levene's test, where significance \( (p<0.05) \) indicates inequality of variance in the group. Had analysis of the study data been found to be significant for these tests then this would have indicated a violation of the assumptions of parametric testing, and required the use of non-parametric tests. However as this was not the case analysis proceeded using parametric tests.
Statistical analysis of hypotheses

Hypothesis 1: the predicted association between hopelessness and depression was analysed by computing Pearson's rho for GHS and PHQ scores. Consideration was also given regarding whether to exclude the spirituality questions on the GHS.

Hypothesis 2: the predicted association between finding meaning and depression was analysed by computing Pearson's rho for ATCFM and PHQ scores. Consideration was also given to the relationship between finding meaning (ATCFM scores) and depression severity/caseness using Spearman's rho due to categorical nature of this data.

Hypothesis 3: the predicted association between finding meaning and hopelessness was analysed by computing Pearson's rho for ATCFM and GHS scores. The relationship between the components of ATCFM and GHS was also considered.

Hypothesis 4: the possible independence of hopelessness and finding meaning in predicting depression outcomes was analysed using hierarchical linear regression. With PHQ score as the dependent variable, the entry order of GHS, ATCFM and CSI scores into the model was based on theoretical considerations derived from HTD and CTSC theory. The model was then examined for its significance and whether any variables made a significant unique contribution suggestive of an independent effect.
**Hypothesis 5:** the possibility of using the ATCFM to predict depression vulnerability was explored by using K-means clustering and linear regression to establish relevant ATCFM scores when PHQ score was 10 (caseness cut-off). Predictive validity of the proposed values was investigated through the use of 2x2 contingency tables.

**Ethical considerations**

In all research with human participants, researchers have a primary duty of care, especially in protecting participants from harm (physical or psychological). Such ethical principles for good research are laid down in the Declaration of Helsinki (WMA, 1964). At all times, the researcher, his supervisors and research assistants, sought to conduct the research in accordance with these principles, and other relevant good practice guidelines for research e.g. BPS (2005). Ethical approval was sought from and granted by three relevant Committees – NHS Ethics, University of Surrey and NHS Research & Development (Appendix 4). Supervision was used to reflect on any issues that arose.

Participants were provided with written information about the study, in sufficient detail for them to make an informed decision about participating. No deception was involved, although questionnaires titles were removed with psychological wellbeing in mind. Participants were provided with a contact number for the researcher if they had any questions about the study. Anonymity was guaranteed, with questionnaire packs being non-identifiable, and carers were under no...
obligation to complete them. However they were cautioned that returning completed questionnaires implied informed consent to participate, and that later withdrawal was not possible due to response anonymity.

Asking people to reflect on their experiences of caring for someone with dementia is a potential sensitive and emotive topic, and has the potential to provoke distress. Although the participants in the pilot study indicated that this was not the case for them, people vary in the ease with which they are able to accept and cope with their relative's diagnosis, and the changes and demands this can bring for both of them. The questionnaire design did restrict to a more predictable range, the level of thought and reflection required by participants, with possible responses limited to multiple choice options regarding agreement with a given statement. This meant there was no scope for the disclosure of any criminal or abusive acts, but responses might have revealed a participant was experiencing a high level of psychological distress. As this study was conducted on an anonymous basis, the researcher could not be present to directly monitor this, and to either stop the process or offer support to the participant. To discharge this duty of care, warnings were given in the instructions that alerted participants to this possibility and to stop if they found themselves becoming upset. Details of appropriate people and agencies they could contact for support should this occur were provided.
Results

Description of the sample

Table 2a – Summary of carer socio-demographic information

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency</th>
<th>Percentage of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16</td>
<td>30.2</td>
</tr>
<tr>
<td>Female</td>
<td>37</td>
<td>69.8</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>15</td>
<td>28.3</td>
</tr>
<tr>
<td>70-79</td>
<td>16</td>
<td>30.2</td>
</tr>
<tr>
<td>80+</td>
<td>22</td>
<td>41.5</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>53</td>
<td>100</td>
</tr>
<tr>
<td>Other</td>
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<td>0</td>
</tr>
<tr>
<td>Religious faith</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>48</td>
<td>90.6</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>9.4</td>
</tr>
</tbody>
</table>

Table 2b – Summary of carer circumstances demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency</th>
<th>Percentage of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>25</td>
<td>47.2</td>
</tr>
<tr>
<td>Fair</td>
<td>26</td>
<td>49.1</td>
</tr>
<tr>
<td>Poor</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Mental Health Problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>No</td>
<td>52</td>
<td>98.1</td>
</tr>
<tr>
<td>Length of time known PwD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-19</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>20+</td>
<td>52</td>
<td>98.1</td>
</tr>
<tr>
<td>How long been a carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-1.11 years</td>
<td>13</td>
<td>24.5</td>
</tr>
<tr>
<td>2-3.11 years</td>
<td>20</td>
<td>37.5</td>
</tr>
<tr>
<td>4 years+</td>
<td>20</td>
<td>37.5</td>
</tr>
<tr>
<td>Time spent caring (hrs per day)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-3 hours</td>
<td>4</td>
<td>7.5</td>
</tr>
<tr>
<td>4-6 hours</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>7 hours+</td>
<td>40</td>
<td>75.5</td>
</tr>
<tr>
<td>Family support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>46</td>
<td>86.8</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>13.2</td>
</tr>
<tr>
<td>Professional support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25</td>
<td>47.2</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>52.8</td>
</tr>
</tbody>
</table>
Table 2c – Summary of PwD demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency</th>
<th>Percentage of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity of dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>12</td>
<td>22.6</td>
</tr>
<tr>
<td>Moderate</td>
<td>26</td>
<td>49.1</td>
</tr>
<tr>
<td>Severe</td>
<td>14</td>
<td>26.4</td>
</tr>
<tr>
<td>Not stated</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Type of dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AD</td>
<td>24</td>
<td>45.3</td>
</tr>
<tr>
<td>VAD</td>
<td>11</td>
<td>20.8</td>
</tr>
<tr>
<td>PDD/DLB</td>
<td>3</td>
<td>5.7</td>
</tr>
<tr>
<td>Mixed</td>
<td>11</td>
<td>20.8</td>
</tr>
<tr>
<td>Other/not known</td>
<td>4</td>
<td>7.5</td>
</tr>
<tr>
<td>Time with dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-1.11 years</td>
<td>11</td>
<td>20.8</td>
</tr>
<tr>
<td>2-4.11 years</td>
<td>25</td>
<td>47.2</td>
</tr>
<tr>
<td>5 years+</td>
<td>17</td>
<td>32.1</td>
</tr>
<tr>
<td>No. of non-cognitive problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>3</td>
<td>5.7</td>
</tr>
<tr>
<td>1-2</td>
<td>12</td>
<td>22.6</td>
</tr>
<tr>
<td>3+</td>
<td>38</td>
<td>71.7</td>
</tr>
<tr>
<td>Can be left alone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>35</td>
<td>66.0</td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>30.2</td>
</tr>
<tr>
<td>Not stated</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>Requires help with physical health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>32</td>
<td>60.4</td>
</tr>
<tr>
<td>No</td>
<td>21</td>
<td>39.6</td>
</tr>
</tbody>
</table>

This study was conducted across two sites. Demographic information for each site is presented in Appendix 5. This indicated a high level of similarity between the groups, so their data has been combined for the purpose of analysis and hypothesis testing and is summarised in tables 2a, 2b and 2c.

The study sample consisted of 53 carers, of whom approximately two-thirds were female and one-third male. Their ages ranged from 60 to 88 years, with a mean age of 75 and median of 78. All respondents indicated White British as their ethnicity (although participation was open to all ethnic groups if people met inclusion criteria), with approximately 90% reporting having a religious faith. All carers were
living with the PwD, and were in a spousal/partner relationship with them.

Data screening

Missing data

Initial data screening resulted in 2 of the original 55 participants being removed owning to insufficiencies in the completion of their questionnaires.

Outliers & Distribution

Data provided by the main study domains was checked for outliers (with entries being verified) and for normal distribution, both visually (box-plots, histograms) and by using statistical tests. As the sample size was relatively small, alpha was set at 0.05, with z scores above 1.96 being considered significant.

Finding Meaning (ATCFM)

Inspection of the box-plots indicated two significant outliers (z=-2.11, p<0.05, & z=-2.20, p<0.05). Comparison was made between the Mean (M=117.79) and the 5% Trimmed Mean (TM=117.97) indicating them to be similar. The Kolmogorov-Smirnov Test indicated scores were normally distributed [D(53)=0.466, p=0.981].

Hopelessness (GHS)

Inspection of the box-plots indicated three outliers (z=2.89, p<0.01 & z=2.44, p<0.05 - two occurrences). Comparison was made between the
Mean (M=6.09) and the 5% Trimmed Mean (TM=5.77), indicating some degree of similarity. The Kolmogorov-Smirnov Test indicated scores were normally distributed [D(53)=0.953, p=0.322].

Depression (PHQ)
Inspection of the box-plots indicated no outliers. The Kolmogorov-Smirnov Test indicated scores were normally distributed [D(52)=1.092, p=0.184]

Coping skills (CSI)
Inspection of the box-plots indicated no outliers. The Kolmogorov-Smirnov Test indicated scores were normally distributed [D(53)=0.743, p=0.64].

Screening conclusions
Although some of the data sets indicated the presence of outliers, this is perhaps not unexpected. In a normal distribution 5% might be expected to have z values above 1.96, with 1% above 2.58 (Field, 2009). The number of outliers found falls within these parameters, and none could be considered extreme (z>3.29). Comparison of Mean and 5% Trimmed Mean indicated little difference between them, suggesting only marginal impact of outliers on mean scores. In a larger sample with an increased range of scores these outliers might not have appeared as such. Given this, and the fact that data was collected from the intended sample group, it was decided to retain these values unchanged, but to bear this in mind during subsequent analysis.
The data was normally distributed, and the results of Levene’s Test were not significant, indicating homogeneity of variance in the data. The assumptions for using parametric tests appeared to be met, and data analysis proceeded accordingly.

Assessment of the measures

The reliability of the measures used in the sample was assessed by calculating Cronbach’s alpha for each questionnaire. The PHQ, GHS and CSI yielded reliability coefficients of 0.86, 0.71 and 0.95 respectively, which were comparable to those reported by the original study authors of 0.89, 0.69 and 0.94. As these exceeded the suggested cut-off point of 0.7 (Field 2009) this indicated these measures to be reliable.

The ATCFM was also found to be reliable, yielding a coefficient of 0.94 (original study 0.91), thus appeared to be unaffected by the removal of the UM component. Field (2009) also stated that where a measure contains components these should also be checked for reliability.

Assessment of ATCpm and ATCIp yielded coefficients of 0.9 (0.88) and 0.93 (0.89) respectively, again indicating reliability.

As the ATCFM could not be used in its entirety, construct validity was re-assessed. The original study utilised confirmatory factor analysis (CFA) to assess this, however it was not possible to use this method in the current study due to software access issues. Whilst factor analysis
is more conventionally used for this type of evaluation, principle components analysis (PCA) also offers a way of examining the structure of a measure. Thompson (2004) notes that the only real difference between using PCA and CFA lies in the inclusion and exclusion of shared variance when calculating factor loadings. Whilst this study had less than the 150 minimum cases recommended by many authors e.g. Tabachnick & Fidell (2007), Nunnally (1978) recommended that the ratio of participants to factors (minimum 10:1) is what is important, and this was met. The correlational matrix demonstrated good inter-correlation between items (coefficients >0.3), and ATCpm demonstrated a significant strong negative correlation with ATCip (r=-0.558, n=53, p<0.001, effect size r²=0.32) as expected. Bartlett’s test of sphericity was significant (p<0.001), and the KMO index was >0.6 (0.612). This suggested suitability for conducting PCA, especially since the aim was to demonstrate replication.

It was expected that only two components would be identified. This was confirmed visually from the scree test, although Kaiser’s criterion reported 9 components with an eigenvalue of 1 or more. However parallel analysis using criterion eigenvalues generated by the Monte Carlo software (Watkins, 2000) (see Appendix 9), indicated only two components should be retained. Item component loadings were then compared to the original study data, which confirmed that items in this study did similarly load onto Farran et al’s original factors, suggesting construct validity of the ATCFM had been retained.
Preliminary data analysis

Initial analysis was performed on the measures according to socio-demographic, caring or PwD factors, to see if these resulted in any significant differences. As assumptions for parametric testing were met, the relevant Independent t-test or One-Way ANOVAs (with post-hoc Tukey’s test) were used. Significance data is summarised in Table 3 (see Appendix 6 for full statistical data).

Table 3 – Showing significance results for factors considered in preliminary data analysis

<table>
<thead>
<tr>
<th>Factor</th>
<th>ATCFM (p)</th>
<th>GHS (p)</th>
<th>PHQ (p)</th>
<th>CSI (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>.226</td>
<td>.921</td>
<td>.528</td>
<td>.101</td>
</tr>
<tr>
<td>Age</td>
<td>.677</td>
<td>.115</td>
<td>.216</td>
<td>.808</td>
</tr>
<tr>
<td>Religious Faith</td>
<td>.477</td>
<td>.228</td>
<td>.888</td>
<td>.776</td>
</tr>
<tr>
<td>Carer physical health</td>
<td>.558</td>
<td>.061</td>
<td><strong>.005</strong></td>
<td><strong>.030</strong></td>
</tr>
<tr>
<td>Time in role as carer</td>
<td>.468</td>
<td>.188</td>
<td>.638</td>
<td>.934</td>
</tr>
<tr>
<td>Hours per day caring</td>
<td>.338</td>
<td>.679</td>
<td>.083</td>
<td>.636</td>
</tr>
<tr>
<td>Family support</td>
<td>.965</td>
<td>.882</td>
<td>.346</td>
<td>.687</td>
</tr>
<tr>
<td>Professional support</td>
<td>.076</td>
<td>.372</td>
<td>.392</td>
<td>.617</td>
</tr>
<tr>
<td>Dementia severity</td>
<td><strong>.006</strong></td>
<td>.878</td>
<td>.074</td>
<td>.775</td>
</tr>
<tr>
<td>Dementia type</td>
<td>.397</td>
<td>.587</td>
<td>.199</td>
<td>.435</td>
</tr>
<tr>
<td>Time with dementia</td>
<td>.272</td>
<td>.376</td>
<td>.229</td>
<td>.878</td>
</tr>
<tr>
<td>No. Cognitive problems</td>
<td>.818</td>
<td>.357</td>
<td>.914</td>
<td>.117</td>
</tr>
<tr>
<td>PwD can be left alone</td>
<td><strong>.035</strong></td>
<td>.353</td>
<td>.177</td>
<td>.847</td>
</tr>
<tr>
<td>PwD requires help for physical health</td>
<td>.206</td>
<td>.495</td>
<td>.189</td>
<td>.132</td>
</tr>
</tbody>
</table>

*Indicates significance at p<0.05; **at p<0.01

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**Socio-demographic factors**

By reference to Table 3, it can be observed that there were no significant differences for any of the study measures based on gender, age or religious faith. As only members of one ethnic group appeared to have participated, this could not be analysed or commented on.

**Carer circumstances demographics**

Unfortunately, several of the factors had categories that contained a frequency of one rendering analysis impossible. This was particularly disappointing for mental health problems, where comparison of scores between carers with and without a diagnosed mental health condition, especially depression (as self-reported), could not be considered.

Caregiver physical health also had one category with a frequency of one, namely 'poor'. It was not known whether this carer might fall into the exclusion criteria of 'physically frail', so their data was retained in the study, but it was thought inappropriate for combining with the 'okay' category in case it represented qualitatively different perceptions about health, and led to a skewing of data and incorrect conclusions. Therefore this category was ignored in the analysis. Instead, an Independent t-test was performed with 'good' and 'okay', which was significant for PHQ \[t(48)=-2.138, \ p=0.005\] and CIS \[t(49)=2.235, \ p=0.03\].

No other factors generated significant results.
Factors related to PwD

The factors of being able to leave the PwD alone at home and severity did produce significant results, and for the same two measures. For ATCFM, can be left alone (M=122.26, SD=21.63) compared to cannot be left alone (M=108.13, SD=21.53) was significant \([t(49)=2.168, p=0.035]\), as was severity of dementia \([F(2,49)=5.723, p=0.006]\). Effect sizes, using Cohen’s (1988) guidelines for interpreting eta squared were approximately moderate (0.088) for being left alone, but large (0.19) for severity. Post-hoc analysis of severity using Tukey’s test indicated significant differences for ATCFM lay between mild and severe \((p=0.004)\).

No other factors generated significant results.

Hypothesis testing

Scatterplots were generated to visually explore the relationship between the study measures. These were all indicative of the presence of a linear relationship (positive or negative) between them, thus rendering them suitable for correlational analysis. As the measures appeared to have met the assumptions for parametric testing, analysis was conducted using Pearson’s rho (\(r\)) to examine associations between the measures (see Appendix 7 for tables summarising correlational data).
Hypothesis 1 – Hopelessness will be positively associated with depression symptoms.

The scatterplot indicated a positive linear relationship between hopelessness (GHS) and depression (PHQ). Correlational analysis indicated a significant strong positive correlation between hopelessness and depression ($r=0.585$, $n=52$, $p<0.001$). The coefficient of determination or effect size $r^2$ was calculated producing a value of $r^2=0.34$. This indicated that hopelessness may help to explain 34% of the variance in respondents' depression scores.

On the PHQ, whilst the raw scores provided a measure for the number/level of depressive symptoms, scores can also be converted to severity ratings using threshold cut-off points, and to distinguish 'clinical caseness' of major depression (see method section). Consideration was therefore also given as to whether the associations between hopelessness and depression would still hold true when using these clinical definitions.

For this analysis, Spearman's rho was calculated as the PHQ data could no longer be considered continuous, thus breaching an assumption for using parametric testing. Although a significant positive correlation was still found, the strength of this was only moderate for both depression severity($r=0.437$ $n=52$, $p<0.01$, effect size $r^2=0.19$) and depression caseness ($r=0.362$ $n=53$, $p<0.01$, effect size $r^2=0.13$).
The GHS was also observed by Heisel & Flett (2005) to contain component categories of FH, IH and SH (see methods section). As the UM component of the ATCFM was removed, consideration was also given as to whether analysis using the GHS should also be conducted with the SH component scores removed. GHS questionnaires were re-scored without the SH items to produce the GHSfi. Correlational analysis was then performed between the GHSfi and PHQ, which generated a significant strong positive correlation (r=0.583, n=52, p<0.001, effect size $r^2=0.34$). As the values of r for GHS and GHSfi were not significantly different suggesting little impact from the SH items in this sample, subsequent analysis continued using the GHS as it was the originally validated measure.

Hypothesis 2 – Finding meaning will be negatively associated with depression symptoms.

The scatterplot indicated a negative linear relationship between finding meaning (ATCFM) and depression (PHQ). Correlational analysis indicated a significant strong negative correlation between finding meaning and depression (r=-0.543, n=52, p<0.001). The effect size ($r^2=0.29$), indicated finding meaning as explaining 29% of the variance in depression scores.

Similarly, finding meaning scores were also considered in relation to the severity and caseness categories of depression, again using Spearman's rho. This analysis revealed a similar association, with
finding meaning demonstrating a significant strong negative correlation with depression severity ($r=-0.590$, $n=52$, $p<0.001$, effect size $r^2=0.34$) and a more moderate significant negative correlation with depression caseness ($r=-0.464$, $n=53$, $p<0.001$, effect size $r^2=0.22$)

**Hypothesis 3 – Finding meaning and hopelessness will be negatively associated.**

The scatterplot indicated a negative linear relationship between finding meaning (ATCFM) and hopelessness (GHS). Correlational analysis indicated a significant strong negative correlation between finding meaning and hopelessness ($r=-0.51$, $n=53$, $p<0.001$). The effect size ($r^2=0.26$), indicated finding meaning as explaining 26% of the variance in hopelessness scores.

As ATCFM contains the component of loss/powerlessness (LP), which is a somewhat similar construct to hopelessness, and provisional meaning (PM) which is the antithesis of it, the components of ATCFM were also analysed for their association with hopelessness. As separate constructs, they only demonstrated moderate correlations with hopelessness albeit in the anticipated direction, with ATCpm being significant and negative ($r=-0.459$, $n=53$, $p<0.001$, effect size $r^2=0.21$), and ATCIp$^3$ being significant and positive ($r=0.449$, $n=53$, $p<0.001$, effect size $r^2=0.20$).

* ATCIp scores were reversed when analysing this so that a high ATCIp score would equate to a high level of loss/powerlessness permitting appropriate correlational conclusions to be drawn.
Hypothesis 4 – Finding meaning and hopelessness may independently account for outcomes in depression.

The ability of meaning and hopelessness to independently predict depression outcomes in caregivers was analysed by using hierarchical (or sequential) regression. This approach enables the researcher to control entry of the independent variables (IV) into the model according to theoretical or logical considerations, and assess how much each additional IV adds to the model after the effect of the previously entered IV's have been accounted for (Tabachnick & Fidell, 2007). The final model can then be evaluated for its ability to predict the dependent variable (depression in this study), and for which IV's are making a significant contribution to this including the extent of their uniqueness.

Based on the theoretical positions presented earlier, both CTSC and HTD suggested cognitive appraisal as having a primary role in responding to a negative event. As HTD proposed an expectation of hopelessness as interacting with this to produce depressive symptoms, it was determined that GHS should be entered first. As HTD proposed recovery via the interaction of an EAS for positive events, ATCFM was entered next. Finally, coping skills (CSI) was entered as CTSC recognises these as being implemented secondary to cognitive appraisal. The results are summarised in Table 4 (see Appendix 8 for complete data set).
### Table 4 – Summary of key statistical data from regression analysis on the questionnaire measure with PHQ and the dependent variable

<table>
<thead>
<tr>
<th>Model</th>
<th>Adj $R^2$</th>
<th>$R^2$ change</th>
<th>F</th>
<th>F Sig (p)</th>
<th>Beta</th>
<th>Beta Sig (p)</th>
<th>Part corr</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 GHS</td>
<td>.330 (33%)</td>
<td>.343 (34.3%)</td>
<td>26.064</td>
<td>.000</td>
<td>.585</td>
<td>.000</td>
<td>.585</td>
</tr>
<tr>
<td>2 GHS</td>
<td>.400 (40%)</td>
<td>.424 (42.4%)</td>
<td>18.014</td>
<td>.000</td>
<td>.417</td>
<td>.002</td>
<td>.358</td>
</tr>
<tr>
<td></td>
<td>ATCFM</td>
<td>.081 (8.1%)</td>
<td></td>
<td></td>
<td>-331</td>
<td>.012</td>
<td>-.285</td>
</tr>
<tr>
<td>3 GHS</td>
<td>.421 (42%)</td>
<td>.455 (45.5%)</td>
<td>13.35</td>
<td>.000</td>
<td>.351</td>
<td>.009</td>
<td>.288 (8.3%)</td>
</tr>
<tr>
<td></td>
<td>ATCFM</td>
<td>.031 (3.1%)</td>
<td></td>
<td></td>
<td>-.296</td>
<td>.023</td>
<td>-.251 (6.3%)</td>
</tr>
<tr>
<td></td>
<td>CSI</td>
<td>-.197</td>
<td></td>
<td></td>
<td>-.197</td>
<td>.104</td>
<td>-.179</td>
</tr>
</tbody>
</table>

() figure in brackets indicates percentage of variance explained

The data was first assessed to check it met the assumptions for regression analysis. Normality was confirmed through visual checks of the scatterplots, and statistically through the lack of residuals $>±3.3$, with a Cook’s distance value of $<1$ and no Mahalonobis distances greater than 16.27 (the critical value for 3 IV’s) indicating no outliers. The possibility of multi-collinearity was explored, however as the IV’s exhibited correlation coefficients $>0.3$ with the dependent variable, and their intercorrelations were $<0.7$, with a tolerance $>0.1$ and VIF$<10$ this was excluded. This suggested the assumptions had not been violated and that analysis could proceed.

From Table 4, it can be seen that $R^2$ was significantly different from zero after each step, and with all three IV’s in the equation $R^2=0.455$ was
significant \( F(3,48)=13.35, \ p<0.001 \). \( R^2 \) change indicated that following step 1 (hopelessness) which accounted for 34% of variance (\( R^2 \) change=0.343), step 2 (finding meaning) only added a further 8% (\( R^2 \) change=0.081), and step 3 (coping skills) a further 3% (\( R^2 \) change=0.031). As this was only a small sample adjusted \( R^2 \) may represent a truer value for the population, which suggested that 42% (adjusted \( R^2 =0.421 \)) of the variation in depression scores in caregivers is predicted by hopelessness, finding meaning and coping skills. From the final model however, reference to Standardised Beta indicated that only two IV's made a statistically significant contribution to this variance. Hopelessness made the largest contribution (GHS beta=0.351, \( p=0.009 \)) and finding meaning also added significantly to this (ATCFM beta=-0.296, \( p=0.023 \)). The partial correlation values indicated that the unique contribution to variance from hopelessness was 8.3% and from finding meaning was 6.3%.

**Hypothesis 5 – The ATCFM may have clinical utility for predicting caregiver wellbeing and assessing vulnerability to depression.**

As a significant negative correlation was found between participants' scores on the PHQ and ATCFM, these were explored further to investigate whether a statistically valid cut-off score could be determined for the ATCFM which might indicate its potential usefulness in screening for caregivers at risk of depression and in need of further assessment and/or intervention. SPSS provides two methods for identifying a cut-off, namely K-means clustering and linear regression.
When K-means clustering analysis was conducted, this suggested that for a PHQ score of 10 (the score at which depression caseness is determined), the corresponding score on ATCFM would be 88. As the correlation between the measures is negative, this would suggest that carers scoring 88 or less might present as being vulnerable to depression as they might be more likely to score highly on the PHQ.

When simple linear regression analysis was conducted, this predicted a score of 84 on the ATCFM when PHQ cut-off was set at 10 \[20.369c + (-0.124b \times 84) = 9.95\].

These two methods suggested that a cut-off score might exist somewhere between 84 and 88 on the ATCFM. To assess the predictive validity of these scores participants were grouped into low and high groups both based on their depression (PHQ) scores (0-9, 10+) and by applying cut-off scores of 84, 86 (to provide mid-range point) and 88 to ATCFM scores. Analysis was then conducted by generating 2x2 contingency tables, to compare the high/low depression groups against the high/low meaning groups for each of the cut-off points.

Inspection of the contingency tables revealed identical results for all three ATC cut-off scores. Some cells had expected frequencies of less than 5, so the result of Fisher's Exact Test was referred to and found to be non-significant. To explore the possible reasons for this a closer examination of the data was made, which revealed that only 11
participants (19%) had PHQ scores in the clinical caseness range (corresponding ATCFM score range 69-114), whilst 17 (33%) could be rated as mildly depression (ATCFM score 71-163), with 25 (48%) indicting no depression (ATCFM score range 106-161). Examination of these ranges suggested that a score of 105 or less might indicate the possible presence of some depression, which in a clinical setting might be suggestive of a need to conduct additional measures such as PHQ or ask further questions regarding wellbeing. Analysis of the possible predictive validity of an ATCFM score of 105 was similarly attempted using 2x2 contingency tables, but again one cell had an expected frequency of less than 5, and Fisher’s Exact Test was non-significant.

Despite the non-significant results obtained, consideration was given to the possible sensitivity and specificity of the ATCFM in predicting depression in caregivers. This analysis indicated that an ATCFM cut-off score of 88 had poor sensitivity as it only correctly identified 18% of caregivers who might be in need of further assessment for depression, but high specificity in correctly identifying 97% of non-depressed caregivers. By raising the ATCFM cut-off score to 105, sensitivity was improved to 45%, but specificity decreased to 81%.

This data is summarised in Table 10 below.
Table 10 – Summarising contingency analysis of caregivers by high/low depression and meaning groups with sensitivity and specificity of meaning cut-off scores

<table>
<thead>
<tr>
<th></th>
<th>High PHQ (positive)</th>
<th>Low PHQ (negative)</th>
<th>Total (n)</th>
<th>Fisher’s Exact sig. (1-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Meaning ATCFM&lt;=88 (positive)</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>0.106</td>
</tr>
<tr>
<td>High Meaning ATCFM&gt;88 (negative)</td>
<td>9</td>
<td>41</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>Total (n)</td>
<td>11</td>
<td>42</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Sensitivity</td>
<td>18%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specificity</td>
<td>97%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>High PHQ (positive)</th>
<th>Low PHQ (negative)</th>
<th>Total (n)</th>
<th>Fisher’s Exact sig. (1-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Meaning ATCFM&lt;=105 (positive)</td>
<td>5</td>
<td>8</td>
<td>13</td>
<td>0.082</td>
</tr>
<tr>
<td>High Meaning ATCFM&gt;105 (negative)</td>
<td>6</td>
<td>34</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>Total (n)</td>
<td>11</td>
<td>42</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Sensitivity</td>
<td>45%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specificity</td>
<td>81%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Discussion

Summary of findings

In comparison to previous studies, the influence of demographic and illness related factors on the caregiver outcome measures, particularly depression, produced mixed results. Similar to Ekwall & Hallberg (2007), no gender differences were found on any of the measures, but contrary to Broe et al. (1999) no age differences were found with depression. The sample had no cultural diversity, so these aspects could not be considered. The presence or absence of both family and professional support did not produce any observable differences either. Possibly the more interesting result was that the level of NCF’s did not produce any differences in depression scores as suggested by Donaldson et al. (1998). However the use of carer self-report rather than independent clinician assessment of these issues may have played a role in this observed disparity.

Hypothesis 1 – Hopelessness will be positively associated with depression symptoms.

As predicted, hopelessness was related to level of depression symptoms. A similar association was also found when considering the categorical constructs of depression, where severity threshold and clinical caseness were again demonstrated to be related to hopelessness.
This was comparable to the findings from previous research. In Fry’s (1984) original validation of the GHS, she found a significant positive correlation between the GHS and the GDS (Geriatric Depression Scale – Yesavage et al. 1983) in a non-clinical population, and this result was replicated by Heisel & Flett (2005) in a mixed clinical/non-clinical sample. Both samples were only slightly larger than the current study at 78 participants with a similar 1:2 male/female ratio, and satisfactory/good health status. In O’Rourke’s (1997) test of the HTD model, he similarly found a significant positive correlation between the BHS and the GDS. Fry also observed a significant correlation between hopelessness and age, but this was not subsequently supported by Heisel & Flett.

**Hypothesis 2 – Finding meaning will be negatively associated with depression symptoms.**

As predicted, finding meaning was related to the level of depression symptoms. This association was also maintained in relation to categorical constructs of depression, where severity threshold and clinical caseness were again demonstrated to be related to finding meaning.

This was comparable to the findings from previous research. Farran et al. (1999) found a significant negative correlation between ATCFM scores and depression scores (as measured using the CES-D: Center for Epidemiological Studies-Depression Scale, Radloff, 1977). Their
sample size was somewhat bigger than this study at N=215, but had a similar 1:2 male/female ratio, and did include caregivers from non-white ethnic backgrounds. Differences due to demographic factors were not evaluated except for private religiosity demonstrating a significant positive correlation with the UM component (related to religious/spiritual meaning). The current study found no differences based on religious faith, although the UM component was omitted. Despite this omission, the ATCFM was observed to maintain its reliability, and principle components analysis demonstrated good construct validity. Two factors were observed to produce significant differences in ATCFM scores: dementia severity and being unable to leave the PwD alone.

Zika & Chamberlain (1992), in a study of older people generally, used the PIL (Purpose in Life Scale, Crumbaugh & Maholick, 1964) to measure meaning and the MHI (Mental Health Inventory, Viet & Ware, 1983) to measure PWB, and also found a significant positive correlation between them, as well as a significant negative correlation between PIL and the depression subscale of the MHI.

Hypothesis 3 – Finding meaning and hopelessness will be negatively associated.

As predicted, finding meaning was related to hopelessness, so that the more meaning participants found in their caregiving role, the less hopeless they felt. However this only accounted for a quarter of the
variance, so other factors may offer a more compelling influence such as the role of self-efficacy.

The individual components of finding meaning (LP & PM) were also considered in relation to hopelessness. Farran & Kuhn (1998) noted how the existential construct of hope may be undermined by the feelings of loss and powerlessness experienced by caregivers (synonymous with Seligman’s (1975) construct of helplessness). In the present study ATClp was positively related to hopelessness, whilst ATCpm displayed a negative relationship.

**Hypothesis 4 – Finding meaning and hopelessness may independently account for outcomes in depression.**

It was theorised that hopelessness, finding meaning and coping skills, in this order of priority, would all have a role to play in determining depression outcomes. The hierarchical regression model developed from this was demonstrated to have good explanatory value, as between them these three variables accounted for nearly half of the variance in depression scores. Whilst hopelessness and finding meaning were both found to uniquely account for some of the variance in depression scores, after their influence was controlled for, coping skills did not display any uniqueness. This suggests that both hopelessness and finding meaning (as positive and negative cognitive appraisals) can independently exert influence on depression as an outcome response to a situation, and that coping responses do not play
a role that is not already explained by the cognitive processes that initiate them.

Support for the contribution of meaning in these findings can be found in Noonan & Tennstadt (1997). They similarly used regression analysis to explore this, (using the Meaning in Caregiving Scale - Giuliano et al., 1990), and found that overload, spousal relationship and meaning all contributed to the experience of depression. They also did not find coping responses (measured as the management of distress and meaning) to be associated with depression. This supports the present study's focus on spouses alone as a control for relationship differences.

Although dementia severity was observed to make a difference to finding meaning, it was not influential on hopelessness, depression or coping skills. In Rapp & Chao's (2000) study of caregiver wellbeing they found that after caregiver appraisals of role strain and gain were accounted for, dementia severity no longer made a difference to wellbeing outcome. On the basis of this evidence, and its potential to confound rather than elucidate the picture concerning hopelessness and finding meaning, dementia severity was not deemed relevant for inclusion in the regression analysis.
Hypothesis 5 – The ATCFM may have clinical utility for predicting caregiver wellbeing and assessing vulnerability to depression.

As finding meaning and depression were demonstrated to have a linear relationship, the possibility was considered that scores on the ATCFM questionnaire might be used to predict depression vulnerability. Although several potential cut-off scores on the ATCFM were identified, they were not found to be significant in predicting the risk of depression identified by the PHQ. Analysis of sensitivity and specificity indicated that although specificity was high, in contrast sensitivity was quite poor. Whilst an ATCFM score of 105 or less had the best sensitivity in correctly identifying 45% of possible depressed caregivers, it only had a positive predictive value of 38% (the ability of this cut-off score to correctly identifying caregivers as depressed), which would result in 62% of false positives also being identified. A better negative predictive value of 85% was obtained (where a score >105 correctly predicted probable non-depression), however this would still result in 15% of possible depressed caregivers being missed (false negatives).

Interpretation of results

The study findings indicated that depression was associated with hopelessness, and as this was a positive relationship, then as hopelessness increased so too did the level of depression symptoms experienced. As this was a correlational analysis, causal inferences may not be drawn from these findings i.e. hopelessness cannot be said to cause depression, however it appears highly likely that hopelessness
is implicated in the level of depression symptoms experienced by caregivers. According to HTD theory hopelessness is not itself a symptom of depression, but represents an expectation about an event. Once established however, it will continue to co-exist alongside the symptoms of depression that emerge from it. Evidence from the regression analysis that hopelessness can uniquely explain some of the variance in the level of depression symptoms may support this assertion by Abramson et al. (1989).

The association between hopelessness and depression would seem to offer support to Abramson et al.'s (1989) notion of depression as a heterogeneous condition of which HD is at least one subtype. HTD theory explains the appearance of HD as being the consequence of a chain of distal and proximal contributory causes that interact with a negative event to culminate in an expectation of hopelessness that is a sufficient and proximal cause of the symptoms of HD. Hopelessness may not however be a necessary cause of depression. As Heisel & Flett (2005) observed, hopelessness does not predict clinical depression, and as the results of this study indicated, when the association between hopelessness scores and depression caseness was explored, although there was still a positive association between them, the effect size was reduced to only a third of that observed previously. As a diathesis-stress model, it is the presence of the diathesis (the DAS that predisposes a person to make depressogenic inferences i.e. global/stable attributions about negative events) that increases
vulnerability to stressors (negative events) through presenting a challenge to positive emotional states whereby hope may be lost and depression is the consequence.

The present study did not measure caregiver attributional style, as O'Rourke et al.'s (1997) test of HTD in caregivers of PwD had already established that caregivers in the group defined as hopeless and depressed demonstrated a significant difference in attributional style (possessing the hypothesized global/stable attributions) compared to caregivers defined as hopeless but not depressed and not hopeless nor depressed. This suggested that the construct of hopelessness effectively differentiated caregivers for this subtype of depression, with caregivers defined as hopeless but not depressed viewed as expressing only circumscribed pessimism. HTD theory states that this pessimistic group may only exhibit the motivational symptoms of depression, which may not necessarily result in the development of HD in the absence of the DAS vulnerability factor, although a decrease in wellbeing may be observed, hence the finding of a positive association between hopelessness and severity of depression symptoms expressed. Although the attributional scenarios used by O'Rourke examined caregivers' tendency to make global/stable attributions about life in general, caregivers do use and/or develop these in connection to their caregiving experiences as evidenced in the research by Coppel et al. (1985) and Cook et al. (1995). If caregivers, especially those with a DAS, have never encountered salient enough negative events in their
lives previously, they will not have developed a history of depression prior to becoming a caregiver. However for those in particular who possess this vulnerability factor, becoming a carer and its associated stresses might be the negative event that precipitates hopelessness and leads to HD.

It has been well documented that caregivers of PwD have many negative factors and situations to cope with. These include: relationship losses, role overload, loss of self-identity and mastery (Adams et al., 2008); loss of social interaction and control over life events (Loos & Bowd, 1997); NCF’s (Donaldson et al., 1998); and watching the PwD suffer (Schulz et al., 2008). O'Rourke et al. noted that although it is rational to feel some sense of forlornness regarding the diagnosis and prognosis of dementia in a family member, this is likely to be insufficient to precipitate HD since HD only occurs when hopeless ideation permeates all or most domains of one's life. However as Abramson et al. posited, the presence of chronic stressors can result in vulnerable people developing HD. Kinney & Stephens (1989) noted how the management of 'daily hassles' is negatively associated with caregiver wellbeing, and in a longitudinal study by Smith et al. (2011) they reported that as dementia progressed and stressors increased, the likelihood of developing depression also increased. Thus a diagnosis of dementia may provide an initial negative event which remains ongoing, and provides a backdrop against which its associated negative factors such as losses and daily stresses begin to increase and permeate.
many areas of a caregiver's life thus setting up the conditions in which
caregivers with a DAS may become particularly vulnerable to
developing HD, with others perhaps only experiencing circumscribed
pessimism.

Ablitt et al. (2009) observed that the prior quality of the relationship with
the PwD, and caregivers reasoning for performing their role e.g.
obligation, will also play a part in how they subsequently frame their
experience of caregiving. Certainly the absence of differences between
groups in this study based on demographic and other stressor factors
(except for caregiver health) and the hopelessness and depression
measures might support the notion that individual aspects lack the
sufficiency to trigger HD.

As dementia is a progressive and (currently) incurable condition,
caregivers of PwD are faced with having to cope with many negative
aspects to their lives that are largely unchangeable, and that may
increase in number and/or the severity of their impact. Yet, as the
results of this study indicate and in line with the observations of
previous researchers, despite their circumstances not everyone
appeared to be overwhelmed or depressed, even those caring for a
relative they rated as having severe dementia. Only about one-fifth of
the participants had possible major depression, with nearly half the
participants falling in the 'healthy' range, and the rest falling somewhere
between the two (Nolan, 2001, notes that typically most carers fall between the extremes).

In Andren & Elmstahl's (2005) study, they found that caregivers could express moderate burden (with its tendency towards depressive symptoms) yet simultaneously express great satisfaction (indicative of wellbeing) in their role. This suggested that positive and negative aspects of the caregiving experience may be responded to independently, which perhaps gives rise to a net effect on wellbeing. Thus the negative aspects of caregiving alone may be insufficient to explain caregiver wellbeing. As the present study demonstrates, both hopelessness (negative) and finding meaning (positive) exert independent and opposite effects on depression symptoms, and are negatively related to each other. This might support a position where they are viewed as acting to counterbalance each other in respect of depression symptoms. With this potential influential role for positive factors in caregiver wellbeing, it is perhaps unsurprising that research focused purely on negative aspects has so far failed to adequately answer the question of why so many caregivers apparently cope.

Models of coping like the stress-adaptation model of CTSC have perhaps suffered from the historical emphasis on psychological dysfunction, as even the revised model (Folkman, 1997) only incorporated positive coping as a means of reframing a negative situation. Contrary to the wider literature, Noonan & Tennstadt (1997)
found coping responses were not associated with depression. The present study similarly found that coping skills did not offer any independent explanation of depression symptoms once cognitive appraisals in the form of hopelessness and finding meaning had been accounted for. This is perhaps not so surprising, as the global/stable attributions underlying hopelessness contain an assumption that whatever you do will make no difference anyway. The converse may well be true for global/stable, and especially internal attributions for positive events.

Stress-adaptation models do not apply themselves to positive events nor consider how responses to positive events might act independently in stressful situations. Folkman (2008) noted that lack of attention to positive events is probably the consequence of their apparent lack of adaptive advantage compared to say the fight/flight responses initiated in response to negative events as coping mechanisms. However from an existential perspective, it might be suggested that being able to observe and respond positively to positive events that do occur in the context of a chronic rather than an acute negative situation would have the adaptive advantage of making the situation feel more bearable (and ensuring survival). This may have some support biologically, as Folkman & Moskowitz (2003) observed that studies of emotion indicated the up-regulation of positive emotion and the down-regulation of negative emotion involve physiological systems that have relatively little overlap.
In respect of caregivers of PwD, existing research has highlighted that despite the ongoing negative aspects in their lives, caregivers can both observe and appreciate positive aspects in their caregiving experience, with PAC's displaying a negative relationship with depression (Cohen et al., 2002). Reker & Wong (1988) also observed that the realisation of meaning is always accompanied by positive feelings of satisfaction and fulfilment, supporting Farran's (1997) assertion of finding meaning as representing both a positive resource and outcome variable. Although Folkman & Moskowitz (2003) observed that positive emotions tend to be more transitory than negative emotions, especially during times of stress, as several researchers have noted (e.g. Ryff, 1989; Keyes et al., 2002; Linley, 2009) it is the underlying constructs such as meaning that support them that may be the key to psychological wellbeing. Whilst positive affect was not measured in the present study per se, as caregiver levels of meaning increased, levels of depressive symptoms were observed to decrease.

Unlike CTSC theory, HTD theory offers an explanatory framework for this. It suggests that through making positive attributions (EAS) about positive events (finding meaning in this study), hope may be maintained (creating resilience to HD), or restored (leading to recovery from HD). This was demonstrated by Needles & Abramson (1990) in an adult clinical population, where the EAS for positive events was observed to operate independently of a DAS despite the ongoing presence of negative events. O'Rourke et al. did not test this in their study with
caregivers. However Houston et al. (2000) did demonstrate this effect in older people, particularly when self-efficacy was promoted and social interaction was involved. Farran et al.’s (1999) construction of finding meaning which includes making choices and taking responsibility, may overlap with self-efficacy, as it was negatively associated with hopelessness as any construct that promotes personal agency is likely to be according to O’Rourke (1995).

Just as the development of HD may be the result of chronic rather than individually salient negative events, so too recovery and resilience may result from the ongoing occurrence of small but not necessarily salient positive events. Farran et al.’s (1999) construct of provisional meaning does not rely on the appearance of exceptional events, but rather occurs through the interaction of everyday life. This is supported by Carbonneau et al.’s (2010) conceptual model of PAC where meaning mediates between the factors present in a caregiver’s role in daily life, and also the outcome from them in terms of wellbeing, continuity and involvement. As Butcher et al. (2001) observed, caregivers of PwD reported finding meaning in identifying the positives in caring and by creating moments of joyfulness together.

From the perspective of the HTD model, it would suggest that some caregivers, especially those with a DAS may be vulnerable to HD if a sufficient degree of negative salience is built up regarding their caregiving experience that leads to an expectation of hopelessness.
However independently of this, wellbeing may be facilitated or recovered through the possession of an EAS that enables positive aspects present in the caregiving experience to be responded to positively. Thus an individual's attribution style act as moderators of their caregiving experience with the net result of this determining wellbeing outcome. Thus not all caregivers will be vulnerable to the effects of their role, and even if they are, the ability to make use of positive events may help to offset this. Whilst undoubtedly many caregivers will not find their role easy, HTD theory suggests that many of them will manage to cope with their role.

Implications for clinical practice
Health and social services in the UK do not have sufficient resources to support the needs of PwD without the assistance of informal caregivers. It is therefore important that the needs of caregivers are addressed, and policy guidelines such as the National Dementia Strategy (DoH, 2009) now make it incumbent on clinicians to offer appropriate assessment and support to them. Adams et al. (2008) observed that from a systems perspective, caregiver outcomes will be inextricably connected to those of the care recipient, thus maintaining caregiver wellbeing not only benefits them but also the PwD's quality of life and survival. Not supporting caregivers may result in poorer physical and psychological health outcomes, placing greater demand on already over-stretched care services. With limited resources, a key question for clinicians is how to identify those most at risk so that resources can be targeted
effectively towards those most in need to avoid caregiver burnout (Peacock et al., 2009).

The findings of this study have highlighted caregiver risk for hopelessness depression through using the HTD theory as an explanatory framework. This has offered a model for both identifying the factors present in caregivers that may make them vulnerable, but also indicated where interventions might be made by clinicians to facilitate recovery or resilience. It supports Cohen et al.'s (2002) assertion that a holistic assessment of caregivers is required to fully understand their experience and needs. As Peacock et al. (2009) observed, the rewards of caregiving are often overlooked when assessing and working with caregivers. Emphasizing strengths may increase caregiver motivation, as the more skilled caregivers are, the more prone they are to finding positive aspects in negative experiences (Farran et al., 2004). Caregivers who feel less effective focus on more negative aspects (Steffen, 2002) and a negative focus leads to decreased motivation (Bandura, 1997) with lowered self-esteem also adding to a decreased desire for involvement (Carbonneau et al. 2010).

From the perspective of considering interventions, the therapeutic predictions of HTD are consistent with the theory and practice of CBT, although any counselling technique or strategy that seeks to undermine hopelessness or helps caregivers to discover new meanings or expectations about themselves and/or their situation should be
effective. Indeed, Farran et al. (1997) speculated regarding whether finding meaning was an ability that could be taught, although Noonan & Tennstadt (1997) suggest that finding meaning in caregiving may be something people come into the caregiving experience already equipped with as part of a more global tendency to find meaning and value in life which counsellors might use to intervene in with caregivers observed to be at risk. Hilgeman et al. (2007) suggested that interventions targeted at caregivers low on PAC may reduce healthcare costs, and be cost effective as caregiver’s low on PAC may have the most to gain from interventions that target skills in this area. Affleck & Tennen (1996) found that simple benefit-finding and benefit reminding can be effective in increasing wellbeing. However Peacock et al. (2009) also caution that positive aspects should not be exploited to keep the PwD at home longer than is reasonably necessary.

Within mental health services where the emphasis is on assessing and managing psychological dysfunction, Clinical Psychologists can play a role in guiding services towards a change of approach, with scope for involvement at many levels ranging from working directly with caregivers, to liaising and consulting with other clinicians on planning and delivering more systemic changes. As reflective scientist-practitioners, Clinical Psychologists have a responsibility for informing clinical colleagues about the issues of caregiver wellbeing, and offering assistance with ongoing training and support in how to identify caregivers who may be vulnerable. It would be helpful if the ATCFM
could be developed into an appropriate screening tool, which could be used as part of the assessment process for caregivers. Psychologists could provide the necessary guidance, support and supervision regarding its use, and assist with developing appropriate and evidence-based interventions that address the issues of caregiver wellbeing that it highlights.

**Critical evaluation**

**Strengths**

Research into the role and potential adaptive significance of positive aspects of psychological functioning has suffered from a lack of attention in the past. This study fits with the Zeitgeist of change towards researching this area which was given formal recognition by Martin Seligman during his tenure as President of the APA in 1998.

Paying attention to the positive aspects of caregiving provides a strengths-based approach (Kramer, 1997a; Peacock et al., 2009), and provides an understanding that may enhance theories of caregiver adaptation and wellbeing. It recognises peoples' capacity for growth and change, and the possibility that they might be supported to achieve insight into their strengths (Saleebey, 2009). From the perspective of maintaining psychological wellbeing, people manage better in the long-term when they are helped to identify, recognise and use the strengths and resources available in themselves and their environment (Graybeal, 2001). Motivation is fostered when strengths are emphasized.
Caregiver wellbeing has often been studied through a lens that is focussed on the burden of care and its associated psychological distress and dysfunction. However by identifying strengths this draws attention away from simply being problem-focused to considering the caregiver (and the PwD) in a more holistic and systemic approach that focuses on the person and considers solutions based on caregiver strengths and resilience.

By taking this approach, it encourages psychologists, other professional, caregivers, PwD and the wider society to view caregiving as something that can elicit benefits in addition to the stresses of the role. It highlights the fact that many people can be successful in their role. This presents a challenge to subjective perceptions of caregiving as a purely negative experience and offers the possibility of reconstructing it in a way that emphasises its values and benefits, thereby producing a more balanced perception that may enable people to feel more empowered to embrace it.

In considering the role of positive aspects, and their contribution to aiding our understanding of why and how many caregivers seem to manage so well under such difficult circumstances, this study has drawn on HTD theory. This explanatory model was itself developed in response to the challenge of explaining why, when any adverse circumstances impact on peoples’ lives there are always some who, despite identical situations do not become helpless, hopeless and
depressed (Seligman, 2006). This made the HTD model a particularly relevant one to use, given its potential explanatory value in answering the same questions in relation to caregiver wellbeing, and its ability to draw together the respective contributions made by both positive and negative factors into a single explanatory framework.

The ATCFM questionnaire used to measure positive aspects of caregiving was found to be reliable and have good construct validity without the UM component being present. Whilst this has only been used with a relatively small sample in this study, analysis indicated it is likely to offer a valid and meaningful tool for use in a clinical setting. The linear relationship it displayed with depression scores suggests it might prove useful in being able to predict depression vulnerability in relation to the experience of caregiving, if this could be subsequently validated using a larger sample of data.

Limitations

Data collection

This study attempted to be inclusive by inviting all eligible caregivers from two clinics to participate. As Dura & Kiecolt-Glaser (1990) noted the most depressed and burdened caregivers are often missed because they are unable to attend research facilities. However, even with a postal survey the self selection process inherent in this method means there is no guarantee that such caregivers felt able to participate.
In comparison to Cuijper's (2005) review of depression prevalence in caregivers, the 19% who scored at the clinical caseness level, was somewhat lower, which may indicate that not all depressed caregivers were represented. However psychometric data alone is insufficient to make a diagnosis and requires to be considered in the context of a clinical interview with an appropriately qualified clinician. However actual diagnosis was not necessary since symptom level was the more important measure for analysis purposes.

Participants were drawn from those carers who accessed a community health service. As Peacock et al. (2010) observed, this group may have greater needs than those who do not access formal support, giving rise to differences which may not be captured. Those who do not seek support may be those who are coping well, and from a positive psychology viewpoint also need to be heard from. It is therefore possible that this study may not be truly representative of all caregivers as the views of those who cope best or struggle most may have been missed.

Whilst the sample size proved adequate for meaningful analysis to be conducted, it was perhaps insufficient when determining the predictive validity of the ATCFM. Although other studies with small sample sizes have achieved this e.g. Schreiner et al. (2006), in the present study the low number of participants combined with the instances where scores were inconsistent with the associated relationship e.g. high meaning
and high depression, appears to have had a detrimental impact when using the data to determine a predictively useful cut-off score which suggests depression vulnerability but that also has good sensitivity and specificity. As a cross-sectional design was used, this also limited data to one timeframe.

Measures
There were some issues noted with the GHS. It was observed that several of the questions received few endorsements, which might raise questions about the usefulness of their inclusion. Furthermore, the inclusion of several religious statements may have introduced a scoring bias since non-agreement with them was scored in the direction of hopelessness, when in fact in the case of a non-religious person this could not be interpreted to indicate this. It was also noted that people did not seem to answer these questions in a way that was consistent with their declaration of having or not having a faith. Examination of the spiritual hopelessness factor identified by Heisel & Flett (2005), revealed that removing this factor would not take out all the religious statements and would also have removed other statements that were relevant. However as there was no significant difference in scores on the GHS between the faith/no faith groups, or the GHS compared to the GHSfi and reliability appeared good it was deemed appropriate to use the GHS in analysis.
Farran et al. (1999) justified the inclusion of the UM component in the ATCFM, as they noted that aspects of religion may play a role in how caregivers appraise and cope with their role, with spiritual meaning being viewed as an important part of the meaning making process within the existential perspective. However both this and the GHS show a Judeo-Christian bias that is perhaps not appropriate for a modern multi-faith world. Equally, faith based questions cannot be scored without creating a bias against those with or without faith. Whilst it is important to acknowledge the religious beliefs that caregivers may have and the role it plays in their lives, inclusion of these within an assessment tool used in a largely secular society is perhaps best avoided, as clinicians are neither qualified to interpret the meanings religious beliefs might have, nor are they in a position to specifically advise or support these.

As the ATCFM was constructed in Canada based on the information gathered from a small local population that were mainly white, middle class and female, care may be needed when using it more widely. Although the questionnaire was subsequently validated using a larger more multi-cultural sample, items of importance/relevance to other groups may have been missed or misrepresented in the initial construction. The demographics for this study indicated the sample to be roughly similar to the group from which the ATCFM was derived, but further studies using it with more ethnically diverse populations may be
needed before the results of this study could be viewed as
generalisable across other groups.

Future research

The present study has merely taken some tentative first steps towards
developing an explanatory framework regarding how the positive
aspects of the caregiving experience might help us to understand why
many caregivers are able to maintain their wellbeing despite their
difficult circumstances. There is clearly still further scope for more
research, and in reflecting on issues that have emerged in the course of
this study the following suggestions come to mind.

Although the HTD theory has been tested, even in caregivers of PwD,
as appears to be a general trend in psychological research, it has only
been investigated from a psychological dysfunction perspective i.e. the
focus has been on the DAS and negative events leading to depression.
From a positive functioning perspective, the role of the EAS and
attributions for positive events would merit further attention, both
examining it in non-clinical populations for its potential as the means of
maintaining wellbeing, and with those who are experiencing negative
life events such as caregivers of PwD, to more fully test the merits and
potential explanatory value suggested by this study. Further
consideration of how the existential construct of meaning may share
similarities with the attributional processes of cognitive psychology may
enable these two paradigms to become linked in a complementary rather than a competing framework.

As the present study was cross-sectional it only considered a single time frame and any comparisons were between participants. It would be useful if the study could be repeated using a longitudinal approach in particular to see if caregivers change their meaning making over time and the impact this has on wellbeing, especially as dementia progresses. Given the problems in recruiting participants and to be more inclusive, this might perhaps be done in the context of using the ATCFM in the course of clinical practice. It would also be useful to evaluate whether any interventions conducted as a result of observations from information gained from using the ATCFM do have an impact on caregivers’ ongoing levels of meaning making and wellbeing.

As this was only a small scale study which used the ATCFM without the UM component, whilst it appears to retain its reliability, this would merit checking in a larger sample, and especially one that included people from other ethnic backgrounds. As the development of the original questionnaire was based on interviews conducted within a limited population group, people from other cultural backgrounds may view situations differently which might lead to the development of different meanings about caregiving. Consideration would need to be given
about whether to incorporate these within the current questionnaire, or to develop other more culturally sensitive versions.

The present study was not able to fully evaluate the usefulness of the ATCFM in predicting depression vulnerability, although the linear relationship observed between scores on the ATCFM and the PHQ would suggest it might be possible to also use the ATCFM as a screening tool for depression. Analysis was able to suggest possible cut-off scores, however evaluation of these is likely to prove more successful in a larger sample, and potentially offer more accurate information about the sensitivity and specificity of such scores. If the ATCFM was found to have good enough predictability regarding depression vulnerability in caregivers, it would offer the dual purpose of assessing the caregivers experience and screening for depression vulnerability related to this, thus reducing questionnaire administration when assessing caregivers. It may be that data for this may need to be collected in the course of using the ATCFM in the course of clinical practice.

If other studies are to make use of the GHS, it would be useful to re-examine the items it contains, and remove those of a religious orientation. As it is now more than twenty years old, it may be worth re-interviewing older people to see if the same hopelessness themes still hold true today, and preferably including people from a variety of ethnic backgrounds to ensure it is culturally sensitive. As hopelessness is a
relevant precursor to depression in older people this may have some merit. It may also be worth evaluating whether particular types of hopeless statements are linked to those with a DAS.

Conclusions

The aim of this study was to explore how positive aspects of caregiving might aid our understanding of why many caregivers do so well despite the difficulties and challenges their role can present. It adopted a quantitative, cross-sectional, survey methodology, using questionnaires to measure three factors present in the caregiving experience (hopelessness, finding meaning and coping skills) and their association with wellbeing outcome (depression symptoms). It highlighted that whilst all three factors contributed to this, only the positive aspect of finding meaning and the negative aspect of hopelessness (both representative of cognitive appraisals) had unique explanatory value. They were found to exert an independent influence on wellbeing, with their negative relationship supporting their opposite effects, where hopelessness was associated with a decrease in wellbeing and finding meaning associated with an increase in wellbeing. Using the HTD model as an explanatory framework, this highlighted how some caregivers may be particularly vulnerable to the negative aspects of role stresses, but that the presence of positive aspects of caregiving might act independently to counterbalance this making life bearable despite the difficulties. Therefore even 'at risk' caregivers have the possibility of maintaining their wellbeing. This study has contributed to the existing
literature on the role of positive aspects of caregiving and has taken some first steps towards answering the question regarding why many caregivers cope. However further research is indicated to enhance our understanding in this area, particularly in relation to evaluating caregivers' cognitive attribution styles in relation to their caregiving experience, and the role of existential aspects such as finding meaning.
References


Appendices

Appendix 1 – Participant Information Sheet (PIS)
  • Beechcroft Site version
  • Hazelwood site version

Appendix 2 – Participant Invite Letter
  • Beechcroft Site version
  • Hazelwood site version

Appendix 3 – Study Questionnaires
  • Participant Demographic Information Questionnaire (PPIQ)
  • Attitudes Towards Caregiving (ATCFM) – Farran et al (1999)
  • Geriatric Hopelessness Scale – Fry (1984)
  • Patient Health Questionnaire (PHQ) - Kroenke et al (2001)
  • Coping Skills Inventory (CSI) – Jerabek (1996)

Appendix 4 – Ethical Approval Documents
  • Berkshire Research Ethics Committee
  • University of Surrey FAHS Ethics Committee

Appendix 5 – Demographics of sample (site split)

Appendix 6 - Statistical Data for Preliminary Analysis

Appendix 7 – Statistical data for correlational analysis

Appendix 8 – Statistical data for regression analysis

Appendix 9 – Statistical data for principle components analysis

Appendix 10 – List of Abbreviations used
Appendix 1 – Participant Information Sheet

1. Beechcroft site version

**Participant Information Sheet**

**Study title:** Finding meaning in caregiving, well-being and carers of people with dementia

We would like to invite you to participate in our study. This study is being conducted as part of an educational qualification by the researcher and is co-sponsored by the Beechcroft Team.

Please take time to read this information sheet, which we anticipate will take you about 15-20 minutes. It is important that you do this, as you need to be able to read and understand this information about why this study is being done and what it would involve for you, so that you can make an informed decision about whether it feels right for you to take part.

If you have any questions about the study, please do not hesitate to contact the study’s Chief Investigator, Aaron Richards, who will be happy to speak with you and answer your questions. Aaron can be contacted by telephone on 07770 109227 or by e-mail at a.richards@surrey.ac.uk.

If you wish, you can talk to others about the study e.g. a family member or close friend, or Chreaanne at the West Berks Alzheimer’s Society, but you should not share your decision about participation with anyone.

**Information Part 1 – this tells you about the purpose of the study and what taking part in it will involve.**

What is the purpose of this study? The aim of this study is to try and gain a better understanding of how carers might maintain their well-being despite the difficulties they are faced with. We hope that the knowledge gained from this study will be able to help healthcare professionals improve their understanding of the experiences of carers, and that the study findings might contribute to the development of how dementia services support carers in future.
Why have I been invited?
The Beechcroft Team are inviting all carers whose husband/wife/partner is registered with their Memory Clinic to participate in this study. You have received this invitation because the team have identified you as being in this category of carers, and meet the participant criteria.

Do I have to take part?
Participation in this study is entirely voluntary. It is up to you to decide.
Your decision will not affect the care or support you receive from the Beechcroft Team. The study has been designed to prevent both the team and myself from knowing who, of those invited, has or has not participated.

What will I have to do?
If you choose to participate, then all you will need to do is simply complete the five questionnaires enclosed. They need to be returned by 5th June 2010, in the pre-paid envelope provided. You are only required to complete this one set of questionnaires, and it is anticipated that it will take you about 35-45 minutes to complete them all. You do not have to complete them all at once, but they should be completed within a couple days of each other if possible.

What will happen to me if I take part?
This study is asking you to complete some questionnaires in the comfort of your own home. It is not intended for this to be an upsetting experience, however you should bear in mind that the questionnaires will be asking you to reflect on some of your thoughts and feelings about yourself and the person you care for. Carers that the study was trialled with did not find the process upsetting, but we are all individuals who respond differently. You are welcome to look through the questionnaires before deciding whether to participate, to assess if the study might cause you any distress. If, at any point, you do find yourself feeling unduly distressed, please stop immediately and do not continue to participate. Please see the section entitled ‘What if I have a problem?’ for sources of help/support.

What are the possible benefits of taking part?
You will not receive any payment or other specific reward for taking part in this study. We cannot promise that the study will help you, but the information that we get from this study may help to improve the support provided to carers of people with dementia. It is hoped however, that by participating in this study you may feel some sense of worth at being able to contribute towards helping to increase the knowledge and understanding that healthcare professionals have about what it is like to care for someone with dementia, and how to support people in this.
Depending on the outcome of the study, this may result in changes to how the Beechcroft Team assess and support carers, which you could then benefit from in the future.

You may also find that having the opportunity to reflect on your experiences as a carer may help you to recognise some strengths in yourself that you may not have consciously thought about before. You may be able to use this information to help you self-generate new strategies that can help you to cope better in the future.

**Information Part 2 – this tells you some additional information about how the study will be conducted**

**What will happen if I don’t want to carry on with the study?**
You will only be deemed to have participated in the study when you return the completed questionnaires to the researcher. Once you have done so, it will not be possible to remove your responses from the study due to the use of participant anonymity. Therefore please be sure of your decision about participating before you return them.

**Will my taking part in the study be kept confidential?**
Yes. We will follow ethical and legal practice, and all information about you will be handled in confidence. Aaron and some members of the Beechcroft Team will know who was invited to participate, however we will not be keeping any permanent record of this. As returned questionnaires will be anonymous, neither of us will know who did or did not decide to participate. All returned questionnaires will go to the researcher only who will store them securely, and the Beechcroft Team will not have access to them.

**Will my GP be informed about my involvement in the study?**
No. The study will be completely anonymous.

**What will happen to the results of the research study?**
The results will be analysed by Aaron, and written as part of his thesis for his educational qualification. Aaron will also produce a short report summarising the outcome of the study for others to read. It is anticipated that this will be available in August 2010, from the Beechcroft Team. A poster will be displayed in the Beechcroft Reception to advise when the report is available, and copies will be placed in their waiting room so that anyone (whether they participated in the study or not) can read about the findings.
Who is organising and funding the research?
This study is being organised and funded by Aaron as part of an educational study for his Doctorate in Clinical Psychology, which includes a nominal expenses budget. No funds are being provided by the NHS nor any other agencies for this study.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by both the Berkshire Research Ethics Committee and the University of Surrey Ethics Committee.

What if there is a problem?
Whilst it is not the intention of the study to cause any distress to participants, it is not always possible to predict how everyone might react.

If your concern is about your health and wellbeing, then we would direct you to the following sources of help and support:

- family and friends
- your GP
- the Beechcroft Team (Tel: 01635 292070); specific staff who can help are
  Carol Brindley (Carers Development Officer)
  Andrew Stevens (Team Manager)
  Dr Daphne Rice (Consultant Psychiatrist)
  your CPN (if you have one)
- West Berks Alzheimer's Society (Tel: 01635 500869): Chreamne
  Montgomery-Smith (Support Worker)
- Princess Royal Trust For Carers (Tel: 0118 950 5177)

If you have a complaint about the study, then in the first instance please contact Aaron on 07770 109227 who will endeavour to resolve it. If your complaint remains unresolved, or you would prefer not to speak to Aaron then you can contact:

- either of Aaron's supervisors:
  → Dr Sue Thorpe on 01483 682916 (University or Surrey)
  → Dr Daphne Rice on 01635 292070 (Beechcroft Team - NHS)
Thank you for taking the time to read this information sheet.

If this study is of interest to you then your participation would be much appreciated.

If, after reading this information and having your questions answered you are still in any doubt about whether participating is something you want to do, then we would suggest that you do not participate. We would not want you to take part in an activity which you might later have regrets about.

If you decide not to participate in this study, then simply dispose of this paperwork.
Participant Information Sheet

Study title: Finding meaning in caregiving, well-being and carers of people with dementia

We would like to invite you to participate in our study. This study is being conducted as part of an educational qualification by the researcher and is co-sponsored by the Hazelwood Team.

Please take time to read this information sheet, which we anticipate will take you about 15-20 minutes. It is important that you do this, as you need to be able to read and understand this information about why this study is being done and what it would involve for you, so that you can make an informed decision about whether it feels right for you to take part.

If you have any questions about the study, please do not hesitate to contact the study’s Chief Investigator, Aaron Richards, who will be happy to speak with you and answer your questions. Aaron can be contacted by telephone on 07770 109227 or by e-mail at a.richards@surrey.ac.uk.

If you wish, you can talk to others about the study e.g. a family member or close friend, or Chr anne at the West Berks Alzheimer’s Society, but you should not share your decision about participation with anyone.

Information Part 1 – this tells you about the purpose of the study and what taking part in it will involve.

What is the purpose of this study?
The aim of this study is to try and gain a better understanding of how carers might maintain their well-being despite the difficulties they are faced with. We hope that the knowledge gained from this study will be able to help healthcare professionals improve their understanding of the experiences of carers, and that the study findings might contribute to the development of how dementia services support carers in future.
Why have I been invited?
The Hazelwood Team are inviting all carers whose husband/wife/partner is registered with their Memory Clinic to participate in this study. You have received this invitation because the team have identified you as being in this category of carers, and meet the participant criteria.

Do I have to take part?
Participation in this study is entirely voluntary. It is up to you to decide. Your decision will not affect the care or support you receive from the Hazelwood Team. The study has been designed to prevent both the team and myself from knowing who, of those invited, has or has not participated.

What will I have to do?
If you choose to participate, then all you will need to do is simply complete the five questionnaires enclosed. They need to be returned by 5th June 2010, in the pre-paid envelope provided. You are only required to complete this one set of questionnaires, and it is anticipated that it will take you about 35-45 minutes to complete them all. You do not have to complete them all at once, but they should be completed within a couple days of each other if possible.

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What are the possible benefits of taking part?
You will not receive any payment or other specific reward for taking part in this study. We cannot promise that the study will help you, but the information that we get from this study may help to improve to improve the support provided to carers of people with dementia. It is hoped however, that by participating in this study you may feel some sense of worth at being able to contribute towards helping to increase the knowledge and understanding that healthcare professionals have about what it is like to care for someone with dementia, and how to support people in this.
Depending on the outcome of the study, this may result in changes to how the Hazelwood Team assess and support carers, which you could then benefit from in the future.

You may also find that having the opportunity to reflect on your experiences as a carer may help you to recognise some strengths in yourself that you may not have consciously thought about before. You may be able to use this information to help you self-generate new strategies that can help you to cope better in the future.

Information Part 2 - this tells you some additional information about how the study will be conducted

What will happen if I don't want to carry on with the study?
You will only be deemed to have participated in the study when you return the completed questionnaires to the researcher. Once you have done so, it will not be possible to remove your responses from the study due to the use of participant anonymity. Therefore please be sure of your decision about participating before you return them.

Will my taking part in the study be kept confidential?
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Will my GP be informed about my involvement in the study?
No. The study will be completely anonymous.

What will happen to the results of the research study?
The results will be analysed by Aaron, and written as part of his thesis for his educational qualification. Aaron will also produce a short report summarising the outcome of the study for others to read. It is anticipated that this will be available in August 2010, from the Hazelwood Team. A poster will be displayed in the Hazelwood Reception to advise when the report is available, and copies will be placed in their waiting room so that anyone (whether they participated in the study or not) can read about the findings.
Who is organising and funding the research?
This study is being organised and funded by Aaron as part of an educational study for his Doctorate in Clinical Psychology, which includes a nominal expenses budget. No funds are being providing by the NHS nor any other agencies for this study.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethic Committee, to protect your interests. This study has been reviewed and given a favourable opinion by both the Berkshire Research Ethics Committee and the University of Surrey Ethics Committee.

What if there is a problem?
Whilst it is not the intention of the study to cause any distress to participants, it is not always possible to predict how everyone might react.

If your concern is about your health and wellbeing, then we would direct you to the following sources of help and support:

- family and friends
- your GP
- the Hazelwood Team (Tel: 0118 960 5959): specific staff who can help are Sarah Gittens & Annette Mullally (Carer Development Officers)
  Sally Calms (Team Manager)
  Dr Jules Mason (Consultant Psychiatrist)
  your own CPN (if you have one)
- West Berks Alzheimer's Society (Tel: 01635 500868): Chreanne Montgomery-Smith (Support Worker)
- Princess Royal Trust For Carers (Tel: 0118 950 5177)

If you have a complaint about the study, then in the first instance please contact Aaron on 07770 109227 who will endeavour to resolve it. If your complaint remains unresolved, or you would prefer not to speak to Aaron then you can contact:

- either of Aaron's supervisors:
  → Dr Sue Thorpe on 01483 682916 (University of Surrey)
  → Dr Daphne Rice on 01635 292070 (Beechcroft Team - NHS)
Thank you for taking the time to read this information sheet.

If this study is of interest to you then your participation would be much appreciated.

If, after reading this information and having your questions answered you are still in any doubt about whether participating is something you want to do, then we would suggest that you do not participate. We would not want you to take part in an activity which you might later have regrets about.

If you decide not to participate in this study, then simply dispose of this paperwork.
Appendix 2 – Participant Invite Letter

1. Beechcroft site version

PSYCHD CLINICAL PSYCHOLOGY
Department of Psychology

April 2010

Dear

RE: Carer well-being research study

I would like to invite you to consider participating in the above study, which I hope might enable the needs of carers to become better understood, and which I hope you might find to be a personally useful reflective experience. I am a third year Trainee Clinical Psychologist based at the University of Surrey, and am conducting this study as part of my educational qualification. This study is being co-sponsored by the Beechcroft Team, who are interested in working alongside me to think about how carers needs can be assessed and supported, and if there are ways of improving this. You have been invited to participate because the Beechcroft Team have identified you as caring for a wife/husband/partner who has dementia, and that you meet the criteria to be a potential participant in the study. If this study does not interest you, then please accept my apologies for the intrusion, otherwise I would appreciate your taking the time to read the rest of this letter and your consideration of my request to participate in this study.

First of all, please read the ‘Participant Information Sheet’ very carefully, as this contains the information you need to consider in order to make an informed choice about whether participating in the study is right for you. I would stress that your participation is entirely voluntary, and your responses will remain anonymous which I hope will enable you to be as open and honest as possible when completing the questionnaires. If after reading the information provided or having your questions answered you still have some worries about participating, then it would probably be better if you didn’t.
If you do have any questions about the study, then please do not hesitate to contact me on my mobile no. 07770 109227. You will invariably need to leave a message, but if you leave your name and a contact number I will return your call as soon as I am able to.

If you want to participate but feel that you need some help with completing the forms, it is okay to ask a friend or family member for help. However please be aware that this will mean they will know that you have taken part in the study, and be sure that they are someone you feel comfortable discussing the issues the questionnaire raises with. Please do not ask a member of the Beechcroft Team to help you with the questionnaires, as neither they nor myself are permitted to help you with them as it is important that we do not know who has or has not participated.

I hope that you will not find completing the questionnaires too arduous a task, nor upsetting. Carers I trialled the study with told me it took them about 35-45 minutes to complete all the questionnaires, and they experienced minimal distress from the task. If, at any point you do begin to feeling distressed by participating in the study you should stop immediately, and if necessary seek assistance from the sources listed in the Participant Information Sheet.

Please do take the time to consider your decision to participate carefully. The final cut-off date for sending questionnaires back is the 5th June 2010. A pre-paid envelope is enclosed for you to return them in. By completing and returning the questionnaires you will be deemed to have given your informed consent to participate in the study. Once questionnaires have been returned, I will be unable to identify which ones are yours, so it will not be possible to remove them from the study once you have sent them back.

Your participation in this study would be much appreciated, and I hope it will be an experience we can all benefit from. I am always happy to be contacted on my mobile to answer any questions you may have.

My thanks in advance for your help.

Yours sincerely

Aaron Richards
Trainee Clinical Psychologist
Dear 

RE: Carer well-being research study

I would like to invite you to consider participating in the above study, which I hope might enable the needs of carers to become better understood, and which I hope you might find to be a personally useful reflective experience. I am a third year Trainee Clinical Psychologist based at the University of Surrey, and am conducting this study as part of my educational qualification. This study is being co-sponsored by the Hazelwood Team, who are interested in working alongside me to think about how carers needs can be assessed and supported, and if there are ways of improving this. You have been invited to participate because the Hazelwood Team have identified you as caring for a wife/husband/partner who has dementia, and that you meet the criteria to be a potential participant in the study. If this study does not interest you, then please accept my apologies for the intrusion, otherwise I would appreciate your taking the time to read the rest of this letter and your consideration of my request to participate in this study.

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My thanks in advance for your help.

Yours sincerely

Aaron Richards
Trainee Clinical Psychologist
Appendix 3 – Questionnaires

1. Participant Demographic Information Questionnaire (PPIQ)

Participant Personal Information Questionnaire

For the purposes of the research study, it is helpful to know some pieces of personal information about you. This information WILL NOT be used in any way that could identify you personally within the study. It will be grouped together, and your ANONIMITY WILL BE GUARANTEED, so please DO NOT put your name on the form.

The reason for collecting this information is to help me understand some of the characteristics about the people who take part in the study. This information will be used in two ways:

i) when I write my report on the outcome of the study, I will be able to give the readers a general idea about who the people were who participated, such as what their age range was, how many were male and female and so on.

ii) I will be able to group the results of participants together based on these characteristics. I will then be able to analyse the group results for any similarities or differences in how participants have responded to the study questionnaires. This will allow me to consider whether these results are meaningful, and what conclusions might be drawn from them about the impact of caregiving.

Please note that some questions may ask you for answers for which you may not be sure of the exact response e.g. a time period. In this instance, your best estimate based on your understanding of the situation is the answer I am looking for.

If you are really not sure of an answer, then it is fine to just write 'not sure' in answer to the question.

If there are any questions you would prefer not to answer, this is okay too. In this case please answer 'I would rather not say', so that I am aware that you have made this choice, as opposed to missed answering the question by mistake.

If, once you have completed all the questionnaires, you have any comments which you would like to pass on to the researcher regarding your experience of participating in this study, or your role as a carer, please feel free to write them on the additional sheet provided at the end of this questionnaire.
PPI Questions

First, I would like to ask you some questions about yourself:

1. How old are you?  (years)

2. What is your gender?  Male / Female  (please circle)

3. How would you define your ethnicity?  
   (please see overleaf for a list of ethnic groups)

4. Do you have a religious faith?  Yes / No  (please circle)
   4a. If you answered 'Yes' above, to which faith group do you belong?
   4b. Do you actively practice your faith by saying prayers, attending services etc?  Yes / No  (please circle)

5. How would you rate your physical health?  
   (please tick the box that you think best describes you)
   □ Good – My health allows me to do most of the tasks of daily life
   □ Okay – My health allows me to do some tasks but not others
   □ Poor – My health makes it hard for me to do most of the tasks of daily life without support

6. Do you have any current mental health difficulties that your GP is treating you for?  Yes / No
   6a. If yes, can you say what the condition is?
What is your ethnic group?

1. White British (inc English, Scottish, or Welsh)
   1a. White Irish
   1b. White European
   1c. White American
   1d. White other background

2. Asian British (inc Asian English, Asian Scottish or Asian Welsh)
   2a. Asian - Bangladeshi
   2b. Asian - Indian
   2c. Asian - Pakistani
   2d. Asian - Chinese
   2e. Asian - Japanese
   2f. Asian - Middle Eastern
   2g. Asian - other background

3. Black British (inc Black English, Black Scottish or Black Welsh)
   3a. Black African
   3b. Black Caribbean
   3c. Black other background

4. Mixed race
   4a. White & Asian
   4b. White & Black African
   4c. White & Black Caribbean
   4e. Other Mixed background

5. Other ethnic background please specify 

6. Prefer not to say
Now I would like to ask you some questions about the person you are caring for:

7. How long have you lived with the person you care for? (yrs)

8. What type of dementia does the person you care for have? (please circle all that apply)
   Alzheimer’s / Vascular / Lewy Body / Parkinson’s related / Other

9. To what extent do you think they are affected by dementia? (please circle)
   Mildly / Moderately / Severely

10. For approximately how long have they had dementia? ........(yrs)........(mths)

11. Do they also have physical health problems for which they require care? Yes / No

12. Are you aware of them having any mental health difficulties? (please tick any that apply)
   □ Anxiety
   □ Low mood / Depression
   □ Apathy – lacking motivation to do things
   □ Hallucinations – seeing or hearing things which are not there
   □ Acting as if suspicious or paranoid about other people
   □ Acting more angrily or aggressively than they did in the past
   □ Problems sleeping

5
Finally, I would like to ask you some questions about your role as a carer:

13. For how approximately how long now would you say you have been acting as a carer?  

14. On average, how many hours a day do you spend providing care?  

15. Are you able to leave the person you care for on their own at home while you go out?  

16. Do you receive practical help from paid homecare assistants?  

17. Do you receive practical and/or emotional support from family and friends?  

18. Do you receive support from the mental health team, e.g. visits from a Community Nurse?  

19. Do you attend any carer support groups?  
   19a. Do you find it helpful to talk to other carers?  

20. Have you attended the Beechcroft Carers Course?  
   20a. Did you find this helpful in your role as a carer?  

Thank you for taking the time to complete this questionnaire.
If you would like to pass any comments about this study on to the researcher please write them here:

**GHS Questionnaire**

This questionnaire consists of 30 statements. Please read the statements carefully one by one. If the statement describes your attitude for the past week including today, then circle TRUE in the column next to the statement. If the statement does not describe your attitude then circle FALSE. Please be sure to read each statement carefully.

<table>
<thead>
<tr>
<th>Statement</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If I allow myself to feel hopeful again, I'll probably be letting myself in for a lot more hurt in the future</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I believe that after I die I will see my loved ones in God care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I might as well give up because I can't make things better for myself or others.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I believe we all deserve the best of life, regardless of age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. All I can see ahead of me is more grief and sadness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I believe that my family and friends will miss me after I am gone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. What's the point of trying; I don't think I can ever get back my strength and energy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Although I'm getting older, I have enough time and energy to finish the things I really want to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I will always be old and useless</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I think I can make myself interesting and attractive to others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I don't think God will ever forgive me for my useless life on earth.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. The future is full of peace and hope.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. All I fear is God's punishment for my sins</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I will get more good things in life than most other persons my age.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

293
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>There is no point in hoping that I will meet my loved ones after I die</td>
<td>True</td>
</tr>
<tr>
<td>I believe my life has a definite purpose and that every day I am getting closer to achieving it.</td>
<td>True</td>
</tr>
<tr>
<td>The notion of ever being happy again is unclear and confusing to me.</td>
<td>True</td>
</tr>
<tr>
<td>I have faith that things will become better for me</td>
<td>True</td>
</tr>
<tr>
<td>There is no point in hoping that anyone here will remember me after I am gone</td>
<td>True</td>
</tr>
<tr>
<td>Although things are going badly, I know they won’t be bad all of the time</td>
<td>True</td>
</tr>
<tr>
<td>There is no use in trying to get something I want because I’ll be too tired and old to enjoy it when I get it</td>
<td>True</td>
</tr>
<tr>
<td>I believe my days of grief and sadness are behind me</td>
<td>True</td>
</tr>
<tr>
<td>I’ve never had much luck in the past, and there’s no reason to think I will now that I am old and tired.</td>
<td>True</td>
</tr>
<tr>
<td>These days there are many different foods and medicines to restore my energy</td>
<td>True</td>
</tr>
<tr>
<td>I cannot believe that anyone would take an interest in me now that I have little to say that is interesting to others.</td>
<td>True</td>
</tr>
<tr>
<td>Even as an elderly person, I can still be useful and helpful to others</td>
<td>True</td>
</tr>
<tr>
<td>The future seems very confusing to me.</td>
<td>True</td>
</tr>
<tr>
<td>I believe that God is kind and merciful to older people</td>
<td>True</td>
</tr>
<tr>
<td>I see no reason why anyone would notice me.</td>
<td>True</td>
</tr>
<tr>
<td>I believe that God in his mercy will forgive me for all my sins</td>
<td>True</td>
</tr>
</tbody>
</table>

Thank you for completing this questionnaire
4. Patient Health Questionnaire (PHQ) - Kroenke et al (2001)

**PH Questionnaire**

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed or hopeless...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself - or that you are a failure, or that you have let yourself or your family down...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Trouble concentrating on things such as reading the newspaper or watching television...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

If you checked off any problems, how **difficult** have these problems made it for you to do your work, take care of things at home, or get along with other people?

<table>
<thead>
<tr>
<th>Not difficult at all</th>
<th>Somewhat difficult</th>
<th>Very difficult</th>
<th>Extremely difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td>[]</td>
<td>[]</td>
<td>[]</td>
<td>[]</td>
</tr>
</tbody>
</table>

Thank you for completing this questionnaire

**CSI Questionnaire**

This questionnaire contains a number of statements relating to coping with situations in life generally. Please read every statement carefully and indicate the degree to which it applies to you, by circling one of the options. Please ensure you answer all questions.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Almost never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite often</th>
<th>Most of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I enjoy and accept expressions of warm feelings from others</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>2. Having time for myself is important to me</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>3. When I am stressed, my mind goes blank</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>4. I trust my judgement</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>5. I have trouble controlling my impulsiveness</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>6. I know where to find the information that I need</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>7. It’s difficult to forget about my problems and worries, and just have fun</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>8. When needed, I am able to accept support from others</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>9. I find myself in overwhelming situations</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>10. I like finding out about new things</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>11. I believe that there is a way out of every situation</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>12. When needed, I use objects for purposes other than those for which they were originally designed</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>13. I am able to apply what I have learned to new situations</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>14. When I am in trouble, it’s hard to find someone to talk to</td>
<td>15. I perceive other people’s emotions</td>
<td>16. I am capable of developing a strategy that would get me where I want to be</td>
<td>17. Before making a decision, I am able to foresee the outcome and possible consequences</td>
<td>18. I prefer being the observer, rather than taking risks by initiating an action</td>
</tr>
<tr>
<td></td>
<td>Almost never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Quite often</td>
<td>Most of the time</td>
</tr>
<tr>
<td>14.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
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<tr>
<td>15.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
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<tr>
<td>16.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
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<tr>
<td>17.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
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<tr>
<td>18.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
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<tr>
<td>19.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
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<tr>
<td>20.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>21.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>22.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>23.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>24.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>25.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>26.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>27.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>28.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>29.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td>30.</td>
<td>AN</td>
<td>R</td>
<td>S</td>
<td>QO</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Almost never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Quite often</td>
<td>Most of the time</td>
</tr>
<tr>
<td>------------------------------------------------------------------</td>
<td>--------------</td>
<td>--------</td>
<td>-----------</td>
<td>-------------</td>
<td>------------------</td>
</tr>
<tr>
<td>31. I find it difficult to learn new things</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. I understand what others expect from me</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. When something I wanted doesn't work out, I get rapidly back on my feet</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. Other people see relationships between things or situations that I cannot grasp</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. I feel free to be playful</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. In a given situation, I react the same way, whatever the circumstances are</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. I enjoy active recreation (the outdoors, sports, reading, interactive entertainment)</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. I rely on others to make my decisions or solve my problems</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. I am able to communicate my needs</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. To solve an important problem, I outline a few strategies and choose the one that seems to be the best</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41. I despise compromises</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. I use my mental ability to it's full potential</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43. When a situation requires a change of plan or strategy, I feel confused</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44. In light of new developments, I am willing to change my opinions</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45. I find reasons to laugh</td>
<td>AN R S QO M</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thank you for completing this questionnaire.
Appendix 4 – Ethical Approval Documents

1. Berkshire Research Ethics Committee

National Research Ethics Service

Berkshire Research Ethics Committee

Building 127
University of Reading
London Road
Reading
RG1 5AQ

Telephone: 0118 918 0559
Facsimile: 0118 918 0550

03 March 2010

Mr Aaron J S Richards
Trainee Clinical Psychologist
Surrey & Borders Partnership NHS Foundation Trust
6 Russell Court
Rowan Close
Guildford
GU1 1PS

Dear Mr Richards,

Does finding meaning through caregiving, as measured by the Attitudes Toward Caregiving Questionnaire, act as a moderating and thus clinically relevant positive factor when assessing well-being in spousal caregivers of people with dementia?

REC reference number: 10/H00557
Protocol number: 2

Thank you for your letter of 02 February 2010, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

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

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission of approval must be obtained from each host organisation prior to the start of the study at the site concerned.

The Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directories within the National Patient Safety Agency and Research Ethics Committees in England.

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For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.research.nhs.uk](http://www.research.nhs.uk). Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

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

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter</td>
<td>1</td>
<td>30 December 2009</td>
</tr>
<tr>
<td>REC application</td>
<td>1</td>
<td>21 December 2009</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>A Richards, v1</td>
<td>12 December 2009</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>S Thorpe</td>
<td>15 December 2009</td>
</tr>
<tr>
<td>Protocol</td>
<td>2</td>
<td>01 November 2009</td>
</tr>
<tr>
<td>Letter of Invitation from A Richards</td>
<td>1</td>
<td>12 December 2009</td>
</tr>
<tr>
<td>Participant Personal Information Questionnaire Information Sheet</td>
<td>1</td>
<td>12 December 2009</td>
</tr>
<tr>
<td>Questionnaire: PPI Questions</td>
<td>1</td>
<td>12 December 2009</td>
</tr>
<tr>
<td>Questionnaire: GHS</td>
<td>1</td>
<td>12 December 2009</td>
</tr>
<tr>
<td>Questionnaire: FH</td>
<td>1</td>
<td>12 December 2009</td>
</tr>
<tr>
<td>Questionnaire: CSI</td>
<td>1</td>
<td>12 December 2009</td>
</tr>
<tr>
<td>Zurich Insurance Certificate</td>
<td>08.07.09 - 31.07.10</td>
<td>08 July 2009</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>2</td>
<td>02 February 2010</td>
</tr>
<tr>
<td>Questionnaire: ATV</td>
<td>2</td>
<td>02 February 2010</td>
</tr>
<tr>
<td>Letter of invitation from Mr A Richards</td>
<td>2</td>
<td>02 February 2010</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td>2</td>
<td>02 February 2010</td>
</tr>
</tbody>
</table>

Statement of compliance

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

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England
The attached document "After ethical review - guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.nhs.uk

Please quote this number on all correspondence

Yours sincerely

Professor Nigel Wellman
Chair

Email: scshs.borkstec@nhs.net

Enclosures: "After ethical review - guidance for researchers"

Copy to: Sponsor contact - Dr Susan Thorpe, University of Surrey
2. University of Surrey FAHS Ethics Committee

Dr Adrian Coyte
Chair: Faculty of Arts and Human Sciences Ethics Committee
University of Surrey

Aaron J S Richards
Trainee Clinical Psychologist
Department of Psychology
University of Surrey

14th March 2010

Dear Aaron

Reference: 423-PSY-10 NHS Approved
Title of Project: Does finding meaning through caregiving, as measured by the Attitudes Toward Caregiving Questionnaire, act as a moderating and thus clinically relevant positive factor when assessing wellbeing in spousal caregivers of people with dementia?

Thank you for your submission of the above proposal.

The Faculty of Arts and Human Sciences Ethics Committee has given favourable ethical opinion.

If there are any significant changes to this proposal you may need to consider requesting scrutiny by the Faculty Ethics Committee.

Yours sincerely

[Signature]

Dr Adrian Coyte
Does finding meaning through caregiving, as measured by the Attitudes Toward Caregiving Questionnaire, act as a moderating and thus clinically relevant positive factor when assessing wellbeing in spousal caregivers of people with dementia?

DR SUSAN THORPE

10TH MARCH 2010

The above Project has received NHS approval and expeditious ethical approval has been granted.

Signed: [Signature]

Dated: 11TH March 2010
### Appendix 5 - Demographics of sample (site split)

**Table 5a – Showing carer socio-demographic information**

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Site B (number)</th>
<th>Site H (number)</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>19</td>
<td>18</td>
<td>37</td>
</tr>
<tr>
<td>Men</td>
<td>10</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Total P’s at each site</td>
<td>29</td>
<td>24</td>
<td>53</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range (yrs)</td>
<td>60 - 88</td>
<td>62 - 86</td>
<td>60 - 88</td>
</tr>
<tr>
<td>Mean</td>
<td>75.2</td>
<td>76</td>
<td>75.6</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>29</td>
<td>24</td>
<td>53</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Religious Faith</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No faith</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Christian</td>
<td>26</td>
<td>22</td>
<td>48</td>
</tr>
<tr>
<td><strong>Carer Physical Health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>14</td>
<td>11</td>
<td>25</td>
</tr>
<tr>
<td>Okay</td>
<td>14</td>
<td>12</td>
<td>26</td>
</tr>
<tr>
<td>Poor</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Carer Mental Health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not being treated by GP for any MH difficulties</td>
<td>29</td>
<td>23</td>
<td>52</td>
</tr>
<tr>
<td>Receiving treatment for depression</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Time lived with PwD</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range (yrs)</td>
<td>27 - 70</td>
<td>12 - 71</td>
<td>12 - 71</td>
</tr>
<tr>
<td>Mean</td>
<td>50.8</td>
<td>50.5</td>
<td>50.7</td>
</tr>
</tbody>
</table>

*indicates some participants may not have given a response to this question*
#### Table 5b – Showing carer circumstances information

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Site B (number)</th>
<th>Site H (number)</th>
<th>Overall (number)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Length of time as a carer</strong>*</td>
<td>Range (yrs)</td>
<td>Mean</td>
<td>0.5 – 16</td>
</tr>
<tr>
<td></td>
<td>0.5 – 8</td>
<td>3.4</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Time per day spent caring</strong>*</td>
<td>Range (hrs)</td>
<td>Mean</td>
<td>2 – 24</td>
</tr>
<tr>
<td></td>
<td>4 – 24</td>
<td>15</td>
<td>16</td>
</tr>
<tr>
<td><strong>Help received from paid care workers</strong>*</td>
<td>Yes</td>
<td>No</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>19</td>
<td>13</td>
</tr>
<tr>
<td><strong>Help/support for family &amp; friends</strong>*</td>
<td>Yes</td>
<td>No</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>21</td>
<td>19</td>
<td>46</td>
</tr>
<tr>
<td><strong>Support recd from Mental Health Team e.g. CPN</strong></td>
<td>Yes</td>
<td>No</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>12</td>
<td>28</td>
</tr>
<tr>
<td><strong>Attends a carer support group</strong>*</td>
<td>Yes</td>
<td>No</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>21</td>
<td>15</td>
</tr>
<tr>
<td><strong>Does it help to talk to other carers</strong>*</td>
<td>Yes</td>
<td>No</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>9</td>
<td>24</td>
</tr>
<tr>
<td><strong>Attended clinic carers course</strong></td>
<td>Yes</td>
<td>No</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>19</td>
<td>19</td>
</tr>
</tbody>
</table>

*indicates some participants may not have given a response to this question
Table 5c – Showing data for demographic factors related to the PwD

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Site B (number)</th>
<th>Site H (number)</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dementia Type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(diagnosis provided by carer)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer's</td>
<td>11</td>
<td>13</td>
<td>24</td>
</tr>
<tr>
<td>Vascular</td>
<td>6</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Mixed AD/VaD</td>
<td>7</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>DLB/Parkinson's</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>other</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td><em><em>Dementia Severity</em> (carer rating)</em>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>8</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Moderate</td>
<td>11</td>
<td>15</td>
<td>26</td>
</tr>
<tr>
<td>Severe</td>
<td>9</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td><strong>Length of time person has had dementia</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range (yrs)</td>
<td>0.5 - 10</td>
<td>0.5 - 10</td>
<td>0.5 - 10</td>
</tr>
<tr>
<td>Mean</td>
<td>3.8</td>
<td>3.7</td>
<td>3.75</td>
</tr>
<tr>
<td><strong>PwD Physical Health requires care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18</td>
<td>14</td>
<td>32</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>10</td>
<td>21</td>
</tr>
<tr>
<td><strong>PwD Mental Health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(non-cognitive difficulties)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>1 or 2</td>
<td>7</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>3+</td>
<td>20</td>
<td>18</td>
<td>38</td>
</tr>
<tr>
<td><strong>Can the PwD be left at home on their own for any time?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18</td>
<td>17</td>
<td>35</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>6</td>
<td>16</td>
</tr>
</tbody>
</table>

*indicates some participants may not have given a response to this question
### Appendix 6 – Statistical Data for Preliminary Analysis

#### Table 6a. Frequency, Mean and Standard deviation data for Socio-Demographic factors and each study measure

<table>
<thead>
<tr>
<th>Level</th>
<th>N</th>
<th>ATCFM Mean</th>
<th>ATCFM SD</th>
<th>ATCpm Mean</th>
<th>ATCpm SD</th>
<th>ATCfp Mean</th>
<th>ATCfp SD</th>
<th>GHS Mean</th>
<th>GHS SD</th>
<th>PHQ Mean</th>
<th>PHQ SD</th>
<th>CSI Mean</th>
<th>CSI SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16</td>
<td>123.44</td>
<td>22.29</td>
<td>72.38</td>
<td>8.92</td>
<td>51.06</td>
<td>16.39</td>
<td>6</td>
<td>4.21</td>
<td>5</td>
<td>5.98</td>
<td>70.63</td>
<td>11.44</td>
</tr>
<tr>
<td>Female</td>
<td>37</td>
<td>115.35</td>
<td>21.94</td>
<td>69.73</td>
<td>10.91</td>
<td>45.62</td>
<td>13.63</td>
<td>6.14</td>
<td>4.63</td>
<td>6</td>
<td>4.78</td>
<td>65.22</td>
<td>10.54</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>15</td>
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#### Table 6b. Frequency, Mean and Standard deviation data for Caregiver circumstance factors and each study measure

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Table 6c. – Frequency, Mean and Standard deviation data for factors related to PwD and each study measure

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Table 6d. Showing results of Independent t-test or One-Way ANOVA conducted for Socio-Demographic factors and each study measure (with any significant results highlighted)

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*df was 50; 2,49 & 50 respectively for PHQ

Table 6e. Showing results of Independent t-test or One-Way ANOVA conducted Caregiver circumstance factors and each study measure (with significant results highlighted).

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*df was 48; 2,49; 2,49; 50 & 50 respectively for PHQ
Table 6f. Showing results of Independent t-test or One-Way ANOVA conducted for factors related to PwD and each study measure (with significant results highlighted).

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*df was 2.48; 4.47; 2.49; 2.48; 48 & 50 for PHQ.

Table 6g. Showing results of Tukey’s post-hoc test for severity of dementia with ATCFM & ATCip

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## Appendix 7 – Correlational data from statistical analysis

Table 7a. Showing correlations between the study measures, and the effect sizes for significant results.

<table>
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<tr>
<th>Measure</th>
<th>PHQ</th>
<th>GHS</th>
<th>ATCpm</th>
<th>ATClp#</th>
<th>CSI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pearson’s Correlation (r)</td>
<td>-.543</td>
<td>-.510</td>
<td>.841</td>
<td>-.923</td>
</tr>
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<td></td>
<td>Significance</td>
<td>.000**</td>
<td>.000**</td>
<td>.000**</td>
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<td>52</td>
<td>53</td>
<td>53</td>
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<tr>
<td></td>
<td>Effect size ($r^2$)</td>
<td>0.29</td>
<td>0.26</td>
<td>0.71</td>
<td>0.85</td>
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<tr>
<td>ATCFM</td>
<td>Pearson’s Correlation (r)</td>
<td>-.585</td>
<td>-.459</td>
<td>.449</td>
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<td>Significance</td>
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<td>.000**</td>
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<td></td>
<td>Effect size ($r^2$)</td>
<td>0.34</td>
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<td></td>
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</tr>
<tr>
<td>GHSfi</td>
<td>Pearson’s Correlation (r)</td>
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<td>-.447</td>
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<td></td>
<td>Significance</td>
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<td></td>
<td>.000**</td>
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<td></td>
<td>N</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Effect size ($r^2$)</td>
<td></td>
<td></td>
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</tr>
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<td></td>
<td>Significance</td>
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<td></td>
<td>.000**</td>
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<td></td>
<td>53</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Effect size ($r^2$)</td>
<td>0.20</td>
<td></td>
<td>0.32</td>
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</tr>
<tr>
<td>ATCpm</td>
<td>Pearson’s Correlation (r)</td>
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<td></td>
<td>.506</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Significance</td>
<td></td>
<td></td>
<td>.000**</td>
<td></td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>52</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Effect size ($r^2$)</td>
<td></td>
<td></td>
<td>0.26</td>
<td></td>
</tr>
<tr>
<td>ATClp#</td>
<td>Pearson’s Correlation (r)</td>
<td></td>
<td></td>
<td></td>
<td>.506</td>
</tr>
<tr>
<td></td>
<td>Significance</td>
<td></td>
<td></td>
<td>.000**</td>
<td></td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>52</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Effect size ($r^2$)</td>
<td></td>
<td></td>
<td>0.26</td>
<td></td>
</tr>
</tbody>
</table>

# Analysis conducted using reverse scoring of LP items

** Correlation is significant at the 0.01 level (1-tailed)
Table 7b. Showing correlations between study measures, and depression thresholds and caseness, with effect sizes for significant results.

<table>
<thead>
<tr>
<th>Measure</th>
<th>PHQ – Depression symptom severity</th>
<th>PHQ – depression caseness</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATCFM</td>
<td>Spearman’s Correlation (r)</td>
<td>-.590</td>
</tr>
<tr>
<td></td>
<td>Significance</td>
<td>.000**</td>
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<td>52</td>
</tr>
<tr>
<td></td>
<td>Effect size ($r^2$)</td>
<td>0.34</td>
</tr>
<tr>
<td>GHS</td>
<td>Spearman’s Correlation (r)</td>
<td>.437</td>
</tr>
<tr>
<td></td>
<td>Significance</td>
<td>.001**</td>
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<td>N</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td>Effect size ($r^2$)</td>
<td>0.19</td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (1-tailed)**
Appendix 8 – Hierarchical Regression Analysis Data

Table 8a. Showing the model summary from hierarchical regression for the questionnaire measures when PHQ is the dependent variable.

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>R</th>
<th>R²</th>
<th>Adjusted R²</th>
<th>Std. Error of the estimate</th>
<th>Change statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>R² change</td>
</tr>
<tr>
<td>1</td>
<td>GHS</td>
<td>.585</td>
<td>.343</td>
<td>.330</td>
<td>4.189</td>
<td>.343</td>
</tr>
<tr>
<td>2</td>
<td>GHS ATCFM</td>
<td>.651</td>
<td>.424</td>
<td>.400</td>
<td>3.962</td>
<td>.081</td>
</tr>
<tr>
<td>3</td>
<td>GHS ATCFM CSI</td>
<td>.455</td>
<td>.455</td>
<td>.421</td>
<td>3.893</td>
<td>.031</td>
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</tbody>
</table>

Table 8b. Showing ANOVA results for the models in table 8a.

<table>
<thead>
<tr>
<th>Model</th>
<th>Sum of squares</th>
<th>df</th>
<th>Mean square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Regression</td>
<td>457.334</td>
<td>1</td>
<td>457.334</td>
<td>26.064</td>
</tr>
<tr>
<td></td>
<td>Residual</td>
<td>877.339</td>
<td>50</td>
<td>17.547</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>1334.673</td>
<td>51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Regression</td>
<td>565.521</td>
<td>2</td>
<td>282.760</td>
<td>18.014</td>
</tr>
<tr>
<td></td>
<td>Residual</td>
<td>769.152</td>
<td>49</td>
<td>15.697</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>1334.673</td>
<td>51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Regression</td>
<td>607.081</td>
<td>3</td>
<td>202.360</td>
<td>13.35</td>
</tr>
<tr>
<td></td>
<td>Residual</td>
<td>727.592</td>
<td>48</td>
<td>15.158</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>1334.673</td>
<td>51</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 8c – Showing coefficients for the models in table 8a.

<table>
<thead>
<tr>
<th>Model</th>
<th>Unstandardised coefficients</th>
<th>Standardised coefficients</th>
<th>t</th>
<th>Sig</th>
<th>Correlations</th>
<th>Collinearity statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
<td>Zero order</td>
<td>partial</td>
</tr>
<tr>
<td>1</td>
<td>(Constant)</td>
<td>1.624</td>
<td>.989</td>
<td>1.642</td>
<td>.107</td>
<td>.585</td>
</tr>
<tr>
<td></td>
<td>GHS</td>
<td>.671</td>
<td>.131</td>
<td>.585</td>
<td>5.105</td>
<td>.000</td>
</tr>
<tr>
<td>2</td>
<td>(Constant)</td>
<td>11.805</td>
<td>3.989</td>
<td>2.959</td>
<td>.005</td>
<td>.585</td>
</tr>
<tr>
<td></td>
<td>GHS</td>
<td>.477</td>
<td>.144</td>
<td>.417</td>
<td>3.306</td>
<td>.002</td>
</tr>
<tr>
<td></td>
<td>ATCFM</td>
<td>-.076</td>
<td>.029</td>
<td>-.331</td>
<td>-2.625</td>
<td>.012</td>
</tr>
<tr>
<td>3</td>
<td>(Constant)</td>
<td>17.450</td>
<td>5.195</td>
<td>3.359</td>
<td>.002</td>
<td>.585</td>
</tr>
<tr>
<td></td>
<td>GHS</td>
<td>.403</td>
<td>.149</td>
<td>.351</td>
<td>2.703</td>
<td>.009</td>
</tr>
<tr>
<td></td>
<td>ATCFM</td>
<td>-.068</td>
<td>.029</td>
<td>-.296</td>
<td>-2.356</td>
<td>.023</td>
</tr>
<tr>
<td></td>
<td>CSI</td>
<td>-.092</td>
<td>.055</td>
<td>-.197</td>
<td>-1.657</td>
<td>.104</td>
</tr>
</tbody>
</table>

Table 8d. Showing residual statistics for the model in table 8a.

<table>
<thead>
<tr>
<th></th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mahalonobis distance</td>
<td>.043</td>
<td>15.845</td>
<td>2.943</td>
<td>3.048</td>
<td>53</td>
</tr>
<tr>
<td>Cook's Distance</td>
<td>.000</td>
<td>.142</td>
<td>.022</td>
<td>.036</td>
<td>52</td>
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</table>
### Table 9a: Showing comparison of Farran et al (1999) original factor loadings compared to the PCA loadings derived in the present study.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 (LP)</td>
<td>2 (PM)</td>
</tr>
<tr>
<td>LP1. I miss the communication and companionship that my</td>
<td>.521</td>
<td>-</td>
</tr>
<tr>
<td>LP4. I miss the little things my relative and I did together in the</td>
<td>.516</td>
<td>-</td>
</tr>
<tr>
<td>LP5. I am sad about losing the person I once knew</td>
<td>.669</td>
<td>-</td>
</tr>
<tr>
<td>LP2. I miss my family member’s ability to love me as he/she</td>
<td>.592</td>
<td>-</td>
</tr>
<tr>
<td>LP3. I am sad about the mental and physical changes I see in</td>
<td>.500</td>
<td>-</td>
</tr>
<tr>
<td>LP12. I miss not having more time for other family members</td>
<td>.510</td>
<td>.176</td>
</tr>
<tr>
<td>LP36. I miss my relative’s sense of humour</td>
<td>.664</td>
<td>-.250</td>
</tr>
<tr>
<td>LP6. I miss not being able to be spontaneous in my life</td>
<td>.593</td>
<td>-</td>
</tr>
<tr>
<td>LP18. I miss our previous social life</td>
<td>.557</td>
<td>-</td>
</tr>
<tr>
<td>LP34. We had goals for the future but they are just folded up</td>
<td>.547</td>
<td>.092</td>
</tr>
<tr>
<td>LP31. I feel trapped by my relative’s illness</td>
<td>.506</td>
<td>.288</td>
</tr>
<tr>
<td>LP24. I miss not being able to travel</td>
<td>.484</td>
<td>-</td>
</tr>
<tr>
<td>LP7. My situation feels endless</td>
<td>.481</td>
<td>-</td>
</tr>
<tr>
<td>LP41. I feel that the quality of my life has decreased</td>
<td>.482</td>
<td>.368</td>
</tr>
<tr>
<td>LP19. I have no sense of joy</td>
<td>.418</td>
<td>-</td>
</tr>
<tr>
<td>LP13. I have no hope; I am clutching at straws</td>
<td>.319</td>
<td>-</td>
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<tr>
<td>LP25. I wish I were free to lead a life of my own</td>
<td>.341</td>
<td>.367</td>
</tr>
<tr>
<td>LP37. I wish I could run away</td>
<td>.240</td>
<td>.498</td>
</tr>
<tr>
<td>LP30. I miss having given up my job or other personal interests</td>
<td>.242</td>
<td>.389</td>
</tr>
<tr>
<td>PM22. I am glad I am here to care for my relative</td>
<td>-</td>
<td>.751</td>
</tr>
<tr>
<td>PM43. Caregiving has made me a stronger and better person</td>
<td>-.190</td>
<td>.703</td>
</tr>
<tr>
<td>PM16. Caregiving makes me feel good that I am helping</td>
<td>-</td>
<td>.682</td>
</tr>
<tr>
<td>PM33. I would not have chosen the situation I’m in, but I get</td>
<td>-</td>
<td>.643</td>
</tr>
<tr>
<td>PM8. I enjoy having my relative with me; I would miss it if they</td>
<td>-</td>
<td>.633</td>
</tr>
<tr>
<td>PM20. The hugs and ‘I love you’ from my relative make it all</td>
<td>-</td>
<td>.582</td>
</tr>
<tr>
<td>PM27. Even though there are difficult things in my life, I look</td>
<td>-</td>
<td>.576</td>
</tr>
<tr>
<td>PM10. Caring for my relative gives my life a purpose and a</td>
<td>-</td>
<td>.559</td>
</tr>
<tr>
<td>PM32. Each year, regardless of the quality, is a blessing</td>
<td>-</td>
<td>.558</td>
</tr>
<tr>
<td>PM9. I count my blessings</td>
<td>-</td>
<td>.549</td>
</tr>
<tr>
<td>PM28. Caregiving has helped me learn new things about</td>
<td>-</td>
<td>.355</td>
</tr>
<tr>
<td>PM38. Every day is a blessing</td>
<td>-</td>
<td>.505</td>
</tr>
<tr>
<td>PM21. I’m a fighter</td>
<td>-</td>
<td>.489</td>
</tr>
<tr>
<td>PM15. I am a strong person</td>
<td>-</td>
<td>.474</td>
</tr>
<tr>
<td>PM42. I start each day knowing we will have a beautiful day</td>
<td>-</td>
<td>.410</td>
</tr>
<tr>
<td>PM14. I cherish the past memories and experiences that my</td>
<td>-.248</td>
<td>.394</td>
</tr>
<tr>
<td>PM40. I am much stronger than I think</td>
<td>-</td>
<td>.369</td>
</tr>
<tr>
<td>PM26. Talking with others who are close to me restores my</td>
<td>-</td>
<td>.300</td>
</tr>
<tr>
<td>PM39. This is my place; I have to make the best of it</td>
<td>-</td>
<td>.180</td>
</tr>
</tbody>
</table>
Table 9b. Comparison of eigenvalues from PCA and the corresponding criterion value from the Monte Carlo PCA for Parallel Analysis.

<table>
<thead>
<tr>
<th>Component number</th>
<th>Actual eigenvalue from PCA</th>
<th>Criterion value from Monte Carlo PCA</th>
<th>Decision</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>12.959</td>
<td>3.1019</td>
<td>accept*</td>
</tr>
<tr>
<td>2</td>
<td>4.781</td>
<td>2.7745</td>
<td>accept*</td>
</tr>
<tr>
<td>3</td>
<td>2.488</td>
<td>2.5678</td>
<td>reject</td>
</tr>
<tr>
<td>4</td>
<td>2.031</td>
<td>2.3737</td>
<td>reject</td>
</tr>
<tr>
<td>5</td>
<td>1.683</td>
<td>2.2162</td>
<td>reject</td>
</tr>
<tr>
<td>6</td>
<td>1.457</td>
<td>2.0735</td>
<td>reject</td>
</tr>
<tr>
<td>7</td>
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<td>reject</td>
</tr>
<tr>
<td>8</td>
<td>1.148</td>
<td>1.7856</td>
<td>reject</td>
</tr>
<tr>
<td>9</td>
<td>1.061</td>
<td>1.6789</td>
<td>reject</td>
</tr>
</tbody>
</table>

*In parallel analysis only components with an actual eigenvalue larger than the criterion value are accepted.
Appendix 10 – List of Abbreviations used

ATCFM – Attitude Toward Caregiving Questionnaire
ATCIp – loss/powerlessness component of the ATCFM
ATCpm – provisional meaning component of the ATCFM
BHS – Beck Hopelessness Scale
CFA – confirmatory factor analysis
CSI – Coping Skills Inventory
CTSC - Cognitive Theory of Stress and Coping
DAS - depressogenic attributional style
DV – dependent variable
EAS - enhanced attributional style
GDS – geriatric Depression Scale
GHS – geriatric Hopelessness Scale
HD – hopelessness depression
HTD - Hopelessness Theory of Depression
IV – independent variable
LP – loss/powerlessness
NCF’s - non-cognitive features (of dementia)
PAC - positive aspects of caregiving
PCA – principle components analysis
PHQ – Patient Health Questionnaire
PM – provisional meaning
PPIQ – Participant Personal Information Questionnaire
PwD – person with dementia
PWB – psychological wellbeing
SWB - subjective wellbeing
UM – ultimate meaning