Burnout and Resilience in Informal Carers of People with Life-Limiting Illnesses

Volume I

By

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VOLUME I - PUBLIC PORTFOLIO

Volume I of the portfolio is a public document and is comprised of 3 dossiers – academic, clinical and research.

ACADEMIC DOSSIER

The academic dossier contains academic work completed as part of training, and includes two essays, three problem based learning (PBL) reflective accounts, and summaries of two case discussion group (CDG) process accounts.

CLINICAL DOSSIER

The clinical dossier provides an overview of my clinical experiences, and includes a brief précis of my placement experiences, and a summary of each of my clinical case reports.

RESEARCH DOSSIER

The research dossier contains a research checklist that summarises my research experiences, the abstract to a group qualitative research project, my Service Related Research Project (SRRP) and my Major Research Project (MRP).
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ACADEMIC DOSSIER

This section contains two academic essays, three problem based learning (PBL) reflective accounts, and summaries of two case discussion group (CDG) process accounts.
ADULT MENTAL HEALTH ESSAY

Is Cognitive Behaviour Therapy (CBT) for Borderline Personality Disorder (BPD) effective and cost effective?

December 2006

Year 1
Introduction

Borderline Personality Disorder (BPD) is one of ten personality disorders (PD)s listed in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994). It is characterised by instability in interpersonal relationships, self-image and mood, coupled with a proneness to impulsive behaviour (Beck & Freeman, 1990; Skodol et al., 2002).

Historically BPD is described as difficult to treat. It is one of the most severe mental health problems and poses several challenges for example due to difficulties with engagement (Linehan, 1993) and a tendency to self-harm (Brodsky, 1997). This essay summarises some of the evidence for and against a range of treatments based on CBT principles including Young’s schema-focused therapy, Manual-Assisted Cognitive Therapy (MACT) and DBT (Dialectic Behaviour Therapy).

I chose to write on the topic of BPD because I had little, or rather no knowledge of the area and (correctly) believed it would be a fantastic learning opportunity. Since discussing the subject with colleagues I have become acutely aware of the prevalence of the disorder and the frustration amongst many staff that hold the belief it is untreatable. I have also found it quite alarming the way many professionals view this client group, with one of the most common descriptives I have heard being “manipulative”. I hope having completed this assignment I will be able to present it to my colleagues to demonstrate that whilst there may not be “a cure”, there are indeed many ways we can work with these fascinatingly complex individuals to support them in achieving a better quality of life.

Definition of Borderline Personality Disorder

The term borderline has been used for many years yet its meaning is still somewhat ambiguous. Personally I dislike the word as a descriptive of a disorder: to me it
signifies one group that borders on another and, unless one has an understanding of what the "other" may be, it has no clinical meaning. It first appeared in the DSM-III in 1980 following extensive work by Gunderson who identified distinct differences between this client group, and a group of people with schizophrenia (Gunderson et al., 1975 cited in Stern, 2003). The medical equivalent of BPD in the ICD–10 is "Emotionally unstable personality disorder" in which slightly different diagnostic criteria are used. However I understand there is current discussion in the American Psychiatric Association regarding changing the term BPD to "Emotional dysregulatory disorder". Personally I welcome this move as I feel there is an ethical dilemma in labeling someone’s whole personality as "disordered". Unlike other conditions such as depression, the term "personality disorder" seems to imply some internal fault of the individual and not an illness which is common to many.

Individuals with BPD may experience intense emotional reactions to other people alternating suddenly between idealisation and devaluation with seemingly little reason for change. They are usually highly sensitive to rejection or abandonment - be it real or perceived, and may react with anger or distress to “mild” separations such as a plan changing unexpectedly (Tyrer, 1998; Levy, 2005). The affective symptoms of BPD involve rapid changes in mood with individuals oscillating between a pervasive depressed mood, agitation or anger - these states usually lasting only a few hours (Gunderson & Phillips, 1991). People with BPD often have a distorted sense of self which is determined by their current situation rather than an aggregation of past experiences (Lumsden, 1993). Such feelings may promote frantic efforts to avoid being alone or to seek interaction from others - often inappropriately. The impulsive nature of people with BPD may manifest itself in self-damaging behaviours such as excessive spending, unsafe sex, substance abuse and chronic suicidality (Wilson et al., 2006).

The prevalence of BPD in the general community is estimated at 2% (Torgersen, Kringlen & Cramer, 2001; Samuels et al., 2002). According to a review by Widiger &
Weissman (1991), this figure increases significantly to between 11-70% in psychiatric services which may reflect the tendency of this client group to actively seek support. However most prevalence figures have been derived from American populations, and according to Brazier et al (2006) the UK community prevalence is likely to be at the lower end of the scale, closer to 0.7% - also quoted in the NIMHE draft document on management of BPD (NIMHE, 2006). The ratio of male to female diagnosed is 1:3 with men more likely to be diagnosed with other PDs (Skodol & Bender, 2003 & Bjorklund, 2006 for reviews). BPD is also associated with lower social class and lower levels of education (Torgersen et al., 2001) which may have management implications.

We have no clear understanding of what causes BPD, but psychosocial factors are believed to play an important role. Linehan (1993) hypothesises that BPD is the result of “an emotionally vulnerable child growing up in an invalidating environment in which the experiences and reactions of the child are regularly disqualified by significant others”. In adults with BPD, issues arising from abnormal attachment in childhood such as abuse, divorce, substance misuse and neglect are all common (Zanarini & Frankenburg, 1997; Harman, 2004; Chaudhry, 2005). In particular, the prevalence of childhood sexual abuse in both male and female people with BPD is staggeringly high (Paris et al., 1994; Chaudhry, 2005) There is on-going debate as to whether a subgroup of women diagnosed with BPD may be better categorised under a diagnostic label of “Complex Posttraumatic Stress Disorder”. Such a label may reduce the stigma some of these women experience, and eliminate some of the treatment complications which may arise from having several “labels”. (It is beyond the scope of this essay to discuss this further but see McLean (2003) for a review). Whilst sexual abuse can be regarded as a risk factor for BPD, it is likely that a series of triggers, abuse being one, can lead to BPD in vulnerable individuals: not all people with BPD have experienced abuse.
Defining effectiveness and cost-effectiveness

When examining the effectiveness of therapy, we are interested in how it impacts under real-life conditions on specific outcome (Streiner, 2002). Comparing the effectiveness of a range of therapeutic approaches can be problematic, as rarely do studies utilise the same outcome measures on equivocal populations.

Although the overall economic cost of BPD is unknown, a 1986 report estimated that the total cost to NHS services for people with all PDs was £61.24 million – four times the spending on alcohol and drug misuse (Smith et al., 1995). Given this huge figure, it is essential new treatments are developed or modified with cost-effectiveness in mind. However assessing this is in therapies can be very difficult as it involves not only the cost of the therapy provided, but also the knock-on financial implications for other services (such as hospitals), the cost of people not able to work, and the cost to an individual’s quality of life.

In many of the studies referenced, cost-effectiveness is measured in terms of “the cost of each parasuicidal event avoided” and quality-adjusted life-year (QALY). This is problematic in that it is not easy to compare BPD with other mental health problems, especially those which do not have self-harming as an associated feature. QALY can be measured by mapping scores from the Beck Depression Inventory (BDI) on to the EQ-5D; where more than one score on the BDI is reported, the mean is used. The EQ-5D is a standardised tool that assesses health outcome. It is usually a self-report questionnaire that asks questions on topics such as mobility, self-care, depression and anxiety. The National Institute of Clinical Excellence (NICE) has recently issued guidelines recommending its use in all UK studies of cost effectiveness.
Definition of Cognitive Behaviour Therapy (CBT)

CBT is a therapeutic approach which involves teaching clients to understand the connections between thoughts, feelings and behaviour. Rather than describing standard CBT, I will describe specific types used in the treatment of BPD.

Schema-focused cognitive therapy (SFT)

This approach was developed by Young in the mid 1980's. It is largely based on CBT principles but integrates techniques from other psychotherapies such as gestalt theory and object relations. Its aim, unlike other therapies described, is to achieve full recovery from BPD. According to Young, during childhood, if the basic needs of the child are not met, the child develops stable and enduring patterns of thinking which he terms “early maladaptive schemas”; such thinking results in maladaptive behaviour patterns which repeatedly reinforce the schemas (Young, 1994). Techniques in therapy include “limited re-parenting”: the adult is taught ways of escaping from their chaotic thinking rather than strategies to cope with it.

Geisen-Bloo and colleagues (2006) compared the effectiveness of SFT to psychodynamically based Transference Focused Therapy (TFT). The intervention involved three years of twice-weekly sessions. Participants (n=86) were referred based on a diagnosis of BPD which was reassessed using a clinical interview and the Borderline Personality Severity Index (BPDSI-IV). Outcome measures included the BPDSI-IV where a score of 15 or less represented the recovery criterion. There was a higher attrition rate in the TFT compared to the SFT group. Improvements on all measures were reported at 1, 2 & 3-year follow-up for both groups. At both one and two years following initial treatment, significant improvements in symptoms were reported. At three years, significantly more people “recovered” in the SFT group. People in the SFT group also significantly improved more than the TFT group on other measures such as abandonment fears, identity disturbance, impulsivity and parasuicidal ideation. No significant effects were found with regard to anger, and SFT
was not consistently more superior to TFT on measures of quality of life. Care must be taken when interpreting these results as there was no control group to compare how individuals may have scored without either treatment.

To assess the cost-effectiveness and stability of effects, Geisen-Bloo and colleagues intend to follow-up their clients for an additional year. However they estimate a net gain of €4,500 for each year each person was in the study. Over a number of years, this figure could increase significantly and indicates SFT has the potential to be cost-effective, however further research is necessary.

In a pilot study of 14 people with personality disorder, the effectiveness of schema therapy was assessed. Effectiveness was measured by noting a reduction in scores on the Social Adaption Scale (SAS-SR, Weissman). There was a significant reduction in scores following therapy (average 13 months duration) however no control group was used in this study and the effects on these scales of measurements may have occurred simply with the passage of time or via non-specific aspects of the therapy. Specific data for those with BPD is also not reported (Hahusseau & Pelissolo, 2006).

Although the evidence for the effectiveness of SFT in treating BPD is limited, Arnez and colleagues (1999) and Butler and colleagues (2002) have both discovered schemas specific to people with BPD; disconnection, dependency and abandonment. Similarly, Nordahl and colleagues (2005) demonstrated that early maladaptive schemas are positively correlated to symptomatic distress in personality disorders. Knowing these schemas may lead to the development of a more specific, short-term option of SFT which intensely focuses on these. The scope for SFT becoming a treatment for BPD is enormous. Although the treatment time is significantly longer than for other therapies, refreshingly it aims and is successful at addressing key features of BPD other than deliberate self-harm. I am aware however that when services are limited financially, addressing the aspects of a disorder that incur the most
costs makes financial sense. SFT may therefore be an appropriate therapy only for individuals with BPD who chronically self-harm.

*Manual-assisted cognitive therapy (MACT)*

MACT was originally developed as a treatment for self-harm, and is goal directed based on DBT principles. The emphasis is on changing core beliefs and teaching clients new ways of relating to others to improve current functioning. Similar to schema focused therapy, behaviours that interfere with therapy are conceptualised in terms of schemas and this technique alongside training in self-help and self-monitoring, are employed to evoke change. The manual consists of 6 booklets which are worked through alone or during sessions with a therapist. Evans and colleagues (1999) compared MACT to TAU (treatment as usual) in a small randomly controlled trial (RCT) of people with PD (antisocial, histrionic or borderline) who had self harmed in the last year. Participants were including following presentation at one of two London hospitals; people were excluded if they were drug/alcohol dependent or had an organic or schizophrenia diagnosis. MACT was slightly more effective than TAU in reducing deliberate self harm, although the results were not significant. The effect sizes pre and post treatment with MACT indicate that this may be an effective treatment for other variables (d=0.65, 0.90 & 0.73 for anxiety, depression and social functioning respectively). However no information was available about the specific effects for those with BPD so the effectiveness in this client group is unclear.

In a large scale follow-up, 480 people were randomly assigned to either MACT or TAU (Tyrer et al., 2003; Tyrer et al., 2004). This study was conducted across 5 centres in Scotland and England. The MACT group was sent the manual and offered up to seven sessions. The TAU group received alternative treatments such as problem solving approaches and dynamic psychotherapy depending on the local provision. 391 people in the sample had a diagnosis of PD - 67 with BPD. 90 individuals in the MACT group did not attend sessions, so their treatment was using the manual independently. There were no differences in the frequency of self-harm behaviours in
the attending and non-attending groups: the therapist’s input did not appear to enhance outcome. How thoroughly people worked through the manual without the support of a therapist is unknown. However in comparable studies if participants do not attend therapy beyond a threshold, their results are excluded. Overall the results showed there were no significant differences between MACT and TAU although those with BPD generally had a greater frequency of self-harm behaviours. No differences were found between the numbers of hospital admissions in the year after the study began. There are several limitations of this study. Although there is a high prevalence of self-harming in people with BPD, BPD was not formally diagnosed and therefore the sample may represent a particularly severe subgroup. I also wonder about the effectiveness of the therapists’ input in this approach; either they were inadequately trained (which the study claims not) or using the sessions to work through the manual is not helpful.

The economic evaluation of the study above was assessed by Byford and colleagues (2003). They took a societal prospective and assessed the costs incurred (or avoided) from hospitals, social services, the criminal justice system and costs due to absence from work. The average societal cost per individual in the MACT programme was estimated at £13,450 per person compared with £14,228 for TAU; this difference was non-significant. Tyrer and colleagues (2004) divided the group and identified the average societal costs for people with BPD to be higher in the MACT group (£16,144) than in TAU group (£14,185). Although MACT is cost-effective for PD in general, it is less so than TAU for individuals with BPD. However the relative costs in setting up this therapy are small compared to others. It is therefore worthy of further study.

Dialectical Behaviour Therapy

The predominant aim of this therapy is to reduce self-harming behaviour and to encourage appropriate emotional regulation: key features in the “blue print” for BPD. DBT was developed by Marsha Linehan in response to experiencing numerous problems when applying standard CBT to people with BPD. Linehan reported that
clients found the constant focus on change invalidating. Additionally, she found it impossible to address all the problems presented and essential to teach the clients more adaptive skills (Linehan, 1993). Linehan adapted the standard treatment to include three strategies which form the foundation of DBT.

1. Acceptance or validation based interventions incorporated into therapy. These communicate to the client that their behaviours, even the damaging ones “make sense”.
2. There is a focus on highlighting “normal” thoughts, feelings and behaviours thus helping clients to learn to trust themselves and their judgements.
3. Dialectic strategies are used to balance acceptance and change. These serve to prevent both the client and therapist becoming stuck in polarized positions that frequently occur in the highly charged emotional sessions.

This form of therapy is delivered in four modes: weekly 1 hour slots of individual sessions, weekly 2½ hours of group skills training, telephone contact and therapist consultations. DBT is a team approach: the individual therapists are supported by colleagues in weekly group supervision.

Numerous studies have examined the effectiveness of DBT for BPD however I will select just a few to highlight some outcome measures used. In a RCT by Linehan and colleagues (1991) the effectiveness of DBT was compared to treatment as usual (TAU) in a group of 44 parasuicidal women diagnosed with BPD according to DSM-IIIR. There were 22 in each group, those in the DBT group received standard DBT. Those in the TAU group received various treatment; each was offered individual therapy, some of whom participated and others who only used the in-patient and day patient services. There were three goals of therapy – to reduce the frequency of parasuicidal behaviours, to reduce behaviours that interfere with the progression of therapy (measured by attrition rate), and to reduce behaviours that interfere with the clients quality of life measured by the number of inpatient hospital days over the year.
There were no significant differences in the groups at baseline who were matched across a number of variables. Each group was assessed blind at baseline, three times during therapy and followed up at 6 and 12 months post-treatment. During the first year of treatment, the rate of parasuicide in the TAU group was higher than the DBT group. The one year attrition rate in the DBT group was 16.7% compared to 50% in the control group, and the number of days as a psychiatric inpatient was 8.46 days and 38.6 days respectively. At initial follow up, (6 months) the rate of rate of parasuicide behaviours was lower in the DBT group although by one year post treatment there were no between-group differences. Six months after treatment there were no differences in the number of inpatient days however, by one year the number of psychiatric admissions was lower in the DBT group who also scored higher on self-reported measures of global and social adjustment.

What strikes me about this study is the apparent inconsistency in the treatment received by the TAU group. It would initially appear that DBT is superior to TAU on all outcome measures however, whether this would remain if there was a more consistent therapeutic approach in the control group remains unclear. With such a small sample size and based only on women with parasuicidal behaviours, these results may not be transferable to other non-matched individuals with BPD. The fact that at by 1 year post treatment there were no differences in parasuicidal behaviours between the groups suggests DBT may be effective in the short-term, but more prolonged therapy or “booster” sessions may be needed to prolong the effects.

The costs for this study include medical and psychiatric costs only – not societal (Heard, 2000). They show that therapy costs for DBT were £13,033 compared to £7,958 for TAU but additional costs mounted to £8,941 for TAU and just £2658 for DBT. Overall the costs for comparison were £15,691 for DBT and £16,898 for TAU. These figures were based on the assumption that a UK based study would be delivered with the same intensity as the original. However, it is likely that inpatient stays would be more frequent in the UK than in America and given this point, I would expect DBT
in the UK to be more cost effective than is represented here. However I would also expect DBT to be less effective when not delivered by the founder and team who developed it although this is not reflected in the possible costs for the UK.

In a follow-up RCT by Linehan and colleagues (1999), DBT was found to be more effective than TAU in reducing drug abuse, again in women with BPD. At 16-month follow-up the DBT group showed improvements in global and social adjustment. Across these dimensions, both of Linehan's studies provide evidence that DBT can be effective in treating dysfunctional behaviours in people with BPD. However care must be taken when interpreting the results for drop-out rates as the criteria for such was significantly different depending on treatment group (failing to attend 4 consecutive sessions in the DBT group, or failing to attend any sessions after the first for the TAU group). Whilst I understand the difficulties in standardising measures used in treatment outcomes, assessing drop-out rates one would expect could be done more consistently than in this study.

Independently of the team who developed DBT with Linehan, and not with an American population, Verheul and colleagues (2003) compared DBT to TAU in a group of 58 women diagnosed with BPD and co-morbid drug abuse. Participants were randomly allocated to their treatment group using a minimisation method to ensure the groups were comparable. The treatment group was found to have no effect on parasuicidal behaviours or drug abuse. Although the DBT group was associated with less suicidal behaviour than TAU, this difference was not significant however the frequency of self-mutilating acts in the DBT group over the year long study. Alarmingly, the number of incidents of self-harm in the TAU group gradually increased to become significantly different from the number of incidents in the DBT group. This highlights the possible harm that can be avoided by using a therapeutic approach that specifically addresses self-harming behaviour. This study demonstrated that clinicians other than those that developed DBT can implement the approach effectively.
In a follow-up to this study (van der Bosch et al., 2005), the effect DBT had on reducing impulsive behaviour, self-mutilating and alcohol consumption remained, and relapse to the pre-treatment level of behaviour did not occur. All three measures remained lower in the DBT group. At the end of the 6 month follow-up, psychopathology scores for impulsive behaviour, self-harm and alcohol abuse increased slightly in the DBT group, and decreased slightly in the TAU group. These effects may be due to the fact that those in the TAU group were allowed to continue with treatment but those in the DBT group were not. These effects have important clinical implications, and again suggest that the effects of DBT may become extinct over a longer follow-up period. It provides further evidence to support the use of booster or follow-up treatment sessions.

The study reported that using DBT as opposed to TAU resulted in a saving of £50 per parasuicidal event avoided. The overall costs for DBT compared to TAU were £17,430 and £16,706 respectively; thus suggesting DBT is not as cost-effective. A criticism of these studies is the variability of treatment in the TAU group. Linehan and colleagues compared the effectiveness of DBT to an alternative structured treatment termed “Comprehensive Validation Therapy” (CVT) in a study of 23 heroin-dependent women with BPD. Both treatments were effective in reducing drug abuse, with the DBT group maintaining reductions throughout the year of treatment. However 3 people dropped out of the DBT group (36%) compared to none in the CVT group (Linehan et al., 2002). These findings indicate that although the attrition rate in DBT groups are generally lower than in TAU groups, compared to a structured control group, this is not necessarily true.

Turner (2000) compared DBT to Client-Centered Therapy (CCT), an alternative psychosocial treatment. His study was conducted in a community mental health setting where real-world complexities and co-morbidities were encountered. The study was conducted with 24 people with BPD including five males, and people of various ethnic groups. The sample reflected the diverse populations seen in real
clinical settings. BPD was assessed via a screening interview based on the Diagnostic Interview for Borderlines and a structured clinical interview. At the second assessment session an independent assessor confirmed a diagnosis using the Personality Disorders Examination and only participants meeting the criteria at both rounds participated. He found both treatment groups to be effective in reducing suicide and self-harm behavior, but those in the DBT group reported greater gains at 6 and 12 months. He also assessed clients' emotional functioning with those participating in DBT scoring significantly lower scores on impulsivity, anger and depression as measured by both self-reports and independent raters.

Blazier and colleagues (2006), reported the costs of DBT in the study to be £15,743 compared to £20,985 for CCT. The cost for DBT is approximately the same as in other studies so suggests CCT is a very expensive alternative. According to the authors, DBT was associated with 9.4 parasuicidal events avoided. Although the cost-evaluations for this study are based on solely medical costs, minimizing the number of parasuicidal events is likely impact on the individuals' ability to work, pay taxes and thus not claim benefits. It is also likely to significantly improve an individual’s quality of life although this needs further study.

The results from three independent research teams have all shown DBT to be partially effective in treating various symptoms associated with BPD. It is encouraging that such positive outcomes have been reported from various sources, and suggests the generalisability of the findings is good. Although DBT can be expensive and requires a lot of preparation and dedication from individual therapists and the team, according to research funded by the National Institute of Mental Health, the treatment is more than economically viable as it is shown to significantly reduce the number of emergency inpatient admissions (Goisman, 1997).
Conclusion

The three CBT-based therapies included have demonstrated limited and varied effectiveness. SFT demonstrated positive effects in reducing abandonment fears, identity disturbance, impulsivity and parasuicidal ideation, and also had a significantly lower attrition rate than TFT. Only one sound study was reviewed and clearly one cannot make judgements based on this. However, I believe this approach has a lot of potential and would be more useful if similar significant effects could be reproduced over a shorter period. Cost-effectiveness was suggested although further research is underway to ascertain this. MACT was found to be inconsistently effective in reducing DSH as compared to TAU. When applied to people with BPD, MACT was found not to be cost-effective. DBT was effective in retaining people in treatment, and reducing the number of inpatient admissions. It was generally more effective at reducing self-harm behaviours although not in all studies, and not at all follow-up points. Significant improvements were noted in global and social functioning in DBT groups across two independent studies, and in another study psychopathology symptomatology was less in the DBT group.

Each study used different measures to ascertain a diagnosis of BPD and thus the samples may not be equivocal. Most of the studies were small and had large drop-out rates so their data may not be reliable. Little research has been conducted on male patients with BPD or on diverse ethnic groups so the generalisability of the results is unknown. In each of the studies, different outcome measures were used and in most cases global measures of assessing improvement were utilised. The limitations of this may be that symptomatology associated with BPD reduces, but underlying psychopathology remains; possibly with the exception of SFT. I have previously acknowledged the benefits of recording frequency of self-harm as an outcome measure however in most studies this was not clearly defined and thus open for misinterpretation. Given that most people with BPD improve over time (Zanarini et al., 2003), this fact was not acknowledged and could explain some of the improvements. Studies with longer follow-up periods are urgently required to assess whether the long-term benefits of treatments for BPD persist.
Further research is also needed into ways long-term therapies such as SFT and DBT can be adapted to be shorter and more cost-effective. During times of crisis when individuals are most likely to engage with services and be motivated to change, (Davison, 2002) brief therapies may be more cost-effective (Hopwood, 2006). NICE guidelines are yet to be released regarding the recommendations for BPD but in line with the NIMHE document “Personality Disorder: No longer a diagnosis of exclusion” (2003), I expect the recommendations to be for the development of more specialist services which may take the form of therapeutic communities or centres where specialist staff can provide up-to-date and effective treatments. Currently there are very few Trusts that have a specialist PD services and thus staff are expected to treat people without the knowledge of how best to do so. As a clinician I strive to provide the best possible service to my clients and expect to use approaches based on current and strong evidence. The current evidence base for the effectiveness and cost-effectiveness of CBT is contradictory and based in many cases on methodologically flawed research. It is essential that this base continues to grow and I see part of my role as a clinical psychologist to contribute to this. I have thoroughly enjoyed researching this topic and although there is significantly more evidence for the treatment of BPD compared to other personality disorders, I am yet to be convinced that we have found the best treatments.
References


What are some of the strengths and weaknesses of multidisciplinary teams from the perspective of staff and service users? How can you as a psychologist contribute to teams functioning optimally?
Choice of essay

I was drawn to this essay as at result of a non-traditional start to my career in psychology and a fascinating first placement in a Community Mental Health Team (CMHT). For the first time on my placement I was immersed deep within a multidisciplinary team (MDT). Until then “working as part of a MDT” had merely been a statement on the bottom of job descriptions, and rarely an entity that I had noticed operating in the “real world”. My original career choice of medicine ended after two years when I discovered my passionate interest in the human body went beyond the physical being. At that time MDT working was not such a prevalent issue, certainly in my experience the message I heard was “do your bit then move on”. Perhaps this is a reflection of the autonomy that was assumed in the profession at the time. The independent and un-relating profession of medicine, as I had witnessed, no longer appealed – I wanted more of an involvement. My curiosity about people and the many layers of their functions and experience is what led me to a career in psychology.

In my assistant posts I was blinkered by my desire to get on the training course and held my supervisors, psychologists, in the highest regard. What they did, the things they said, and their way of interpreting a situation – theirs was the best way. Other professionals did not seem as able to hang on to the complete picture– teachers placed “too much attention” on education, doctors placed “too much attention” on health – psychologists held the balanced view. Then, in my first placement I shared an office with social workers and nurses; I was overwhelmed by how much we had in common – particularly our shared vision and overlapping methodologies. Each had their own professional background but as a MDT, we shared common values and worked towards the same superordinate goals. Our differences were a source of strength and expertise, they were neither threatening nor undermining: for the first time I understood the meaning and value of multidisciplinary working.
What is an MDT and how do they work?

Multidisciplinary teams are teams comprising of individuals from various professional backgrounds who are interdependent, and work together to achieve a common purpose. Not only do they have the value of offering several different professional perspectives, they also embody the richness of diverse perspectives including those based on ethnicity, age, gender, culture and race (Foster & Roberts, 1998). Team members need to have shared goals and values, and need to both learn from and respect different disciplinary views. MDT working often requires individual members to let go of their exclusive claims to specialist knowledge or expertise to allow the team, through whichever member, to provide the most appropriate care to service users.

Why have multidisciplinary teams?

The need for collaborative MDTs in the NHS that work in partnership with service user colleagues is well documented (Pearson & Spencer, 1995; NHS and Community Care Act, 1990; DoH, 1998; DoH, 1999b). The Department of Health paper “Continuing Professional Development, Quality in the new National Health Service (NHS)” (DoH, 1999a), stressed the importance of “striving to find opportunities for interdisciplinary leaning...and the need to build a culture of shared values between different professional groups”. With modern day legislation and the future aim of increasing care in the community, integration between health and social services is more important than ever (Carpenter & Barnes, 2001). As important is the continuity of care between in-patient and community settings (Haggerty et al., 2003).

Much debate has emerged regarding the effectiveness and challenges of multidisciplinary working (Galvin & McCarthy, 1994; Borrill et al., 2000; Jefferies & Chan, 2004; Holland et al., 2005). Similarly, many studies have investigated the consequences of ineffective MDT working for both staff and service users (Hilton, 1995; Morley, Eccleston & Williams, 1999; Fay et al., 2006).
Lack of service user views

Whilst reviewing the literature in preparation for this essay, I was struck by the extremely limited research depicting service-user views of how services, particularly mental health services operate. This is despite the political move towards consumerism, and many government papers documenting their commitment to obtaining (and using) service user perspectives to aid service evaluation and drive policy making (DoH, 1999b; 1999c; 2001). One interesting paper explored service users understanding of a rehabilitation team and the professionals in it (Meddings & Perkins, 1999). The research concluded that although the (highly experienced) service users could differentiate between different professionals and name some of their disciplinary duties, they seemed to lack a general understanding of the nature of the team and of whom it was comprised. With this in mind, gathering research related to the rather more specific question of the strengths and weaknesses of MDTs proved challenging.

My personal view about multidisciplinary teams is that they provide the best opportunity for interdisciplinary collaboration that ultimately enhances the care offered to patients. Some of the strengths of MDTs from the perspectives of staff and service users are presented below, a proportion of which will be discussed further.

Strengths of MDTs:

1. Increase training opportunities for staff (Carter, Garside & Black, 2003; Sharma et al., 2007).
2. Facilitate more creative ways of working (Molyneux, 2001)
4. Improve the quality of care of patients (Dargis et al., 1999).
5. Enhance the perception of team functioning (Onyett, 1992; Onyett & Ford, 1996; Carpenter, Schneider, Brandon & Woff, 2003).
6. Increase knowledge about the unique skills of each profession (Hudson, 2002; Dombeck & Karl, 2005)


Training opportunities

Many professionals at both undergraduate and post-graduate level are trained independently. Although there is currently a drive to provide more integrated training opportunities, such were scarcely available when training the majority of the workforce in post today. Some argue that working within a multidisciplinary team allows for the development of more creative methods of working that draw upon the collective expertise of its team members (Molyneux, 2001). Professionals who have previously been trained, supervised and managed from colleagues of the same discipline, have the opportunity within MDTs to learn from, and share with, other disciplines. The shared values of the team allows for exploration of treatment options from various theoretical frameworks for example integrating medical, psychological and social models (Carpenter, Schneider et al, 2003).

In a study examining the training needs of CMHT nurses, service users highlighted the need to have user representatives as part of the training pre-qualification, and later integrated within MDTs (Simpson, 1999). Such provision, they argue, enhances the team’s understanding of the needs of service users, and facilitates communication in an empowering way. It allows information to be conveyed openly between all professionals and service users without the risk of misinterpretation. Similarly, carers of service users also wanted more involvement in training of professional teams with an aim of conveying the experiences and viewpoints of carers to facilitate attitude change and enhance quality of care.
Creative ways of working

A study of MDT working in a secure mental health unit found that some staff viewed the creativity offered by MDT working as positive. However other staff suggested that the creativity of the MDT only comes to light after the initial application of the medical model (Shaw et al., 2007). Perhaps this view is simply a reflection of the setting of this study where clients were admitted at times of crisis, or perhaps it is an example of one of the weaknesses of MDTs. Both social workers and psychologists within this team reported that the opportunity for interdisciplinary working facilitated dynamic working that resulted in productive and creative interventions. Medical team members however acknowledged the benefits of having a MDT, but only; “after he is bit better... as personally, medication is really important”. Such statements highlight the potential for MDTs to be unsuccessful in delivering integrated care due to some staff retaining their disciplinary position and not committing to the team approach. (Obviously it is quite possible that in some cases medication is the most beneficial first step; however the challenge within MDTs is often to create a forum where it is not assumed always to be the best option).

Continuity of care

In a study exploring service user perspectives of the support they received when managing their health following a crisis, one individual commented that “[the team] breaks the hardness of the step...while I felt ready to come out of hospital; I didn’t feel ready to be on my own” (Godfrey & Wistow, 1997). The option of having support from a team connected to, and working in partnership with the crisis team was valued enormously. Continuity of care is frequently noted as one of the most valuable aspects of a team approach. It provides a central core of support from which service users can access a range of professionals with, hypothetically, the minimum of delay and least bureaucracy.
Within an inpatient context, service users positively valued the role of the MDT in collaborative decision making (Barker & Walker, 2000). In particular, service users commented on the advantage of having multiple perspectives presented to the consultants when considering their discharge. One commented that the nurses “got to know them better” and therefore were better placed than other team members, particularly psychiatrists, to provide insight into their readiness for discharge.

Noting service user views on their lack of understanding about what “the team” represents (Meddings & Perkins, 1999), it is important to remember that without a concept of team identity, the multidisciplinary team and its members may shift across the lifespan. For example, the MDT supporting a disabled child may first comprise of the parents, doctors and psychologists to ascertain a diagnosis. Over time as the child gets older, other professionals may become involved from education, therapy and social work services. These professionals may become more or less involved at any stage. Parents of disabled children reported that they placed enormous value on the continuity and coordination of services (Rosenbaum et al., 1992). Similarly, research with people with severe and enduring mental health difficulties highlighted an advantage of a team approach as “always having someone who knows about you there” (Beeforth et al., 1994). A team that remains stable during periods of crises and transitions was highlighted as critically important – particularly as these are the times when people often lose contact with services. In order for this team approach to be effective, it must essentially adopt a multidisciplinary framework whereby all professionals within the team commit to the same shared goals.
Weaknesses of MDTs

1. MDTs create the potential for interprofessional jealousy and conflict (Loxley, 1997; Carpenter et al., 2003).
2. Potential issues around confidentiality (Frost et al., 2005).
4. Dissonance between managerial and clinical expectations (Barker & Walker, 2000; White et al., 2000).
5. Current set-up is ineffective and possibly leads to costly delays and unnecessary suffering (Kerr et al; 1996; Barker & Walker, 2000; Sharma et al., 2007).
6. Lack of support for team working by some professionals (Davis et al., 2006; Shaw et al., 2007).

Potential for interprofessional jealousy and issues around confidentiality

The ethos of MDTs is that all team members are committed to a shared goal and that this goal is decided through collaborative working of all staff, the service user and their carer, if appropriate. In reality, this ideal rarely arises and may be attributable to longstanding issues:

'...conflict is interwoven with inter-professional collaboration because there are deep-rooted social differences in the division of labour which have developed over the last 200 years in the health and welfare service'. (Loxley, 1997).

Prior to undertaking professional training courses, we all hold stereotypes about the roles of other professions; these are further cemented throughout our training which, as stated, is predominantly independent from other MDT professionals. The ignorance about differences in professional roles may be particularly problematic in
competitive individuals. One source of jealousy may be the use of separate
disciplinary notes which are commonly kept in therapeutic services. Guidance from
the Division of Clinical Psychology (DCP) states that “Generally, clinical
psychologists are expected to keep their own notes of sessions...separate from the
shared record” (DCP, 2000). Although the majority of psychologists keep contact
notes in MDT files, one study found that up to 97% of psychologists held separate
files from the MDT as it was inappropriate to share some information with the team
and thus recorded separately (Scaife & Pomerantz, 1999). Such practise may give rise
to professional rivalry as other professionals feel excluded from the right to know
certain information, and thus psychologists are positioned in the more senior
“knowing position”. This can be damaging to the ethos of MDTs, particularly if the
reasons for keeping separate notes are not understood.

In a study exploring social workers perceptions of MDTs, one commented that a
barrier to good interprofessional relations is “the status of different professionals”
(Frost et al., 2005). This comment was in relation to a consultant assuming the
dominant position in the team, for example by chairing meetings, and not recognising
her position as “the most senior social worker in the hospital”. (A comment that in
itself is suggestive of interprofessional conflict).

The notion of professional power and status is one that can frequently lead to certain
professional groups feeling disempowered in their role: not least the service user who
is often in the position of least power, despite current legislation. Mental health
nurses in one forensic setting, although acknowledging support for the MDT model,
stated that their lack of status within the team was an obstacle to their effective
participation (Coffey & Jenkins, 2002). Within a mental health context, another of the
possible obstacles to effective MDTs is the issue of legal responsibility which is
located with consultant psychiatrists. This responsibility effectively places them in a
more superior position and thus some staff have queried the point of MDT meetings if
all decisions are ultimately in the hands of the psychiatrist. As one nurse interviewed
in an acute psychiatric setting commented: “...at the end of the day it is the consultant’s decision, he/she “carries the can”...” (Barker & Walker, 2000). This comment was in relation to discharge planning in particular, and not a reflection of the nurses’ views of the more general operating of the MDT. In the same study, nurses were asked about the role of service users within the MDT as partners in care planning, they reported that collaboration “normally occurs with just a few (who) just sign it (the care plan), and depends upon how ill they are”. Similarly the role of family members and carers within the MDT was not recognised as important: some families were described as “taking over” or of being “too involved”. It is clear from such comments the potential for conflict and “us and them” thinking to emerge, and thus highlights the need for an agreement regarding who is part of the MDT and what are its goals.

**Blurring of professional boundaries**

The potential for MDTs to blur professional boundaries has been debated for many years (Munley et al., 1982). Some argue the advantages of more shared responsibilities, particularly with regard to less formal boundaries between staff and service users (Williams et al., 1999). However in a study of professionals in an MDT, different staff groups reported different levels of job satisfaction and burnout (Onyett et al., 1997). The authors hypothesised that increased dissatisfaction experienced by social workers “might be a consequence of their more marginal position within the MDT, resulting from their having a different employer”. As a consequence of working within a predominantly medically orientated CMHT, social workers acknowledged themselves as at risk of losing their professional identity. This finding was replicated later by Carpenter and colleagues (2003), who also found that social workers experienced higher levels of role conflict, and consequent stress and job dissatisfaction.

Within an acute psychiatric setting, staff perceptions of multidisciplinary working were examined in relation to the care pathway process (Jones, 2006). Nurses reported
that the MDT model leads to "dissatisfaction with the current role of the nurse", which has changed "by the presence of other professional groups, most notably OT (Occupational Therapy)". The research suggested that many professionals, particularly nurses were not sure about their professional role and stated their role was "ambiguous to both themselves and the patients". Within this team, a psychologist suggested that the confusion around roles and professional identity was more related to the field of psychiatry in general, as opposed to the format of multidisciplinary working:

"I used to work with kids, teachers, social workers and psychiatrists and they all had a definitive job despite overlap in the jobs...in psychiatry there's such conflict and confusion in roles and besides what is psychology, it's such an unexplored science".

(What struck me about this comment was the apparent clarity about the role of a psychologist. My personal experience has been that like other professionals, I too am often confused about my role. This confusion is sometimes exacerbated by the MDT context when I struggle to see what it is that I am offering which is different. However, perhaps with greater confidence in my abilities I will be more able to identify my professional competencies and roles and therefore feel threatened by question of what do I do.).

In a study gathering service users' perspectives of MDTs in a secure unit, the professional's concerns regarding hierarchy of roles were far less significant to service users (Shaw et al., 2007). Rather, all professionals were noting as being a single category. One service user speaks of his request to have unescorted leave considered at the ward round: "so I put my request in this week...if they want to see me, they will call me". Such comments highlight the apparent lack of agency this man feels for his
own care: he is separate from the team, yet a team, as opposed to separate individual professionals take decisions.

**Conclusion**

Multidisciplinary teams are the prominent format for the delivery of health and social care in mental health services today. Although much research has ascertained staff perspectives of this approach, little is truly known about what service users think. As Meddings and Perkins (1999) discovered, the concept of “the team” is often a mystery to service users. In addition, many of the studies gathering their perspectives of team working have been typically one-off events relying almost exclusively on self-designed interview schedules and questionnaires. It is therefore incredibly difficult to make comparisons across services or to pull-together a coherent perspective. Clearly there are differences in how MDTs work in each service and despite the damning report into their format in CMHTs by Galvin and McCarthy (1994), I believe they are the most useful framework for delivering mental health services in today’s NHS.

**How can I, as a psychologist, contribute to teams functioning optimally?**

Psychologists are increasingly located within MDTs and therefore in an ideal position to enhance team functioning by fostering relationships within, and between team members and their service user and carer colleagues. An advantage of our position is that our training experiences encourage systemic thinking both in relation to direct clinical work, but also in terms of wider systems such as families, the MDT and the service as a whole. The application of which can encourage us to think more broadly than “a disease specific perspective”, which can potentially alleviate some of the sources of conflict within teams that arise out of focus on disease and its treatment (Vetere, 2007). More so than other professionals within the MDT, the very nature of our work and its relational component are ideal skills to apply to the MDT system to enhance its functioning.
Some of the ways I may contribute to optimal team functioning:

1. Offering individual support to team members
2. Modelling positive and respectful communication
3. Offering training opportunities
4. Providing consultation services
5. Conducting research (for example into the functioning of the team or measuring outcomes).
6. Contributing to the design of services for maximum cost effectiveness

Underpinning all of the above is the role for psychologists to engage in evidence based practice and to work reflectively. The traditional role of clinical psychologists is rapidly changing with less emphasis on direct clinical work, and more on consultation to other staff to facilitate the delivery of more psychological interventions (DoH, 2004). The New Ways of Working document titled “Working Psychologically in Teams” (BPS, 2007) is a comprehensive paper which details many ways in which psychologists can contribute to teams functioning optimally and presents evidence to support these contributions. Rather than reproducing that document, or its summary, I have extracted some of the key themes which are of particular interest to me as a clinician.

*Promoting effective participation of service users and carers*

Despite extensive legislation documenting the necessity for service users and their carers to be involved in planning their own care and services (DoH, 1999b; 1999c; 2001), research has consistently shown that this is often not the case, and service users feel disempowered in their role as “partners” (Poulton, 1999; Rutter *et al.*, 2004). This can lead to “us and them” thinking and the potential for splitting within teams as service users seek to get their needs met (Hodge, 2005). However the advantages of involving service users and their carers in service delivery are well
documented (Beeforth et al., 1994). As a psychologist, one could enhance team functioning by ensuring the views of service users and their carers are always heard. Through offering training about the context of the service, the team and its structure, service users may feel more empowered and confident when contributing their views which in turn can facilitate more effective joint working (Clarke, 2006). Similarly, psychologists have a role in educating staff about the benefits of service-user and carer involvement, and may also offer staff training about how to work collaboratively with service users and carers whilst being mindful of issues of power.

As stated previously, the lack of service user perspectives on multidisciplinary working, one of the key changes to how services are delivered, is quite remarkable. With our responsibility to contribute to the evidence base, and to engage in reflective practise by consistently monitoring the effectiveness of what is being delivered, psychologists must ensure the perspectives of service users and their carers are collected and utilised when revising operational policies.

Providing opportunities for peer consultation

In addition to offering clinical supervision, psychologists must embrace the role of providing a consultancy service to team members. Such a service can enhance team functioning by creating a space to explore complex issues relating to client work. The components of effective relationships for peer consultation are outlined by Beinhart (2004) and are based upon mutual trust and respect. It is essential that psychologists maintain a position of curiosity and interest and examine not only the issues of relevance to the client, but also seek to explore the impact of the work on the individual. Similarly issues of power and dependency may be easier to explore with the addition of a consultant into the system which changes the nature of the worker-client relationship from linear to triangular thus creating a reflective space (Roberts, 1998 cited in BPS, 2007). By offering a consultancy service, psychological therapies can be delivered in the form of a stepped care model. Professionals can discuss the psychological needs of their clients and their capabilities to address them, and
negotiate with the psychologists about the appropriateness of delivering interventions themselves, or referring to more specialist services (Bower & Gilbody, 2005). Not only does consultancy empower professionals, it also serves to enhance working relationships through more joint working, and allows for the delivery of psychological therapies to many more individuals than if delivered by psychologists alone.

Facilitating the development of effective teams and leadership

Most teams I will enter in the initial phases of my career are likely to be established and multidisciplinary. However, as a clinical psychologist, I am likely to enter a team in a position of relative leadership – an incredibly daunting task. As it is so daunting, it would be easy for me settle into a team with blinkers on regarding my specific role as a psychologist to contribute to its optimal functioning. Accessing the literature for this essay highlighted the necessity to have clear shared goals and defined roles within the team. Psychologists have a role in supporting the development of these goals and then evaluating the degree to which they are being achieved as research has demonstrated that the benefits of team working are not always consistent (Allen & Hecht, 2004). The role I will have as a psychologist is one that seems distant and alien at this stage of my career. Currently on placement, we enter teams largely viewed (in my experience) as students. However our skills in interpreting research place us in an ideal position in the team to be responsible for ascertaining the components necessary for successful team working and then disseminating this knowledge to our colleagues in our role as training providers (BPS, 2007).

Conclusion

The role of a psychologist stretches beyond the realms of direct clinical work, and we have a key role in supporting the development and growth of teams. New Ways of Working guidelines (BPS, 2007), highlight our responsibilities to the team and to the shareholders to integrate our knowledge and skills within the framework of the team thus facilitating its optimal functioning. Through the encouragement of more
effective service user and carer participation, I hope to develop the concept of
effective person-centred planning in a way that is empowering, and that contributes to
the team’s understanding of service user and carer needs. By offering consultancy
services to staff, the capacity of the team to deliver more psychological therapies will
be increased. The aim of encouraging reflective practice will be to support staff
individually, and in a group context, to explore the impact of client work on them. It
will seek to develop greater awareness of issues such as transference and
countertransference which has the capacity to enhance clinicians’ understanding of
their clients and themselves. Greater understanding may lead to improved outcomes.

Reflections

I have enjoyed the opportunity to explore some of the wider roles of clinical
psychologists and to think about some of the challenges I will face. It is has been
encouraging to see the links between the theoretical models that are applied to direct
individual work, and their usefulness in thinking about teams and wider systems. I am
pleased that my placements so far have enabled me to experience personally both the
advantages and disadvantages of MDTs and that through the reading associated with
this essay I have a clearer idea about how to manage some of the challenges I face.
My overriding thought is that I feel encouraged and positive about working in a
healthcare system that, although failing to deliver in some aspects (effective service
user participation), is largely functioning effectively and delivering high quality care
to service users.
References


PROBLEM BASED LEARNING REFLECTIVE ACCOUNT 1

The Relationship to Change

February 2007

Year 1
All quotations are extracts from my reflective journal.

**Introduction**

“The Relationship to Change - what does that mean? It’s not even a proper sentence. How do we know what do to? Who do we ask? …This feels like the blind leading the blind”.

Just a few of my thoughts when we were assigned the task of doing a presentation. My anxiety levels were rocketing. I had just started the clinical psychology course, was feeling excited yet nervous and here I was about to reveal myself as someone who does not understand simple task instructions. I have since wondered if this is how clients feel when they come to see me. The fear of meeting a new person you might have to “reveal all” to, confusion about what is expected and experiencing distress all at once I imagine is an extremely unpleasant combination. It has reinforced the importance of being clear about goals, aims and expectations when clients come to therapy and also how crucial it is to check understanding of tasks and processes explicitly. I would have done anything to mask my uncertainty to the strange people in my group and by doing this initially, as were the other people in the group, we got nowhere with our task. This task has taught me the importance of taking initial responsibility to model honest and open communication in all settings and in every role as a clinical psychologist.

The problem based learning (PBL) task was assigned to us in our small case discussion groups (CDG). We met weekly for six weeks with a member of the course team joining us on three occasions as a group facilitator. Although I recognised the names of my fellow group members, I knew little about them and their working style and felt uneasy about my personal lack of confidence in our first task. At the time the task felt ambiguous and vague and I wondered when “the staff” or our facilitator was going to disclose more information. I often looked to our facilitator to clarify the task and felt lost, uncomfortable and “on-trial” when she did not. I can therefore
understand the frustration some clients may feel when they expect psychologists, like their medical colleagues to be experts. With this expectation it may feel disheartening to hear that we are not going to “prescribe” what to do to get better. I have learnt that this must be made clear from the offset. Following is a brief summary of our presentation and my reflections on our group processes. Throughout the account I will attempt to reflect upon some of the ways the exercise has impacted on my clinical and academic styles of working.

Overview of presentation

Our group decided to map the relationship to change on to a theoretical model of mental health promotion. The model highlights the various levels of action (micro, meso and macro) which are important to recognise as spheres of influence in any given situation. The most “effective” changes occur when consideration is given to the impact of, and interaction between, these levels. It is not sufficient to work solely with individuals but rather to work with individuals in the context of their wider systems and at wider social levels (MacDonald & O’Hara, 1998). We conceptualised the micro level as us as trainees, the meso level as the university training course and the macro level as the British Psychological Society (BPS), National Health Service (NHS) and the government. In discussing our own relationships to change, we reflected upon the impact we have on the training course and the future of psychology and acknowledged the pressures the course team experience as a result of the current uncertainty in the profession. For me personally, this was a powerful exercise in unpicking the “us and them” phenomena that often exists between staff and students. Using this model also encouraged me to think more widely than the therapeutic role of a Clinical Psychologist: it generated thinking about the responsibilities I will have in making important professional decisions that will influence the ways services are managed and delivered. Until we began focusing on change in the exercise I had not considered the ways in which training would inevitably change me and the impact this would have on my relationships: the very nature of the task viewed through this model encouraged me to become more systemic in my thinking.
First session

It is important to reflect on this initial session as I feel it shaped the way the task was tackled and how our group has subsequently run. Our facilitator led the session initially and ensured each of us had an opportunity to talk. She modelled how we might include people in conversations without putting pressure on them to contribute. She also encouraged us to view discussions as something more than statements being fired in random sequence. To be asked by a staff member whether their comments and suggested ways of working were “ok” felt strange and unexpected. This approach quickly enabled me to feel part of a training course, and not like a student who was being taught: it was the beginning of my days as an adult learner. On reflection I am wondering whether this powerful feeling of being part of a “training team” without a staff/student split was a major influence on the format our presentation eventually followed.

We were encouraged to scan over some information about PBL as a method of learning (Wood, 2003) and allocate a Chair and Scribe for each session – these roles have been rotated each session to allow each of us an opportunity to develop these key skills. From this initial meeting our way of using the sessions was grounded in providing opportunities to learn and practice skills which we utilise professionally. I valued this aspect of the CDG been drawn to our attention: as trainees it is easy to see each task and assignment as something to do in order to progress. In my previous degree and jobs I have seen the content and final product as the aspects to be valued yet in the CDG it is the process one goes through that is of the most importance. I feel quite ignorant to have only realised that at this stage in my life. Certainly as clinical psychologists the focus of our work will be in examining processes and how people cope with and adapt to change. It is not situations or demands that cause distress but rather the ways in which we interpret, manage and make sense of them (Lovallo, 1997). My relationship to change was metamorphosing as the exercise progressed: I became less obsessed with hypothesising about what the change is from and to, and more concerned about what happens in between. The task took on a different, less content-focused meaning as it progressed.
Process

To my horror the format and content of our presentation kept changing; by week four we had *still* not decided on who was saying what and when. I felt uneasy; and it felt out of control. We would agree on one direction and in the light of “a great study I’ve found” we would change our ideas the following week. The fluidity of the process felt unnatural - I had yet to learn the importance of an evolving piece of work and the constant reshaping that takes place over time and with the addition of new information. The concept of formulation and reformulation were becoming part of my academic work – I could see my thinking patterns beginning to shift. I had entered the group as someone who believed success came with “doing”. My science A-levels and approach to psychology thus far encouraged me to “think then do”; I labelled myself as a “Scientist Practitioner”. The PBL task brought me together with people who seemed comfortable with allowing the presentation to emerge and unfold over time - I wanted to strip it bear straight away. I had heard the term “Reflective Practitioner” often and interpreted it as something to incorporate into my style of working. Until I compared myself to others, I did not realise that it was so lacking and as such I felt seemingly more uneasy than any anyone else when there were pauses and silences in the discussion. That night I felt determined to learn “how to do reflection” – my heart sank as I realised it was not a quick skill to learn but rather something to constantly work at (Cushway & Gatherer, 2003; Lavender, 2003). I had initially felt frustrated at what I interpreted as a refusal or inability of some group members to commit to a decision but after reading I realised I had completely misinterpreted their actions. I remember this lesson everyday in my clinical work: I am at the beginning of training and there is an awful lot I do not know and am not expected to know. I am constantly learning and my knowledge is being updated and reshaped daily – I need to acknowledge my limitations to clients and to myself.

The curiosity about what the other groups were doing was constant throughout the task. We were all quite secretive and I would have felt disloyal had I shared any of our ideas. There was a definite sense of camaraderie building in our group, I suppose as a result of us “being thrown in at the deep end”; we were united in uncertainty and
needed to work together in order to complete the task. The trusting space and relationships that stemmed from that unity have remained and I cherish the protected time we have each fortnight to share our ideas and anxieties in a manner that in supportive and non-threatening. For me that has been the most beneficial consequence of setting a vague task. In addition I value enormously the opportunity to see just how different I am to others and vice versa. Naively I presumed we all thought and learnt in a similar way in order to have succeeded academically and make it on to the course – how wrong I was! The different experiences and expertise we bring to the group widens our knowledge base and I feel comfortable drawing on the skills of my fellow CDG members. Similarly it is so uplifting to be asked for my opinion on a range of matters and to be known as the “expert on X” in the group (Although I am not an expert!). It allows me to feel confident about myself and my abilities and to value my personal experiences as something others can learn from.

The group consisted of six women and one man: Five heterosexuals and two homosexuals: Five British people and two non-British. We drew attention to the diversity and richness of this mix during our first session. It felt strange to identify differences as until then we had focused on the similarities - all seven of us embarking on a three year rollercoaster. It was the first time I had been in a group where we pointed out differences: I felt uncomfortable and judgemental at the time. In hindsight I realise the importance of identifying ourselves and taking ownership of who we are; it cannot be assumed that we are all the same. In my clinical work since I have been cautious about making assumptions about clients based on limited information and careful not to presume their thinking pattern is similar to my own.

Summary

From this task I have gained a greater understanding of how people learn and interact. I have learnt to tolerate ambiguity and uncertainty and to call upon my fellow trainees for support. Through conceptualising the relationship to change as a product of a series of actions working dynamically and across multiple directions, I have a greater
understanding of the systems that interact when an individual is attempting to change in therapy and of how best to change and shape services by considering the multiple levels of action involved.
References


PROBLEM BASED LEARNING REFLECTIVE ACCOUNT 2

Child Protection, Domestic Violence, Parenting and Learning Disabilities

February 2008

Year 2
Introduction to the family

The Problem Based Learning (PBL) task evolved from consideration of the Stride family which consists of Mr & Mrs Stride, and their twin girls Sally and Sarah, who are three years old. The girls are currently placed in short-term foster care. Mrs Stride is one of two children, has a mild learning disability and suffers from depression. She was raised in the Looked After Children system. Mr Stride is one of four children and was raised by his parents who live locally - they are supportive of the family. Mr Stride has a history of physical abuse against his wife.

The Stride’s provided an opportunity to discuss many issues relevant to our current placements within either learning disabilities, or family settings. Our group has seven members (six female, one male) – five currently on learning disability placements, two on child. We have not yet swapped placements, which meant that at least some group members have not worked clinically (or indeed at all) with the other client group. This unequal division of members, and therefore imbalance of clinical experience shaped our presentation greatly.

Overview of group work and presentation

Initially our group split up and researched topics relevant to the case and of particular personal interest. We spend the first couple of sessions feeding back the information and highlighting further sources to consider. For example we looked broadly at definitions of domestic violence and categories of abuse (which the twins allegedly suffered). We then explored the relationship between abuse and child development (Cooper & Vetere, 2005). Following on, we looked at guidelines relating to the management of abuse, and the impact it has on children consulting sources such as The Children’s Act 1989 and The Child Protection Portfolio (British Psychological Society, 2007).

After much discussion, we presented the material in the format of a play re-enacting a court case. This allowed us to portray different perspectives, and to present lots of
information in an engaging and digestible manner. In the court we called “expert
witnesses”. These were child or learning disability psychologists and Mrs Stride. We
showed a video depicting the attachment style of the twins to their mother, and had a
“jury” who pulled the threads of the arguments together and summarised the salient
issues. On reflection the persuasiveness of the argument from the learning disability
psychologist indicates that as a group we were mainly in favour of the girls being
returned to their parents and services being tailored to better support the specific needs
of the family.

Reflection on successes and weaknesses of approach

The format of our presentation was very different from the one in the first year. It was
much livelier, and reflected our decision as a group to use the exercise as an
opportunity to learn, rather than an opportunity to exhibit our finest presentation skills.
In the first year, being much more content driven and anxious to show how good we
were at presenting clinical information, our group presentation was very dry. I did not
realise this at the time but with the passage of time and a shift in my understanding
about the function of PBL exercises, my opinion has changed.

I found the practise of initially discussing our hopes and aims for the exercise
incredibly useful as it served to structure and contain the task. I have carried forth this
skill on my current placement. Within learning disability services, I have found that
most issues one is called upon for are extremely complex and interlinked. As learning
disabled clients often have contact with services for years, there is usually a great deal
of information known about them. An essential skill for any professional, but more so
for a psychologist, is the ability to gather relevant information and piece it together so
that specific questions can be answered. That essentially involves creating the
boundaries to tasks and focusing yourself and the team you work with. I entered this
task with an open mind and vowed to myself and my group that I was not going to
concentrate on the outcome of the presentation, but rather the process we go through
as a group to get there. This largely shaped how I contributed to group decisions and
seemed to be a decision many of us in the group made. This resulted in conflict between group members for the first time and stemmed from us adopting a more relaxed approach to the task – one that would emerge rather than be driven.

I think our approach worked well and that delivering the material in a courtroom drama made an interesting presentation for our peers. However I am aware that on occasions we became quite animated and I wondered about the appropriateness of this when discussing such sensitive issues. Perhaps using humour removed some of the discomfort we felt when discussing parenting in people with learning disabilities. I cannot help but think that this echoes what happens in the real world sometimes when there is a sense of “jollying along” people with learning disabilities. I have experienced this on placement when I have witnessed painful or embarrassing topics being glossed over using humour – as though people with learning disabilities do not need to know such information.

Having taken the opportunity to use an allocated video session to discuss the presentation and group task, we were able to look back and see how our group functioned during the planning stages. This was incredibly helpful and is something that we are hoping to do more frequently. My reflections from memory and watching the video revolve around one key theme – conflict.

Conflict

Throughout the PBL task our group had many heated discussions. Some of these evolved from consideration of The Stride’s, which generated a split between who was on “whose side”. Some group members were adamant that the risks to the children were too great and that they should be permanently removed from their family. Others of us were much more in favour of supporting the parents to care for their girls. We spoke in detail about the unfair scrutiny parents with learning disabilities face (Woodhouse, 1997; McGaw, 2000). I have since noticed this a lot in my learning
disabilities placement. Whilst theoretically people are supportive of equal rights and opportunities for people with learning disabilities, in practise there seems to be an undercurrent of professionals and services policing people’s lives. This has been particularly apparent when topics such as parenting abilities or sexual relationships are discussed.

I am currently working with a couple (both who have learning disabilities), and who want to develop their relationship sexually. As may be expected, there are mixed views amongst staff on this subject – as is common (Heyman & Huckle, 1995). Some argue that staff have no right to an opinion on the matter, whereas others talk of their duty of care to act in the best interests and support the people they care. As the female in the relationship has a history of being a victim of serious sexual abuse, and the man is cognitively much less able, there are also concerns about vulnerability for both individuals. This topic has evoked strong emotional reactions in me and in the support staff I have been working with. Through discussions with peers in my case discussion group, I have been able to reflect upon the challenges involved in this work, and to safely explore my thoughts about people with learning disabilities having children and the support they may need.

As I have witnessed clinically, and in consideration of the Stride family, there is variation in the degree to which services and professionals “get involved in personal matters”. The Stride family had lots of different professionals involved, yet none of them seemed to take a meta view of their situation. It appeared no thought was given to considering the impact of multiple stressors on someone’s ability to parent. Within our group this sparked some really interesting discussions about people’s personal circumstances. Conflict arose when the commitment to the group was questioned after one member suggested working on the task until late in the evening. We spoke about the challenges of balancing home and work demands, and the fact that we all have different responsibilities and commitments outside of our role as trainees. Being aware of the demands on others has helped me to get a sense of where people are
coming from, and what life is like for them. It has enhanced our group cohesiveness and facilitated communication. Throughout the task I have learnt a great deal about our group in terms of their personal views and life circumstances, this has aided our development as a group. We are now much more confident in appropriately challenging each other.

**Personal and professional growth of self and others**

I am pleased that this experience has led to a greater understanding about the boundaries regarding expression of personal opinions. It has always been an area of my professional persona that I have been mindful to develop. I understand that part of the role of a psychologist is to enable clients to be heard, and to sometimes advocate on their behalf when otherwise their preferences may be disregarded or lost. What can be challenging sometimes is when their desires or behaviours conflict with our personal morals. I believe that through our presentation were able to make the voices of the Stride family heard. Interestingly however, we only ensured this for Mrs Stride. The opinions of Mr Stride went unnoticed and I wonder if this is what sometimes happens in our group when we have one male among six females.

The consideration of topics such as domestic abuse, neglect and parenting all had the potential to stir up strong personal feelings. That certainly happened in our group and because it did, it forced us to explore issues with each other that we had not done so previously. This facilitated honest group communication, and gave us an opportunity to practise owning our opinions but conveying them in a way that is respectful to other. This will be a key skill in our role as psychologists.

**Learning points for self and others**

Much of my learning from this task has come from understanding the pressures that people with learning disabilities face. It is very easy to notice things that are not
going well, and to gloss over what is. Thinking about the case from the position of Mr & Mrs Stride, most of what was documented was negative (e.g. depression, abuse, neglect). I was aware of my curiosity about what they can do and in what areas of their lives they have success. In our career we are likely to be shown only our clients’ weaknesses and “problems”. This case and my subsequent learning on placement have taught me that I need to work hard to uncover people’s strengths and foster their resilience. The literature I accessed will also be helpful in preparing me for some of the issues I may come across in my child and family placement. For example in thinking about the effects of witnessing abuse or being separated from their families (McGee, 2000). As a group, I think it is important that we continue to speak honestly with each other and use the safe place of the CDG as a space to explore our views.

Summary

With the benefit of time for reflection, I have learnt a lot from this task. It was stressful and awkward to challenge group members on what I perceive to be unusual beliefs. However as the group developed, it became safer to do so and thus enabled us to practice a key skill of talking sensitively about difficult and often controversial subjects.
References


Prosecution

The prosecution would like to call the Child Psychologist to the witness stand.

*Child Psychologist sits at the stand.*

Prosecution

Dr Playtime, would you be so kind as to tell the court what domestic violence is?

Child Psychologist

Domestic violence can include emotional abuse, such as bullying, verbal abuse and verbal threats as well as actual physical or sexual violence

Prosecution

And is there any evidence that domestic violence has occurred in the Stride’s family home?

Child Psychologist

From the information I have read and from my own conversations with Mrs Stride it would appear that there has been some domestic violence towards Mrs Stride from her husband. But...

Prosecution

...And if you would be so kind Dr Playtime. Could you please tell us, is there any evidence that the children of Mr and Mrs Stride witnessed this domestic violence at any time?

Child Psychologist

It seems likely that on some occasions the children were in the same or next room when the violence occurred. But this was...

Prosecution

...And in your professional opinion, what impact might this domestic violence have had on the children?

Child Psychologist

Um well...
<table>
<thead>
<tr>
<th><strong>Prosecution</strong></th>
<th>...Yes Dr Playtime?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Psychologist</strong></td>
<td>...There is evidence indicating that children may be greatly distressed by witnessing domestic violence. Parents’ suffering domestic violence may also show signs of an impact on their ability to look after their children. Domestic violence can have a serious impact on a child’s development and emotional well-being and can lead to serious anxiety and distress.</td>
</tr>
<tr>
<td><strong>Prosecution</strong></td>
<td>Is it not also true that witnessing domestic violence can affect a child’s cognitive, social and emotional development?</td>
</tr>
<tr>
<td><strong>Child Psychologist</strong></td>
<td>Um yes...</td>
</tr>
<tr>
<td><strong>Prosecution</strong></td>
<td>I have just one further avenue of enquiry for you Dr Playtime.</td>
</tr>
<tr>
<td><strong>Prosecution</strong></td>
<td>Have you read the 2007 British Psychological Society document the ‘Child Protection Portfolio’?</td>
</tr>
<tr>
<td><strong>Child Psychologist</strong></td>
<td>Yes I have.</td>
</tr>
<tr>
<td><strong>Prosecution</strong></td>
<td>Does this document not state in connection with parents with a learning disability, and I quote, “their children’s health and development is likely to be impaired”.</td>
</tr>
<tr>
<td><strong>Child Psychologist</strong></td>
<td>Yes I think it does but...</td>
</tr>
<tr>
<td><strong>Prosecution</strong></td>
<td>No further questions. Would the defence like to cross-examine?</td>
</tr>
<tr>
<td><strong>Defence</strong></td>
<td>Yes we would. Hello Dr Playtime.</td>
</tr>
</tbody>
</table>
Child Psychologist: Hello.

Defence: May I ask you Dr Playtime, have you read the 2003 document 'Every Child Matters'?

Child Psychologist: Yes of course.

Defence: Is it not true that this document states that all efforts should be made to support children in their own families?

Child Psychologist: Yes it does.

Defence: Could it not be argued then that Mr and Mrs Stride need support in order for them to care for their children in their own home?

Child Psychologist: It's more complicated than that...

Defence: A yes or no will do Dr Playtime.

Child Psychologist: Yes but...

Defence: Is that a yes Dr Playtime?
<table>
<thead>
<tr>
<th><strong>Prosecution</strong></th>
<th>Objection. The Defence is badgering the witness.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Defence</strong></td>
<td>Please would you answer the question that has been put to you Dr Playtime?</td>
</tr>
<tr>
<td><strong>Child Psychologist</strong></td>
<td>Well yes.</td>
</tr>
<tr>
<td><strong>Defence</strong></td>
<td>Thank you Dr Playtime. And who is responsible for providing that support?</td>
</tr>
<tr>
<td><strong>Child Psychologist</strong></td>
<td>Well in that case it would be the responsibility of local authority departments, health authorities and community services. But that...</td>
</tr>
<tr>
<td><strong>Defence</strong></td>
<td>...Thank you Dr Playtime. A final question for you. Do you think that Mr and Mrs Stride have been treated in the same way as parents you have worked with who don’t have a learning disability?</td>
</tr>
<tr>
<td><strong>Child Psychologist</strong></td>
<td>(thinks for a while)- well, I would question whether...</td>
</tr>
<tr>
<td><strong>Defence</strong></td>
<td>A yes or no answer will suffice, Dr Playtime!</td>
</tr>
<tr>
<td><strong>Defence</strong></td>
<td>I would say no, they haven’t been treated the same.</td>
</tr>
<tr>
<td><strong>Child Psychologist</strong></td>
<td>No further questions</td>
</tr>
</tbody>
</table>
Jury’s script

It seems that 4 risks have been highlighted in court today.

1) The first factor is the issue of domestic violence. Mr. Stride has been violent towards Mrs. Stride in the past as we have heard and this can have an influence on the children’s development. However, it is not clear if Mr. and Mrs. Stride remain violent towards each other and if the children are still at risk or not. Domestic Violence is clearly a risk issue. Yes but the children may be underdeveloped and withdrawn because they may also have a learning disability and not because they are witnessing or actually being abused.

2) The second factor is the concerns regarding Mr. & Mrs. Stride’s ability to parent. Frankly what I’m curious about is whether such concerns would have been raised had Mrs. Stride not had a learning disability. It’s interesting that there is no direct correlation between IQ and parenting competency yet papers such the BPS Child Protection Portfolio highlight the presence of a Learning Disability as a risk issue.

3) The third factor considering the evidence presented here today implies that Mrs. Stride’s learning disability is the most salient factor in her and her husband’s inability to parent their children. Yes but a more prominent issue may be the fact the family is living in poverty. Perhaps with additional financial support, Mr. & Mrs. Stride may be better able to provide a more stable family home and additional resources that would facilitate their ability to parent. However, whether this would be to an adequate is unknown at this stage.

4) The fourth issue is a concern regarding how Mrs. Stride’s depression will impact on her ability to parent her children, as emotionally she may not be available for her children. However, Mrs. S is now receiving counseling and taking anti-depressants,
which clearly lowers the risk that her depression could have on the children’s development.

**Closing points.**

In addition to the specific risk factors, there are wider issues to consider in this case. For example, has any of this process been understandable to Mr. & Mrs. Stride? I guess not with the amount of jargon used. Is this a reflection of what has happened all along for them? Also, why is it that interventions only seem to be offered in a crisis?

I think it’s crystal clear that everything that has been offered to this family has been inappropriate. This has led the family to withdraw and people have assumed they are uninterested in getting help. However, the most salient issue for me has been the lack of communication between services and the family. Whilst there has been specific input from parenting services, and also learning disability services, neither has been able to look at the whole picture. How do you negotiate parenting whilst having a learning disability?
PROBLEM BASED LEARNING REFLECTIVE ACCOUNT 3

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

February 2009

Year 3
Introduction

The Problem Based Learning (PBL) task arose from consideration of Mr Nikolas and his family. Mr Nikolas is a 69 year old gentleman who was referred to a psychology department due to concerns about his memory. Upon assessment there were further concerns about his ability to look after himself, and complex family relationships provoked questions around possible abuse. His background history provided rich information about his family of origin and current networks, and the task involved presenting some of the issues to our peers in a way that demonstrated our engagement with the task. My learning from the task stemmed largely from my reflections on the group process and this shall form the basis of my account.

Overview of group and presentation

Over the past three years the format for the PBL groups has changed. In year one our group was comprised of all members of our Case Discussion Group (CDG) where the focus of the presentation was “The relationship to change”. In year two, again we were with our CDG, but the focus was The Stride family: a family in which one parent had a learning disability and the children were being cared for by Looked After Children’s Services. For this task, our CDG was split into two groups and each group was joined by half of a CDG from the second year. This division and the fact that we were approaching the task from different levels of knowledge and experience added a different dynamic to the task and created new learning opportunities. On reflection, the mix between two different years was rather more important than I initially realised and it shall be referred to throughout this account.

Within my group there were three third year trainees (myself included) and three second years. All group members were female. It was the first time anyone in our group had formally met the second years (and vice versa) initially we got to know each other and discussed our preferred styles of working. During the first session we identified our hopes for the task and set boundaries around when we would work. Our
group met five times over a six week period. Unlike previous tasks, we did not have a course team facilitator. This allowed us to be more flexible with the task, and encouraged us to assume greater responsibility for our preparation and final presentation. I valued this level of autonomy and think it better reflects the responsibilities we adopt on placements. Part of our role as a psychologist is to gather and select information, often from multiple sources, to form a useful formulation. This task provided an opportunity to look at some important issues which are likely to inform our understanding when working with many other clients (e.g. issues around loss and family life cycles).

**Reflections on successes and weaknesses of approach**

Our presentation took the format of re-enacting a peer supervision session. We selected this method as it naturally reflected what occurred in our group. During initial discussions we were each drawn to different aspects of the story. It was interesting to notice the difference between issues raised by each year group. Very generally speaking, the third years' focus was on systemic issues related to the professional and family systems, and the second years tuned into specific topics. I wondered if this was a reflection of where we were at in terms of our training, or whether it was more to do with the personal interests of the group members. The issues we focused on were – differential diagnosis between depression and dementia (Emery & Oxman, 2003), life cycle stages and transitions (Cowan & Hetherington, 1991), loss, old-age and attachment (Bowlby, 1997), elder abuse (Crosby *et al.*, 2007), and the role of a psychologist in complex cases (British Psychological Society, 2007).

Having a peer supervision format stemmed out of the supportive and interactive dialogue that developed. Individually we brought different experiences and levels of expertise to the group and that naturally created opportunities for people to discuss their perceptions of the most salient issues. My experience of peer supervision has been similar. During the task there was sense that there was not “a right way” of going about it, but rather an opportunity to discuss multiple approaches that would
enhance our understanding of the relevant issues. I have since reflected on this idea in the context of my clinical work. Working effectively with clients and within teams demands a communication style that is respectful and non-judgemental. Many of our previous PBL presentations have been gimmick performances which are undoubtedly very entertaining for the audience, but which often have a central theme of different professionals jockeying for the position of "expert". I believe part of the reason we adopted this more collaborative approach was because we were a mixed year group. Within our CDGs there is a level of intimacy out of which we can more readily challenge each other and adopt roles through which we can play out conflict theatrically. Wanting to be supportive, encouraging and valuing towards our second year peers was extremely important to me. The forum of a peer supervision session facilitated this process.

A drawback of our approach (as noticed by the markers) was the lack of visual aids. We displayed one poster which depicted a “spider diagram” summarising the key issues for discussion. This was a conscious decision born out of our shared hope that we would use the task primarily as an opportunity for personal learning. Our reasoning for this decision came from our experiences of watching other PBL presentations. All groups are given the same information and this generally results in all groups researching and presenting similar topics. Rather than focusing our efforts on creating an informative and factually accurate PowerPoint presentation, our energies were spent understanding the clinical issues and practising skills that are essential to good supervision such as reflection, discussion and feedback (British Psychological Society, 2003). In hindsight I remain pleased with the approach we assumed however it reinforced the need to be clear about the purpose of the task, the audience for whom it is intended and their expectations. Spending some time introducing the presentation and the rationale for its format may have been helpful.
**Personal and professional learning for self and others**

Throughout this assignment I was aware of my status as a third year trainee and the possible issues of power associated. I was mindful that Mr Nikolas was an elderly gentleman and the timing of the exercise was more congruent with the third years' stage of training; some of whom were about to embark on older adults placements. In the initial session I volunteered to make brief notes and was aware that by doing so I seemed to position myself in the role of Chair. (This is something I have noticed previously; when I am responsible for writing minutes I have a tendency to clarify information which often impacts on the flow of the conversation). I was conscious of this almost immediately and felt very uncomfortable. I had wanted this PBL exercise to be an opportunity for me to be process rather than content driven, and had anticipated taking a "back-seat" with regard to organising our group and the presentation. Assuming a faux position of Chair through the role of scribe immediately seemed to challenge this ideal and I was conscious that perhaps I had not given others sufficient chance to volunteer. Likening this task to my clinical work has provoked thoughts about how by setting the scene for therapy, initiating conversations about boundaries and asking assessment questions, therapists are immediately positioned with greater power. Although these tasks are essential before embarking on therapeutic work, I wonder how dominating the initial sessions impacts on the long-term and often unspoken roles that are adopted in therapeutic relationships. I am curious as to whether this issue partly informs the decision in some psychodynamic services to have different assessment and intervention therapists.

Despite my annoyance at initiating action in the first session, I noticed my uncomfortable feeling. Being aware of this allowed me to be more alert to how I was impacting on the group dynamics. Slowing down my actions and being tuned in to the present moment is an area of personal growth that has developed significantly over training: practising mindfulness techniques has been incredibly helpful in this process (Kabat-Zinn, 1994). During our meetings, we took turns to comment upon the discussion process and the ways in which we were working as a team (or not). It was quite amazing the impact this had: we discussed afterwards that knowing our
contributions were being observed encouraged us to be more aware of issues such as equity of floor space and the tendency we have to interrupt or talk over our colleagues. On my current placement, a huge part of my learning stems from listening to audiotapes of all of my clinical sessions. Discussing this in the group gave rise to the idea of observing our group from the outside, and we reflected on the benefit of this to our understanding of our group. I wonder how this technique can be used helpfully (and without assigning blame) to assist communication and group cohesiveness in clinical teams in the National Health Service.

Throughout training I have often lacked confidence in my abilities. The task of interacting professionally with the second years helped me to recall the journey I have been on in the last three years. It was a confidence boost to realise that the contributions I made to the task were not "just common sense" (which everyone knows), but had originated from three years studying psychology theory and practice. Similarly, the second years commented that having a glimpse into the knowledge and understanding they would accrue about the role of a psychologist in complex cases, was extremely helpful.

It is only with the benefit of hindsight that I am aware of our lack of discussion around the personal impact of the material we studied. We did not discuss our own experiences in terms of having elderly relatives or what personal issues the case provoked. I am curious as to why this was, especially as I currently live with my father-in-law who has early-onset dementia. Perhaps there was some unconscious reasoning on my part to remain process as opposed to content orientated. On reflection I realise that the issues I chose to research were very much related to the professional role of a psychologist, particularly the role for consultation in such a case. Whilst this input was valued by my group, I wonder if it may have been helpful to discuss my experiences of being in a family where cognitive impairment has had a huge impact on the system and the relationships within.
Summary

This task was thought provoking during both the presentation and reflective writing stages. I have an increased awareness of the issue of power, especially in relation to those we may perceive as "more junior" to ourselves, and those who are perhaps less vocal. As I am yet to embark on my older adults placement my learning from this task has been around generic issues. However I am looking forward to integrating specific ideas into working my future work with this client group. I have learnt there is a balance to be struck between paying attention to content and process and that one without the other skews understanding, and inhibits learning and development. It has reinforced the need to be clear when delivering presentations about the aims and expectations of everyone in the group including the audience, and this also applies to working individually with clients. Through the task I have become more aware of the knowledge I possess and have developed in confidence as a result. I have witnessed how effective and respectful communication enhances other people's confidence and how collaborative as opposed to directive working facilitate a more productive context for group work.
References


CASE DISCUSSION GROUP (CDG)

GROUP PROCESS ACCOUNT 1 - SUMMARY

September 2007

Year 2
The Case Discussion Group (CDG) provided a regular, safe and contained space in which member of my cohort, assisted by a facilitator, could reflect upon clinical issues.

Personal and professional learning

Throughout the first year, my contribution to the CDG changed markedly. I was initially very anxious and struggled to tolerate silences. As I learnt the value of silence clinically, I became more aware of the impact of my talking on the space for others to do so. In order to create opportunities to develop key skills, we allocated the roles of chair and scribe each week. This set the scene for using the sessions to bridge the gap between university teaching and clinical skills necessary for placement. The group context helped to challenge my belief that to contribute meant “to do”. Through observing others, I became aware of the importance of combining a “scientist practitioner” with a “reflective practitioner” approach to learning. The group also created a forum in which language was repeatedly unpicked and challenged – we became more aware of how our language may be perceived, and the meaning our words convey.

Group processes

To understand the development of our group, I utilised Tuckman’s model of group formation (1965). The model proposed four stages of group development – forming, storming, norming and performing, and provided a theoretical framework on which I mapped our group experiences. It was helpful to link experiences within the group with issues that may arise when working with clients or within teams in the National Health Service.

CASE DISCUSSION GROUP (CDG)

GROUP PROCESS ACCOUNT 2 - SUMMARY

July 2008

Year 2
Personal and professional learning

In contrast to previously, I felt happy and relaxed during the second year of our CDG and was more confident expressing myself in front of my peers. I felt less uncomfortable with silences but still somewhat frustrated by what I perceived as ambivalence to our group learning opportunity. Adopting a more observatory position, I witnessed the growth of quieter group members and was better placed to comment upon the process our discussions as opposed to solely their content. The challenges of second year gave rise to conflict in the group and this created opportunities to learn how to manage it appropriately.

Group processes

In addition to continuing with roles such as scribe and chair, our group elected to have a rota for presentations. By expanding the remit of the group from “case” to “clinical” discussions, we adopted greater responsibility for our own learning. We explored roles within the group from a diversity perspective and used the work of Belbin and colleagues (Belbin et al., 1976; Belbin, 1981) to illuminate the benefit of having a heterogeneous group. By identifying the personal strengths of each group member, we drew attention to the ways in which individual members enhance our group functioning. This led to more cohesive and collaborative teamwork within the CDG.


CLINICAL DOSSIER

This section aims to provide an overview of the range of clinical experiences I have had over the course of training. Due to the sensitive nature of material relating to placements and case reports of clinical activity, only summaries are provided in this volume. This volume contains a brief précis of my clinical placements and outlines the nature of the work undertook. It also includes a summary of each of my case reports of clinical activity.

All case material has been anonymised to preserve the identity of the clients, families and services. Full written consent was obtained from each client to include anonymised summaries of our work in this portfolio – this was checked by each of my supervisors.

Complete case reports and a more detailed account of my placement experiences are included in Volume II of this portfolio.
SUMMARY OF CLINICAL EXPERIENCE
ON PLACEMENTS

1\textsuperscript{ST} November 2006 - Present

Years 1, 2 & 3
Summary of clinical experiences on placements

Throughout training I have worked with a diverse range of clients with regard to presenting problems, age, gender, ethnic background and socioeconomic status. Each placement provided unique opportunities to learn new skills and develop my competence as a Trainee Clinical Psychologist. I shall briefly outline some of my experiences; however more details are in the placements documents located in Volume II of this portfolio.

Adult Mental Health Placement (AMH)

(Community Mental Health Team (CMHT) - 1st November 2006 – 21st September 2007)

During my AMH placement I worked with 18 clients who presented with a range of mild, acute, severe and enduring problems. I carried out individual therapy, co-facilitated 2 group focused on “Managing moods” and “Living with chronic pain”, and worked as part of a reflecting team during multi-family group therapy sessions. I shadowed staff in the acute in-patient service and worked closely with the assertive outreach team and other professionals including the family therapy team. I attended monthly Carer Support groups and 2 information days run by Rethink for carers. I participated in a monthly “Risk forum”, monthly business meetings for the multidisciplinary team and regular Care Program Approach (CPA) meetings. I conducted a range of assessments both neurocognitive and for therapy, and worked within a Cognitive Behaviour Therapy (CBT) and Systemic framework. Presentations were delivered to the psychology department, the MDT and the health and social governance managers, and covered topics such as borderline personality disorder and the evaluation of psychological therapies in 5 CMHTs in the locality (my SRRP).
People with Learning Disabilities Placement (PLD)

(Community Learning Disabilities Team (CLDT) – 10th October 2007 – 28th March 2008)

The PLD placement involved working with clients, families and staff teams in a range of community locations such as individual homes, care homes and day centres. I worked with people with both mild and profound learning disabilities, including people with Down’s syndrome, dementia and autistic spectrum difficulties, and used a biopsychosocial framework when formulating problems. I worked individually with clients, conducted a piece of couples work and worked with a parent-child dyad. I provided consultation to staff teams regarding managing challenging behaviour, and understanding complex family dynamics surrounding one client. I worked jointly with my supervisor, a speech and language therapist, community nurses and the challenging behaviour service. Several extended neurocognitive assessments and functional analyses of behaviour were conducted. I adopted an integrative approach to my work drawing on behavioural, cognitive behavioural, systemic, psychodynamic, transactional and cognitive analytic theory. I planned and delivered a full day’s training on dementia awareness, and arranged meetings with the advocacy service and a service user to discuss Valuing People meetings.

Child and Young People / Child and Families Placement (CAF)

(Split placement – Child and Adolescent Mental Health Team (CAMHS) and Looked After Children Service (LAC) – 9th April 2008 – 26th September 2008)

This placement involved direct and indirect work with children, families and foster carers from diverse ethnic backgrounds. I worked jointly with psychiatrists, schools and other community services, and offered regular consultation to social workers. I spent time at the inpatient adolescent unit, the adolescent outreach service, the youth
offending team and a local parenting centre. I worked therapeutically from within psychodynamic (particularly attachment theory), behavioural, systemic, and cognitive behavioural frameworks. A full day’s training was delivered to staff from a local children’s home about how to utilise solution focused ideas individually and organisationally. I co-facilitated a parenting group for young people leaving care, and delivered training on increasing positive behaviours. A further half day training session was delivered on understanding attachment issues and behavioural problems in fostered and adopted children. I participated in fortnightly CAMHS business meetings and trainee seminars, and carried out an audit of all assessment tools in the trust.

Advanced Competencies Placement

(Community cancer and palliative care service – 10th October 2008 – 28th March 2009)

This was a specialist placement which focused on developing my use of cognitive behavioural therapy with people facing adverse circumstances due to illnesses such as cancer, motor neurone disease, multiple sclerosis, Parkinson’s disease and chronic heart failure. It involved working with patients and carers at all stages of an illness journey: at the time of diagnosis, in the process of adjustment, in the terminal phase and through bereavement. I offered formal consultation to the rest of the MDT and facilitated a monthly psychology MDT meeting for complex clients or those with co-morbid mental illness. I formally discussed my reflections on team functioning to the manager of the service, and wrote a piece on the team to be included in the service newsletter. I participated in a carers conference examining how changes to government policies such as the End of Life pathway and Giving Carers Choice would impact on them. I led a 24 week Emotional Health and Well-being group for patients and carers that involved presenting information on anxiety, depression, guilt, anger, irritation, euthanasia and managing stress, and facilitating discussions around these topics. I worked jointly with a variety of local services such as the family history
screening service for breast cancer, local hospices and the local acute medical cancer centre.

I audio taped all individual sessions with clients (patients and carers) to facilitate the development of specific therapy skills such as guided discovery and case conceptualisation, and was graded by my supervisor using the Cognitive Therapy Rating Scale (Young & Beck, 1980). I delivered 6 full days teaching on using cognitive behavioural techniques to palliative care staff from various disciplines (nurses, radiographers, doctors, physiotherapists).

Older People Placement (OP)

(Community Mental Health Team for Older Adults - 8th April 2009 – 25th September 2009)

My Older Adults placement involved direct and direct work with clients, carers and staff teams. I worked with a range of presenting problems including anxiety, depression, obsessive compulsive disorder and paranoid schizophrenia. I conducted four full dementia assessments under the supervision of a Consultant Clinical Neuropsychologist which involving in depth cognitive and personality assessments and close liaison with the psychiatry team. As part of the placement, I planned and led a “Managing Moods” group with an Occupational Therapist as a co-therapist. I was responsible for selecting appropriate participants, planning all sessions and evaluating the intervention. I provided consultation to a local Continuing Care Team on a fortnightly basis which involved presenting information and facilitating discussions on a range of topics including functional analysis and positive behaviour support. In the latter part of the placement, I supervised an Assistant Psychologist delivering CBT based interventions to Older Adults. I regularly attended a Service User and Carer Advisory Group to better understand their role, and took part in a workshop event hosted by Age Concern focused on recognising mental illness in older people.
ADULT MENTAL HEALTH

CASE REPORT 1 SUMMARY

Cognitive Behavioural Therapy (CBT) with a
32 year old lady presenting with recurrent depression.

April 2007

Year 1
Presenting problems

Mary was a 32 year old lady referred due to exacerbation of her recurrent symptoms: she was feeling lower in mood, was more tearful than usual and was having difficulty sleeping.

Assessment & Formulation

Mary grew up in an environment in which there were unrealistically high expectations for achievement. This led to her developing a set of depressive schemas such as “I am worthless”, “I am unlovable” and “I am alone”. Critical incidents such as the breakdown of her marriage activated these schemas, and led to a stream of automatic negative thoughts in which Mary made thinking errors. Mary feared failure, and withdrew from activities and challenges that previously gave her pleasure. Padesky’s model (1986) was used to demonstrate the link between situations, cognitions, feelings, physical reactions and behaviour.

Intervention

Activity monitoring and behavioural activation techniques were used to explore and increase Mary’s activity levels. Teaching Mary how to use thought diaries and the process of cognitive restructuring enabled her to become more aware of her thinking patterns, and the traps she falls into which impact on her mood.

Outcome

Mary developed greater insight into her difficulties, and altered her behaviour to include more exercise and further opportunities to enhance her self-esteem. Her depression improved as rated by the Beck Depression Inventory. Following our work Mary began 3 years of group psychotherapy.
ADULT MENTAL HEALTH

CASE REPORT 2 SUMMARY

Cognitive Behavioural Therapy (CBT) with a 39 year old lady presenting with obesity.

September 2007

Year 1
Presenting problems

Lucy was referred due to exacerbation of physical health problems related to morbid obesity. Lucy experienced chronic sexual abuse perpetrated by her father, and acknowledged this as a trigger to her overeating.

Assessment & Formulation

Lucy was ambivalent about her weight and its associated health complications. She had a life-long history of obesity probably caused by a combination of genetics and a sedentary lifestyle. Lucy described her size and fat as a “protective shield” to discourage her father. Although the treat of being abused had gone, her thoughts about the meaning of her fat remained. Lucy used food both as a reward, and for comfort. The meaning of food and the ways in which it satisfied her (when bored, lonely, or as a way of socialising) made eating a functional activity that fulfilled many needs. In Lucy’s family refusing food was perceived as rude.

Intervention

Initial sessions involved education about food, exercise and small changes that can contribute to a healthier lifestyle. Behaviour modification was encouraged and obstacles were discussed. Assertiveness techniques were taught to encourage greater confidence when refusing food. Her thoughts about food and weight were explored, however due to dyslexia and a reluctance to complete written homework, a more behavioural approach was adopted.

Outcome

Lucy established a regular exercise and eating plan, and recruited a friend to help her maintain it. She had a better understanding of her eating habits and reported having more control over her choices and portion size.
PEOPLE WITH LEARNING DISABILITIES

CASE REPORT SUMMARY

An extended assessment to determine if a 48-year old man with Down’s syndrome has the capacity to consent to a sexual relationship

April 2008

Year 2
Referral

Peter was referred due to exhibiting “inappropriate sexualised behaviour” with his girlfriend at the day centre they both attend. Both partners had expressed a desire to develop their relationship sexually, and given Peter’s degree of cognitive impairment, an assessment of his capacity to consent was required.

Assessment & Formulation

Peter and his girlfriend had been in a relationship for approximately 1 year, and saw each other at the day centre twice a week. Peter’s carer and the daycentre staff requested guidance about how to support a safe relationship between the couple. I initially assessed Peter’s communication and memory skills, and tailored my capacity assessment accordingly. The assessment focused on exploring Peter’s understanding of body parts, sexual behaviour, appropriate places, consent, power issues, consequences of sexual intercourse and illegal relationships. Peter demonstrated limited knowledge of sexual relationship issues, and his cognitive abilities and lack of education were likely to have contributed to this. Although Peter could engage in some intimate acts with his girlfriend at the daycentre (e.g. holding hands), they had no opportunity to develop the relationship further in an appropriate environment.

Recommendations

Recommendations were made to: (1) Offer Peter education about sexual relationship issues to minimise his vulnerability in such situations. (2) Provide Peter and his girlfriend opportunities outside of the daycentre to enjoy each other’s company.
CHILDREN AND YOUNG PEOPLE

CASE REPORT SUMMARY

Oral case presentation
Using a consultation approach to work
systemically with a 10 year old boy.

September 2009

Year 3
Presenting problems

Robert was referred due to concerns raised by his foster carer, Betty. He was reluctant to talk about his emotions, had a tendency to “always please others”, and had difficulty controlling his anger with his brothers. The referral was prompted by a plan for Betty to apply for Special Guardianship to make the placement more secure.

Assessment & Formulation

Robert was removed from his birth family 4 years previously for reasons of neglect, domestic violence and parental substance abuse. His upbringing was such that his emotional needs were unlikely to have been met by his parents, resulting in an insecure attachment style. In emotionally challenging situations Robert responded either aggressively or by withdrawing into himself. He had difficulty forming relationships, and thus working indirectly with Betty using a consultation approach was appropriate. This also avoided another “loss” when the work ended.

Intervention

For Betty: (1) to help her understand Robert’s difficulties from an attachment perspective, (2) to increase her confidence in her role as his carer. For Robert: (1) to increase conversations about emotions in everyday life, (2) to enable him to talk both positively and negatively about aspects of his life, (3) to reduce the frequency of aggressive outbursts.

Outcome

Intervention aimed to empower Betty in her role, thus was assessed by her ability to manage Robert. Pre and post assessments revealed Betty had a greater understanding of Robert’s difficulties, increased confidence, enhanced perceptions of their relationship and additional skills to assist in her role.
ADVANCED COMPETENCIES

CASE REPORT SUMMARY

A cognitive assessment of a 36 year old man
with an advanced brain tumour

April 2009

Year 3
Referral

Jack had an advanced brain tumour and was referred to determine how best the care team could communicate with him in a way that was meaningful and supported his safety. He had a degree of dysphasia (exacerbated by anxiety) which prompted concerns about his cognitive functioning.

Assessment

Jack collapsed following a seizure in 2001 which led to the discovery of his brain cancer. He underwent several craniotomies to enable debulking of the tumour and several courses of chemotherapy and radiotherapy. He was engaged in palliative chemotherapy during assessment. Jack’s father reported behavioural and personality changes. The impact of the location, type and grade of his tumour, treatments for cancer (surgery, chemotherapy, radiotherapy and corticosteroids), and epilepsy and subsequent medications were explored to identify domains of functioning likely to be impaired. Jack exhibited global deficits with particular difficulties relevant to the referral questions in executive functioning, memory, attention, language and visuospatial skills. Results were fed back to Jack, his parents (identified carers) and the staff team who requested the assessment. Letters summarising his difficulties and brief guidelines to assist communication were sent to all professionals involved in his care.

Recommendations

These were developed collaboratively with Jack and centred on reducing the cognitive demands during communication (e.g. speaking slower and in shorter sentences). Jack and I devised a credit-card summary of his difficulties with pointers on how best to communicate with him. He uses this to assist communication in other circumstances such as in the bank.
RESEARCH DOSSIER

The research dossier contains a research checklist that summarises my research experiences, the abstract to a group qualitative research project, my Service Related Research Project (SRRP) and my Major Research Project (MRP).
**RESEARCH LOG CHECKLIST**

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Formulating and testing hypotheses and research questions</td>
<td>✓</td>
</tr>
<tr>
<td>2</td>
<td>Carrying out a structured literature search using information technology and literature search tools</td>
<td>✓</td>
</tr>
<tr>
<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
<td>✓</td>
</tr>
<tr>
<td>4</td>
<td>Formulating specific research questions</td>
<td>✓</td>
</tr>
<tr>
<td>5</td>
<td>Writing brief research proposals</td>
<td>✓</td>
</tr>
<tr>
<td>6</td>
<td>Writing detailed research proposals/protocols</td>
<td>✓</td>
</tr>
<tr>
<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly</td>
<td>✓</td>
</tr>
<tr>
<td>8</td>
<td>Obtaining approval from a research ethics committee</td>
<td>✓</td>
</tr>
<tr>
<td>9</td>
<td>Obtaining appropriate supervision for research</td>
<td>✓</td>
</tr>
<tr>
<td>10</td>
<td>Obtaining appropriate collaboration for research</td>
<td>✓</td>
</tr>
<tr>
<td>11</td>
<td>Collecting data from research participants</td>
<td>✓</td>
</tr>
<tr>
<td>12</td>
<td>Choosing appropriate design for research questions</td>
<td>✓</td>
</tr>
<tr>
<td>13</td>
<td>Writing patient information and consent forms</td>
<td>✓</td>
</tr>
<tr>
<td>14</td>
<td>Devising and administering questionnaires</td>
<td>✓</td>
</tr>
<tr>
<td>15</td>
<td>Negotiating access to study participants in applied NHS settings</td>
<td>✓</td>
</tr>
<tr>
<td>16</td>
<td>Setting up a data file</td>
<td>✓</td>
</tr>
<tr>
<td>17</td>
<td>Conducting statistical data analysis using SPSS</td>
<td>✓</td>
</tr>
<tr>
<td>18</td>
<td>Choosing appropriate statistical analyses</td>
<td>✓</td>
</tr>
<tr>
<td>19</td>
<td>Preparing quantitative data for analysis</td>
<td>✓</td>
</tr>
<tr>
<td>20</td>
<td>Choosing appropriate quantitative data analysis</td>
<td>✓</td>
</tr>
<tr>
<td>21</td>
<td>Summarising results in figures and tables</td>
<td>✓</td>
</tr>
<tr>
<td>22</td>
<td>Conducting semi-structured interviews (as part of clinical placement)</td>
<td>✓</td>
</tr>
<tr>
<td>23</td>
<td>Transcribing and analysing interview data using qualitative methods (However I have analysed newspaper articles using discourse analysis)</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Choosing appropriate qualitative analyses</td>
<td>✓</td>
</tr>
<tr>
<td>25</td>
<td>Interpreting results from quantitative and qualitative data analysis</td>
<td>✓</td>
</tr>
<tr>
<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
<td>✓</td>
</tr>
<tr>
<td>27</td>
<td>Producing a written report on a research project</td>
<td>✓</td>
</tr>
<tr>
<td>28</td>
<td>Defending own research decisions and analyses</td>
<td>✓</td>
</tr>
<tr>
<td>29</td>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
<td>✓</td>
</tr>
<tr>
<td>30</td>
<td>Applying research findings to clinical practice</td>
<td>✓</td>
</tr>
</tbody>
</table>
ABSTRACT OF QUALITATIVE RESEARCH PROJECT

Media constructions of schizophrenia:

How Britain’s national newspapers construct an understanding of schizophrenia

in their reporting of John Barrett’s conviction for manslaughter?

May 2007

Year 1

1 This was a group project and thus only the abstract and my personal reflections on the task are submitted.
Abstract

Four trainee clinical psychologists collaborated on a qualitative study into the construction of schizophrenia by Britain’s national newspapers. A critical discursive approach was used to analyse discourse in the Telegraph, Mirror, Guardian and Sun from February 26, 2005 following the conviction of John Barrett for the manslaughter of Denis Finnegan in September 2004. Prominent themes which emerged were a construction of dangerousness focusing on mad or bad; responsibility expressed via a failure and blame dialogue; and the positioning of the readership within an us and them paradigm as either ‘respectable’ or ‘criminal/animal’. The implications of public perception on understanding schizophrenia, destigmatising mental illness and supporting sufferers or carers and are discussed.
Personal reflections on completing the qualitative research project

This research provided an invaluable opportunity to think about language and how it is used. It is something I rely upon daily, have used at every stage of my career and something I would be nothing without: certainly not a psychologist for whom the medium of language is our most valuable tool.

Prior to beginning the task, I believed language was simply the choice of words used to describe any given situation – how much my belief has changed! I have been astonished by the power of language to evoke such strong and varied emotional reactions to a specific event. Each article I read about the death of Dennis Finnegan made me view John Barrett, and consequently a person with schizophrenia, in a different light. At one time I imagined a vicious crazed man who is both unpredictable and incredibly dangerous because of “The Schizophrenia”. At another I pictured a vulnerable, seriously ill patient who was terrified of loud commanding voices that forced him to kill. The position I adopted shifted both across articles and within. By spending time paying attention to what the language is attempting to do, I became aware of the fact that the story in the text is created by the language and not just told by it.

Before embarking on my clinical training course, I had little or rather no experience of working with people with schizophrenia. What little I knew about the illness was gathered largely from the mass media and snippets from books when required. I am ashamed to admit that I did perceive schizophrenia to be associated with violence and unpredictability, and having an opportunity to research this has furthered my understanding of the topic. This, coupled with my ignorance about the power of language, meant I approached the analysis with caution. It took longer than expected for me to buy into the approach and to shake off the cynical attitude of “It has to be described with some words”. After fumbling over the huge amounts of data we collected and getting over my distress about not being able to comment on all of it, I enjoyed the process enormously.
I am aware that my experiences shaped how I approached the text and also acknowledge that there were probably unconscious processes contributing to my positioning too. Working as a group to practice the skill of discourse analysis really helped to refine my technique and ensured we were all approaching the text similarly, but from our individual perspectives.
SERVICE RELATED RESEARCH PROJECT

Evaluation of the provision of psychological therapies
in five community mental health teams.

June 2007

Year 1
ABSTRACT

This evaluation collected information on waiting times and client characteristics of all clients referred to psychologists within five Community Mental Health Teams in one locality. It provided an overview of the number of clients seen across one year from 1st April 2006 until 31st March 2007. There were differences between the percentages of clients who were assessed only (ranging from 8-22%) and the percentages of clients who were subsequently offered therapy (ranging from 56-79%). Comparisons were made across services of the average waiting time form referral to assessment (range 4-12 weeks), and waiting times from being placed on the therapy waiting list and commencing therapy (range 1-29 weeks). The general client characteristics with regard to gender, ethnicity and diagnosis were also collected. This research discusses equity of access to psychological services and also raises issues relating to the collection of data using the piloted spreadsheet.

INTRODUCTION

The National Health Service (NHS) is a dynamic organization responsible for providing mental health services to thousands of people. Changes to services provoked by the NHS Modernization Agency specify that the NHS should increase the availability of and the access to treatments offered to patients. (Organising and Delivering Psychological Therapies (Department of Health (DoH), 2004)). Since NICE (National Institute for Health and Clinical Excellence) guidelines recommend psychological therapies as a treatment option for many mental health problems including anxiety, depression and schizophrenia, services providing such options have been stretched enormously. Feedback from service-users has consistently indicated that access to psychological therapies is at the top of their list of unmet needs (Mind “My Choice”, 2002). In order to monitor and improve the quality of services offered to clients, it is essential to collect data at a local level (Scally & Donaldson, 1998).
The information regarding acceptable waiting times for clients is unclear with different sources citing different figures. According to Layard’s report (Mental Health: Britain’s biggest Social Problem, 2004) there are no targets indicating the maximum length of time clients should wait for mental health services. In 2005 the Organisation for Economic Cooperation and Development (OECD) reported that patients “waited on average between six and nine months to access psychotherapy leading to conditions becoming more entrenched”. Furthermore a Reform document highlighted that non-consultant led services (such as psychology services) are exempt from the 18 week waiting time target (Bosanquet, de Zoete & Haldenby, 2006). A study in a child and adolescent service indicated that waiting times of more than 30 weeks resulted in “families giving up”, whereas waiting less than 1 month was too short to lose transient problems (Foreman & Hanna, 2000); similar patterns may be present in adult mental health.

According to a cognitive stress theory, stress caused by waiting primarily occurs because loss or degeneration “are perceived as situational outcomes” (Lazarus & Folkman, 1984). For example one might expect loss of social contact with others, or degeneration of memory in clients with depression. It is important to consider the physiological as well as the psychological effects waiting can have on people’s perhaps already unstable mental health.

Locally there is a drive by the Director of Psychological Therapies (Edeleanu, 2007) to have zero waiting times for clients who require access to formal psychological therapies. This drive is sought to be achieved through various methods including altering the referral pathway to reduce the number of inappropriate referrals, offering stepped care options, offering group therapy and offering supervision and consultation to other professionals providing psychological input. In order to provide a baseline for waiting times individually and collectively, this evaluation will compare the waiting times for psychological assessment and therapy in five CMHTs.
This audit also seeks to discover who services are being delivered to. It is important services monitor their clients to ensure they are not excluding groups based on factors such as diagnosis. The government document “Personality disorder: No longer a diagnosis of exclusion” (NIMHE, 2003) highlighted the often unequivocal access to services this client group faces and thus it is essential to collect data ascertaining whether such clients are accessing formal psychological therapies. Historically services often fail to meet the need of clients with dual diagnosis; at a local level there is interest in discovering if there is equity across the teams providing therapeutic interventions to such clients.

In the current climate of the NHS, services need to be more able than ever to demonstrate they are delivering high quality services. The National Service Framework for Mental Health (DoH, 1999) outlined seven standards by which services can be assessed and developed. Information from this audit will be as a baseline to assess delivery primarily around standard five: Accessible and Responsive Care. This standard stipulates there should be equity of access to services for all and that service users should not experience “unnecessary delay at any stage” of service delivery. This audit will collect information regarding the flow of clients through the services by taking a snapshot of the number of individuals on the caseloads of the psychologists’ priors 1st April 2007 and after 31st March 2007. It will also investigate who the services are seeing with regard to gender, ethnicity, and diagnosis.
Objectives

To discover to whom psychological therapies were delivered across five CMHTs between 1st April 2006 and 31st March 2007. Factors explored include:

1. Number of clients on caseloads prior to year beginning, and number of clients on caseloads at the end of the year.
2. Waiting times from referral to assessment.
3. Waiting times from assessment to therapy.
4. Client characteristics with regard to gender, ethnicity and diagnosis

METHODS

Setting

Five Community Mental Health Teams in one locality.

Data sources

Data were collected on every individual who was referred to the psychologists. In one CMHT where the spreadsheet was piloted, relevant data were collected directly from the spreadsheet. Here, individual psychologists were responsible for entering their own data (Appendix 1). In the other four services, it was necessary to liaise with the psychologists to assist in the set-up of the spreadsheet to record the data. The researcher agreed to assist in the collection of all data although only some of the categories were relevant to this project.
Procedures

The researcher visited each service in early 2007 to explain what data needed to be collected. Where needed, assistance was given to set up the database, and follow-up sessions were arranged to support the psychologists filling this in. The data were then collected from the services and anonymised before leaving the premises. Following the completion of this report, a summary of the findings will be fed back to the services in the psychology locality meeting (11th July 2007). The findings, recommendations and implications will be discussed with regard to issues of equity of access and waiting times.

RESULTS AND DISCUSSION

Due to several factors being discussed, the results and discussion about each of these sections are presented simultaneously. The service related implications have been presented separately at the end of this section.

General findings

The relevant sections from each of the datasheets were collated to produce a complete research spreadsheet. Table 1 summarises the total number of people on the psychologists’ caseloads, the number of people receiving individual therapy on 1st April 2006 and the number of active cases after 31st March 2007.
Table 1 – Total number of clients on psychologists caseload, number of clients seen prior to 1st April 2007 and still active, number of clients active after 31st March 2007.

<table>
<thead>
<tr>
<th>Location</th>
<th>Total number on</th>
<th>On books prior to 1st April 2007</th>
<th>Still active after 31st March 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT 1</td>
<td>28</td>
<td>10 (36%)</td>
<td>9 (32%)</td>
</tr>
<tr>
<td>CMHT 2</td>
<td>66</td>
<td>16 (24%)</td>
<td>24 (36%)</td>
</tr>
<tr>
<td>CMHT 3</td>
<td>39</td>
<td>0 (0%)</td>
<td>22 (56%)</td>
</tr>
<tr>
<td>CMHT 4</td>
<td>42</td>
<td>16 (38%)</td>
<td>15 (36%)</td>
</tr>
<tr>
<td>CMHT 5</td>
<td>161</td>
<td>33 (20%)</td>
<td>66 (41%)</td>
</tr>
<tr>
<td>Average</td>
<td></td>
<td>30% (excluding CMHT 3)</td>
<td>42% (all CMHTs)</td>
</tr>
</tbody>
</table>

(All numbers are rounded to the nearest whole percentage)

CMHT 5 serves the largest population, and has the most psychologists working - as reflected by the largest caseload (N=161), CMHT 1 serves the smallest population. The lack of clients in CMHT 3 prior to 1st April 2007 reflects the absence of a psychologist in post at that time. Excluding CMHT 3, the average percentage of clients carried forward from the previous year is 30%, the average percentage of clients still active after 31st March 2007 is 42%. Both CMHT 2 and 5 had below the average percentage of clients before and after the designated time frame. From these data, it appears they have the highest percentage through-flow of clients. This does not imply that these services are better, but can possibly reflect services offering shorter-term therapies or referring clients on to other services. Given that demand for psychological therapies is greater than supply, it is worth noting this point with the view to signposting future research.

Table 2 shows information relating to who is seen by the psychologists and what for. In addition to those receiving group therapy who were individually assessed, a further 51 clients attended groups during the timeframe with 2 on the waiting list.
Table 2 – Number and percentage number of clients assessed only, and offered individual or group therapy

<table>
<thead>
<tr>
<th>Location</th>
<th>Total number on caseload</th>
<th>Assessed only</th>
<th>Offered individual therapy</th>
<th>Offered group therapy</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT 1</td>
<td>25</td>
<td>5 (20%)</td>
<td>17 (68%)</td>
<td>1 (4%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>CMHT 2</td>
<td>63</td>
<td>14 (22%)</td>
<td>39 (62%)</td>
<td>1 (2%)</td>
<td>12 (14%)</td>
</tr>
<tr>
<td>CMHT 3</td>
<td>36</td>
<td>3 (8%)</td>
<td>20 (56%)</td>
<td>0 (0%)</td>
<td>13 (36%)</td>
</tr>
<tr>
<td>CMHT 4</td>
<td>42</td>
<td>5 (12%)</td>
<td>33 (79%)</td>
<td>0 (0%)</td>
<td>2 (9%)</td>
</tr>
<tr>
<td>CMHT 5</td>
<td>153</td>
<td>18 (12%)</td>
<td>101 (66%)</td>
<td>7 (5%)</td>
<td>35 (17%)</td>
</tr>
</tbody>
</table>

The percentage of clients assessed only varies greatly from 8% in CMHT 3 to 22% in CMHT 2. This variability may be accounted for by a number of factors. Some psychologists spoke of conducting extended assessments which may be a therapeutic intervention sufficient for some clients. Others spoke of having strict referral criteria in order to reduce the number unnecessary assessments and ensure the psychologists’ time was used to provide therapy. This variability in policy undoubtedly impacts on how the service is delivered and to whom. It would be interesting to investigate this to ensure all services are aware of how other services are managed and helpful strategies to deal with the difficulty of being a stretched resource may be highlighted.
Waiting times

Table 3 displays waiting time information. All units for waiting are in weeks – all are rounded to the nearest full week.

Table 3 – Mean, standard deviation and range of the number of weeks waiting between referral and assessment

<table>
<thead>
<tr>
<th>Location</th>
<th>Mean number of weeks waiting for assessment</th>
<th>Standard deviation (2 d.p)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT 1</td>
<td>8</td>
<td>3.67</td>
<td>1-17</td>
</tr>
<tr>
<td>CMHT 2</td>
<td>4</td>
<td>3.03</td>
<td>1-14</td>
</tr>
<tr>
<td>CMHT 3</td>
<td>12</td>
<td>5.61</td>
<td>1-23</td>
</tr>
<tr>
<td>CMHT 4</td>
<td>5</td>
<td>4.78</td>
<td>0-23</td>
</tr>
<tr>
<td>CMHT 5</td>
<td>8</td>
<td>10.30</td>
<td>0-70</td>
</tr>
<tr>
<td>CMHT 5 (removing 5 outliers)</td>
<td>6</td>
<td>4.64</td>
<td>0-20</td>
</tr>
</tbody>
</table>

The longest waiting times were in CMHT 3 (mean=12, s.d=5.61), the shortest were in CMHT 2 (mean=4, s.d=3.03). With the removal of 5 outliers from the CMHT 5 dataset, the variance in the waiting times becomes more comparable (s.d=4.64). The reason for such variance is unclear. Relating these figures to those previously, all CMHTs are performing well within a timeframe of 18 weeks although this not specifically required. Despite the local drive for a zero waiting list, discussions highlighted there were mixed feelings regarding this. As shown by Bosanquet et al (2006), psychologist here also believed shorter waiting times would lead to more unnecessary assessments when individuals do not have time to improve spontaneously. This is perhaps supported by evidence from CMHT 2 who had the shortest waiting time (mean=4), but also the highest percentage of clients being assessed only (22%). Similarly, the longest waiting times in CMHT 3 (mean=12), had the fewest number on clients who were assessed only (8%).
Table 4 shows the mean waiting times for the clients in each service between when they were placed on the therapy waiting list, and when they began therapy.

Table 4 - Mean, standard deviation and range of the number of weeks between being placed on the therapy waiting list and the date therapy commences.

<table>
<thead>
<tr>
<th>Location</th>
<th>Mean number of weeks waiting for therapy</th>
<th>Standard deviation (2 d.p)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT 1</td>
<td>8</td>
<td>7.96</td>
<td>0-24</td>
</tr>
<tr>
<td>CMHT 2</td>
<td>2</td>
<td>1.94</td>
<td>1-10</td>
</tr>
<tr>
<td>CMHT 3</td>
<td>1</td>
<td>0.92</td>
<td>0-3</td>
</tr>
<tr>
<td>CMHT 4</td>
<td>29</td>
<td>20.27</td>
<td>0-53</td>
</tr>
<tr>
<td>CMHT 5</td>
<td>5</td>
<td>7.99</td>
<td>0-44</td>
</tr>
</tbody>
</table>

There is great variation between how long clients wait both across and within teams. The waiting times in CMHT 4 could not be made more comparable to the others by removing outliers, as 14 out of 29 clients (48%) waited over 40 weeks for therapy. There were no clear patterns as to when or why clients waited so long - this needs to be investigated as may indicate therapist(s) under enormous pressure or unequivocal access to psychological services in this area.

In CMHT 3, there is a long wait for assessment after which clients who are offered therapy are taken on very quickly. This may reflect the new posts in this job having no initial waiting list for therapy. Whilst collecting these data, I discussed with the psychologists the many difficulties with recording waiting times. Whilst it is important to have a record of actual starting dates, some psychologists found clients requested delays to accommodate for holidays or therapists recommended later starts.
due to clients being unstable or in hospital. These results do not reflect these possibilities and there may have been inconsistencies with what dates were recorded.

**Client characteristics**

**Gender**

The bar chart shows the gender split in each CMHT. Figures are expressed as percentages. Approximately one third of clients in the CMHTs are male with the exception of CMHT 3 (18%). It is unclear why this is, although historically men have used mental health services less than women.

![Bar chart showing gender split](Image)

*Figure 1 – A bar graph displaying the percentages of male and female clients in each CMHT.*
Ethnicity

The ethnicity of each client referred to the psychologists was recorded with the exception of in CMHT 4. As is expected and representative of the area, the predominant category was White British.

Table 5 – A table displaying the percentages of each ethnic group in each CMHT.

<table>
<thead>
<tr>
<th>% data collected</th>
<th>CMHT 1</th>
<th>CMHT 2</th>
<th>CMHT 3</th>
<th>CMHT 4</th>
<th>CMHT 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>100%</td>
<td>95%</td>
<td>90%</td>
<td>88%</td>
<td></td>
</tr>
<tr>
<td>Any other mixed</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td>2%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not given</td>
<td></td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White Other</td>
<td>3%</td>
<td></td>
<td>5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td></td>
<td>4%</td>
<td></td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>White &amp; Asian</td>
<td></td>
<td></td>
<td></td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2%</td>
</tr>
<tr>
<td>White &amp; Black African</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1%</td>
</tr>
<tr>
<td>Pakistan</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1%</td>
</tr>
<tr>
<td>Any other Asian</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1%</td>
</tr>
</tbody>
</table>
Diagnosis

The primary presenting diagnoses were determined by the assessing clinician. The presence or absence of a personality disorder (PD) or dual diagnosis (DD) is also recorded. A bar chart is displayed for each CMHT identifying the percentage of clients with each primary diagnoses. The percentage of clients with a personality disorder or dual diagnosis will be recorded on the same graph but these data are independent of the presenting problem.

CMHT 1

![Bar chart showing percentages of diagnoses]

*Figure 2 – A bar graph displaying the percentage of client with particular diagnoses and the percentage of clients with a personality disorder or dual diagnosis in CMHT 1*

The majority of clients referred primarily had a diagnosis of depression (64%). 29% were categorised as having a PD, whilst 21% were deemed to have difficulties with drugs or alcohol.
Most clients were referred due to mood disturbance. 9% of clients were referred due to difficulties arising from a development disorder and 20% were referred due to needing support directly related to their PD. This clinician recorded the presence of a PD based on her clinician judgement - not necessarily when this was in the notes. This is an example of where standardised methods of data collection need to be implemented to ensure data are comparable across services and there is equitable provision of services based on an identified need, whether this be highlighted by a psychiatric diagnosis or based on clinical judgement.
CMHT 3

As previously, the majority of clients were referred due to depression. This CMHT is located close to a specialist eating disorder service yet 13% of the clients presented with an eating disorder. This may reflect the therapists’ competence in this area or perhaps some good joint working amongst services – it would be interesting to research this further. Unlike in the other CMHTs, no clients here were categorised as having a PD and few (5%) as having DD. Clinicians commented “Don’t know” in the relevant boxes. To me this raises questions regarding the lack of authority of psychologists to diagnose conditions balanced with the need to identify what services clients may benefit from.

Figure 4 – A bar graph displaying the percentage of client with particular diagnoses and the percentage of clients with a personality disorder or dual diagnosis in CMHT 3.
Mood disorder was the most prevalent diagnosis (60%). Like in CMHT 3, there was notable caution when assigning the label of PD.
Mood disorder was again the most prevalent problem (41%). The high percentage in the “other” category reflects the lack of diagnosis specified by the clinician; it was not clear whether this was missing, or the absence of a diagnosis. 10% of clients referred had schizophrenia whereas only 1 client in CMHT 1, 1 client in CMHT 4 and no clients in the other CMHTs having this diagnosis were referred. In addition to the above, a further 9 clients with schizophrenia received a psychosocial therapeutic intervention from a CPN working within CMHT 5.

Based on all the CMHT data, the majority of clients referred have a diagnosis of mood disorder, but there is variability in clients seen in each service. It seems there is inconsistency in the numbers of clients seen with PD but this may not represent this client group being excluded, but rather perhaps unclear guidelines on who has the authority to diagnose. As the numbers are relatively small, it would be unwise to assume this snapshot is representative. Further research is required to collect data.
over longer time periods to increase the sample size and thus the reliability of the results. This may cast light on whether services need further education as to the variety of clients who can benefit from psychological input for example those with schizophrenia. Psychologists may need to utilise their skills in research and training to ensure all refers are aware of who may benefit however, with a resource that is already stretched, whether this is possible is unknown.

**Service-related implications**

Collecting demographic information of clients provided the services with an overview of their client group; such information will be helpful in highlighting whether psychological therapies are offered to a broad range of clients or specific groups. Future research may investigate whether the cross-section of people referred to psychology is representative of those referred to the CMHTs as a whole and of the local area.

Collating the caseload and waiting time data across all the services provides an overview of the delivery of psychological therapies in the locality. By standardising the method of recording in the services, re-audits and further research will be facilitated by data being easily accessible. It is essential all staff completing the datasheets agree upon common guidelines for example about how to record clients choosing to delay assessments. These inconsistencies in recording undoubtedly effect how a service appears to be performing. It would be interesting to discuss the pros and cons of clients waiting for either assessment or therapy as some CMHTs favoured a longer wait at either stage. Given that one must not experience “unnecessary delay at any stage”, waiting for which stage is preferable? Only when there is consistent approach to how and what is recorded will the spreadsheet be useful to compare performance and service delivery across teams. When feeding back to the team, the researcher will present a list of the main areas where it appeared the teams with recording things differently – this can generate conversations about a standardised method of data recording.
References


URL:http://www.reform.co.uk/filestore/pdf/Mental%20health%20services%20in%20the%20NHS.%20Reform.%202006.pdf.


Appendices

Appendix 1 – Categories for psychology datasheet and coding information

<table>
<thead>
<tr>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client’s name</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>Referred by</td>
</tr>
<tr>
<td>Urgent/routine</td>
</tr>
<tr>
<td>Date referred</td>
</tr>
<tr>
<td>Date assessed</td>
</tr>
<tr>
<td>CPA standard/enhanced</td>
</tr>
<tr>
<td>Problem</td>
</tr>
<tr>
<td>Action taken (CODED)</td>
</tr>
<tr>
<td>Assessor</td>
</tr>
<tr>
<td>CPA care co-ordinator</td>
</tr>
<tr>
<td>Date added to therapy waiting list</td>
</tr>
<tr>
<td>Date started therapy</td>
</tr>
<tr>
<td>Diagnosis 1</td>
</tr>
<tr>
<td>Diagnosis 2</td>
</tr>
<tr>
<td>Personality disorder</td>
</tr>
<tr>
<td>History of sexual abuse</td>
</tr>
<tr>
<td>History of self-harm</td>
</tr>
<tr>
<td>History of drug and/or alcohol abuse</td>
</tr>
<tr>
<td>Duration of mental health problem</td>
</tr>
</tbody>
</table>

### Coding

<table>
<thead>
<tr>
<th>Status</th>
<th>Action</th>
<th>Diagnosis</th>
</tr>
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<tbody>
<tr>
<td>1 = New referral</td>
<td>1 = Inappropriate referral</td>
<td>1 = Schizophrenia</td>
</tr>
<tr>
<td>2 = Waiting list</td>
<td>2 = Assessed only</td>
<td>2 = Bipolar disorder</td>
</tr>
<tr>
<td>3 = Active</td>
<td>3 = Accepted for therapy</td>
<td>3 = Other psychotic disorder</td>
</tr>
<tr>
<td>4 = Discharged</td>
<td>4 = Accepted for group</td>
<td>4 = Mood disorder</td>
</tr>
<tr>
<td></td>
<td>5 = None/DNA</td>
<td>5 = Anxiety disorder</td>
</tr>
<tr>
<td></td>
<td>6 = Moved away</td>
<td>6 = Eating disorder</td>
</tr>
<tr>
<td>Disorder Code</td>
<td>Disorder Description</td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Follow-up support</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Dissociative disorder</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Pervasive developmental disorder</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Impulse control disorder</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Sleep disorder</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Sex and Gender disorder</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Somatoform disorder</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Factitious disorder</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Personality disorder</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>None</td>
<td></td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Therapy Type</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Psychodynamic</td>
<td>1 = Therapy completed</td>
</tr>
<tr>
<td>2 = CBT/SFT</td>
<td>2 = Client ended/dropped out</td>
</tr>
<tr>
<td>3 = CAT</td>
<td>3 = Therapist ended</td>
</tr>
<tr>
<td>4 = Systemic</td>
<td>4 = Assessed only then discharged</td>
</tr>
<tr>
<td>5 = Humanistic</td>
<td>5 = Referred on to further therapy</td>
</tr>
<tr>
<td>6 = Integrative/eclectic</td>
<td>6 = DNA</td>
</tr>
<tr>
<td>7 = PSI</td>
<td>7 = Moved away</td>
</tr>
<tr>
<td>0 = No therapy, assessment only</td>
<td>8 = Deceased</td>
</tr>
</tbody>
</table>
To whom it may concern,

This is to certify that:

Michelle Conn

has presented the following pieces of work on her Adult Mental Health placement:

1. Is CBT effective and cost effective for BPD?
   Presented to MDT (21 March 2007) & Psychologists at the locality meeting (11 April 2006)

2. Service Related Research Project (SRRP)
   A service evaluation of the provision of psychological therapies in 5 CMHTs
   Presented to Psychologists at the locality meeting (11 July 2007) & To managers at the Health & Social Governance Meeting (30th August 2007)

Dale Van der Watt

Placement Supervisor
Burnout and Resilience in Informal Carers of People with Life-Limiting Illnesses

By

Michelle Conn

Submitted for the degree of Doctor of Psychology
(Clinical Psychology)

Department of Psychology
Faculty of Arts and Human Sciences
University of Surrey

July 2009
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I wish to thank all staff at the local services who assisted with recruitment for this study. Thanks also to the online administrators who allowed me to post information on their websites. My sincere appreciation goes to all of the carers who kindly took the time to participate - without their assistance this project could not have happened.

On a more personal note, I wish to thank my parents Harry and Siobhan for making me who I am, and for all the sacrifices they made to allow me to follow my dreams. Thanks also to Kathy for her kindness and generosity over the last nine years, and for her help with the never ending task of producing the questionnaire packs. To my friends at university, particularly Daisy, Becca, Alley and Gemma who helped me to keep going when faced with the challenges of the training.

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Volume I – Research Dossier

Major Research Project

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ABSTRACT

Objective: This study explored burnout and resilience in informal carers of people with life-limiting illnesses, namely carers of people with cancer, multiple sclerosis (MS) and motor neurone disease (MND).

Methods: It adopted a cross-sectional, quantitative survey design utilising the Maslach Burnout Inventory (MBI), The Resilience Scale (RS) and an adapted version of the Quality of Life – Family version tool. 152 family carers participated. Carers were recruited from a number of local and online sources including a community palliative care team, 3 hospices, local branches of national organisations for patients, a national carers’ organisation, and online support services for people with the identified illnesses.

Results: Burnout, particularly emotional exhaustion, was common and severe in this sample. Emotional exhaustion and depersonalisation were highest in carers aged 61-70 years, and in those caring for people with MND. Gender, the relationship between the carer and cared for, the length of time caring, and quality of life (physical, psychological, social and spiritual well-being) were all important factors predicting burnout. Resilience was the only significant predictor of all 3 domains of burnout: it was associated with lower emotional exhaustion and depersonalisation and greater personal accomplishment.

Discussion: Burnout in informal carers is discussed in relation to our understanding of the phenomena in professionals. Certain groups of carers are identified as particularly vulnerable, and possible reasons for this based on differences in carer demographics (including resilience) and the context of caring are explored. Clinical implications of the findings and ideas for further research are discussed.
INTRODUCTION

Who cares? Caring is not a role preserved only for those who want it. It has no respect for boundaries such as age, gender, physical health, competency or desire. Carers are not a homogenous group and everyone has the potential to become one. Unlike professionals who choose roles such as nurses, psychologists or doctors, those who care for ill relatives rarely have a choice. The role of a carer is often assumed automatically or ascribed by healthcare professionals (Payne, 2007). For people with life-limiting illnesses (pwLLI), the traditional source of care provided by the family is often crucial in enabling them to have greater choice in their care and to live as independently as possible with optimum quality of life (Lloyd-Williams, 2008).

Overview

The introduction is structured to lead the reader towards the rationale for the current study. It begins with a general introduction about carers: a definition of the term and incidence and prevalence rates. It leads to a description of carers of pwLLI and discusses the impact of caring for a person with cancer, multiple sclerosis (MS) and motor neurone disease (MND). A specific impact of caring – burnout, is highlighted: the concept is defined and a theoretical model presented. The prevalence and impact of burnout are acknowledged. A factor thought to be protective against burnout – resilience is identified. The links between resilience and coping, caring and burnout are explored. Finally, the political context of the research is defined which maps the way for the present study.

Definition of a carer

The role of an informal carer\(^2\) can be defined a number of ways and varies depending on context:

\(^2\) Hereafter, informal carers shall be referred to as carers.
"A carer is someone who spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems".

(Department of Health, 2008, pp. 19)

Although this definition is broad, it fails to acknowledge the emotional aspect of caring. The National Institute of Clinical Excellence (NICE) defines a carer in the context of caring for someone with cancer: it can be appropriately applied to carers of people with other LLIs:

"Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management".

(NICE, 2004, pp. 155)

These descriptions serve to differentiate between professional carers and carers who emerge from existing relationships. Caring is viewed by some as an extension of the normal, dynamic family relationships that naturally adapt to changing life circumstances (Thomas et al., 2002). Consequently, many family members reject the label of "carer" despite adopting its roles and responsibilities. For others, the role is assumed out of sense of obligation (Graham, 1983; Stajduhar et al., 2008), and to conform to the pressure of powerful social norms (Burridge et al., 2007). Perhaps someone’s perception of caring being either a chosen or burdensome role can account for some of the differences in how it is experienced. There is an assumption in most health and social services that family members, particularly spouses, are willing and able to accept the responsibilities and challenges of caring (Braithwaite, 1990).

Advances in medical technology and healthcare support the trend towards a more aged population with more people living longer, and a greater number living with chronic...
illnesses (Kinsella & Velkoff, 2001; Dahlberg et al., 2007). Coupled with a shift in how services are being delivered - fewer and shorter hospital stays, less institutional care and more home-based care and treatment, more people are taking on caring roles, and more carers are caring for longer (Kirk & Glendinning, 1998; Heaton, 1999; Morris & Thomas, 2001).

**Prevalence and Incidence**

In the 2001 Census, data were collected for the first time about the provision of unpaid care - it revealed 5.2 million people were providing care to family or friends (Office of National Statistics, 2003). Of these, 1.5 million were carers over 60 years. Figures from the government’s Carers Strategy (DOH, 2008) estimate 1 in 10 people in the UK are carers — 9 per cent of men and 11 per cent of women. Every day approximately 6,000 people take on new caring responsibilities.

**Carers of people with Life-Limiting Illnesses (pwLLI)**

Approximately 500,000 people in the UK are caring for relatives or friends with LLIs (Help the Hospices, 2009). The majority of carers are women, typically around 60 years of age, and generally caring for a spouse (Taylor, 2003). Under the umbrella of “life-limiting”, there are a number of illnesses that vary according to onset, course, prognosis and level of dependency. The usual features are that the illness is progressive and degenerative, and the patient’s life is limited functionally and/or in terms of life expectancy. Three common LLIs are cancer (the most common), MS and MND. Research suggests almost 90 per cent of pwLLIs spend the majority of their last year at home (Robbins, 1998), and 50-70% prefer to die at home in their familiar environment (Grande et al., 1998). It is important we monitor if carers are able to facilitate this and cope with the challenges this presents.
Impact of caring

Research suggests carers may be viewed as “hidden” (Andolsek et al., 1988) or “second order” patients (Cohen et al., 2006) as they also share the pain of the illness (Cameron et al., 2002; Proot et al., 2003). As such, within a palliative care approach the patient and family are often considered the “unit of care” (Strada & Breitbart, 2009). A large UK study exploring the experiences of carers reported 51 per cent endured a physical injury as a result of caring, and 52 per cent needed treatment for a stress-related illness (Henwood, 1998). The Caregiver Health Effects Study revealed carers were at a 60 per cent increased risk of “all-cause” mortality as a result of their role (Shulz & Beach 1999). Many studies report the significant financial strain associated with caring (O’Brian, 1993; Knight et al., 1997; Nijboer et al., 2000 & Mockford et al., 2006).

Studies indicate that caring alters the nature of family relationships, particularly when caring for a spouse (Anderson & Bury, 1988; Twigg, 1992; Bendelow & Williams, 1998). In research exploring the experience of carers of people with terminal illness (Riley & Fenton, 2007), carers reported feeling responsible for maintaining peace in the home, putting their own life and emotional needs on hold, and “putting on a brave face” to avoid upsetting the ill person. In a longitudinal study by Wegner and Jerrome (1999), the onset of a terminal illness was linked to carers losing their usual confidant. The impact of not having needs met, being unable to process emotionally difficult circumstances, and the loss of a confiding relationship are all related to poor emotional health and psychological distress in carers (Guarnaccia & Zautra, 1989; Faller et al., 1995, Payne & Ellis-Hill, 2001).

Quality of Life (QoL)

Caring is associated with deterioration in the QoL in carers (Ramirez et al., 1998). Ferrell and colleagues (1995) describe QoL in a four component model comprised of physical, psychological, social and spiritual wellbeing. Their research indicates that
caring for someone with cancer impacts on the QoL of carers, particularly in the domains of psychological, social and spiritual wellbeing (Ferrell *et al.*, 1995; 1999). In both of their studies, physical well-being was least affected by caring. Keeping each domain separate facilitates an understanding of how the illness affects different areas of the carers' lives. McKeown and colleagues (2003) identified similar consequences of caring in carers of people with MS – they found physical, psychological and spiritual well-being were all affected by caring. Additionally, studies indicate caring for a person with MND negatively impacts on the carer’s QoL. For this group, research suggests the health and QoL in the carer is closely associated with that of the patient (Jenkinson *et al.*, 2000; Hecht *et al.*, 2003). However because of the measures used in these two studies, it is not possible to identify which components of QoL are most affected by caring for someone with MND.

So, caring can affect QoL, often social well-being. The importance of social support from family, friends and services in coping with chronic illness is well documented (Thoits, 1995; Soothill *et al.*, 2001). Evidence suggests it can be an important indicator of general health and well-being in carers (Ducharme *et al.*, 2006), and the degree of subjective burden experienced (Bolsmjo & Hermeren, 2003; Dawson & Kristjanson, 2003). Spousal carers are more likely to experience a higher degree of carer burden3 (Cantor, 1983; Rees *et al.*, 2001), and are less likely to receive assistance than other informal caregivers (Horowitz, 1985). In addition, younger carers4 often experience higher levels of psychological distress than older carers (Payne *et al.*, 1999). Given this, spousal and younger carers are identified as perhaps being most vulnerable.

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3 Where burden is described as the physical and psychological demands placed on the carer as a result of illness.

4 Where younger in this instance is between 18-44 years.
Some studies suggest the amount and type of care impacts on the burden carers experience (Nijboer et al., 1998), whereas others found no correlation (Nolan, 2001; Khan et al., 2007). Providing emotional and psychological support is repeatedly acknowledged as one of the most challenging tasks of caring (Anderson, 1992; Wellwood et al., 1995), and often leads to the greatest sense of burden (Carey et al., 1991). In carers of pwLLI, providing support over a long period of time can be extremely difficult (Stetz, 1987). Distress may also be accentuated by acknowledging the lack of power they have to halt the disease, and the realisation that their family member is likely to die as a consequence of it.

Specific life-limiting illnesses and caring

Cancer

Cancer is an umbrella term used to describe a group of diseases that emerge following uncontrolled growth of abnormal cells (Ogden, 2005). Although cancer affects younger people, it is primarily a disease of older age. Different types present in different ways in terms of functioning, prognosis and level of dependency. Stages of disease also affect its presentation and the impact it has on the people affected and their families (Schofield et al., 2006). Given this, there is likely to be greater heterogeneity in the experiences of people caring for relatives with cancer than other illness (such as MS or MND). There are approximately 2 million people living in the UK with cancer at any one point in time (Cancer Research, 2009).

Caring for a relative with cancer can have a huge impact on a carer’s health and wellbeing (Thomas et al., 2002), and is associated with increased rates of depression and anxiety (Payne, 1999; DOH, 2008). Some studies highlight similar levels of psychological distress in carers and patients (Northouse et al., 1998), while others suggest the needs and distress of carers are greater, particularly in the later stages of the disease (Cliff & MacDonagh, 2000; Grunfield et al., 2004). Evidence regarding the impact of chronicity on carer distress is inconsistent: some reports suggest distress
is greatest post-diagnosis and decreases over time (Blood et al., 1994; Hoskins, 1995), whereas others report distress increases over time (Ell et al., 1988; Given et al., 1992). Many carers of people with cancer report physical consequences of caring such as difficulties with sleeping (Carter, 2003).

Contrary to the dominant assumption that all caring is "burdensome", more than half of carers of people with cancer report their role as "rewarding" (Ramirez et al., 1998). Strang and Koop (2003) suggest that alongside formal and informal support, caregiver characteristics such as "strength from within", self-knowledge, decision making ability, and self-belief were important factors facilitating carers’ ability to cope. These factors may be grouped together under the umbrella of Resilience. In a qualitative study of 29 carers (Stajular et al., 2008), successful coping was associated with a positive approach to life, and an ability to recognise and ask for support when needed. Carers that described themselves as “coping well” spoke of drawing on internal resources and expressed a “just-do-it” attitude in relation to the demands of their role. Again, such an attitude is common in resilient people (Kaplan et al., 1996)

**Multiple Sclerosis (MS)**

MS is a chronic, degenerative neurological disorder that leads to a variety of symptoms including difficulties with balance, co-ordination, fatigue, vision and sensation (Swan, 2006). Approximately 85,000 people currently live in the UK with MS (MS Society, 2009). It is an unpredictable disease as the patient’s functional ability can fluctuate over the course of a day, and relapses can occur at any time (McKeown et al., 2004). Caring for a person with MS can span many years as it is usually diagnosed between the ages of 20-40 years and does not generally shorten the lifespan (Scheinberg, 1985). Some forms of MS can be treated with disease modifying drugs (which reduce the frequency and intensity of replaces) but there is currently no cure.
Research suggests that caring for someone with advanced MS and caring for a long period of time are associated with poorer QoL and increased carer burden (Good et al., 1995; Gregory et al. 1996; Aronson, 1997; Chipchase & Lincoln, 2001). In other studies, length of time caring was not correlated with carer burden (Knight et al., 1997). Caring for a person with MS is reported as particularly stressful due to the unpredictable nature of the illness and impact it has on planning for everyday life (O’Brien 1993; Hakim et al., 2000; McKeown et al., 2004). Research indicates there can be multiple losses associated with caring, loss of: partner, self, source of support, lifestyle and future plans, which can lead to psychological distress in carers. Carers in this same group also spoke of gains from their role in terms of increased self-sufficiency and resilience, and new opportunities for making sense of life (Cheung & Hocking, 2004).

Motor Neurone Disease (MND)

MND is a progressive neurodegenerative disorder that usually affects people between 50-60 years. It is characterised by progressive muscle weakness and usually results in death within 3 years. It is commonly referred to as “locked in syndrome” (Voltz et al., 2004) as the patient becomes paralysed in their body with intact cognitive function and personality (Hecht et al., 2003). Although the annual incidence of MND is similar to MS (Beresford, 1995), the life expectancy is much less and thus at any one time there are approximately 5000 living with the disease (MND Professional Network, 2009).

Relatively few studies have focused on the impact of caring for a person with MND. One study of 94 families reported that carers provided a median of 11 hours a day caring, despite receiving home care support. Half of this sample reported feeling “physically and psychologically unwell” (Krivickas et al., 1995). In many carers of people with MND, the loss of functional capacity in the patient is associated with increased anxiety and depression in carers (Goldstein et al., 1998). In one autobiographical account, the need to constantly adapt to a rapidly deteriorating
condition posed the biggest challenges for carers (Mowat, 2000). Rabkin and colleagues (2000) reported increased burden was associated with depressive symptoms, fatigue and poor QoL in carers, and those who reported the most burden were least likely to access professional support: although part of this study was longitudinal, the authors were not able to infer the direction of causality. This study also found that burden was correlated with finding meaning in caregiving, and suggested that this indicates that “finding meaning” can be viewed as an effective coping strategy.\(^5\)

From the research presented, it is clear that caring can have both positive and negative consequences for carers. It is difficult to compare the impact of different illnesses as different studies use different methodologies and measures (Goldstein et al., 2006; Corry & While, 2008; Stajduhar et al., 2008). Given that many health and social services provide support to carers of people with all three illnesses, it is important that we understand how they are similar or different so that services can be tailored accordingly.

**Burnout**

_**Definition**_

Burnout is an individual response to chronic job stress (Maslach et al., 2001). It was noticed by clinicians before it was academically studied which had important implications for how the concept was defined. In the early burnout literature, the term was widely used without a shared understanding of its meaning (Schaufeli et al., 1993). Practitioners focused on describing characteristics of “burnt-out” groups and offered recommendations for interventions. Defining the concept was thought unnecessary. It was only through Maslach and colleagues’ work that a definition emerged. Burnout is defined as “a psychological syndrome of emotional exhaustion

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\(^5\) This conclusion is supported by Folkman and Moskowitz’s work on meaning-based coping strategies (2000).
and cynicism that occurs frequently among individuals who do people-work of some kind” (Maslach & Jackson, 1981, pp.99).

Burnout was first studied in people working in human services and health care where the nature of work involved some degree of emotional and interpersonal stress (Freudenerberger, 1975; Maslach, 1976). In recent years, several studies have explored burnout in professional carers of pwLLI (Mallett et al., 1991; Hayter, 1999; Payne, 2001; Italia et al., 2008). This study hopes to extend our understanding by studying burnout in informal carers of pwLLI. Only 3 previous studies have investigated the concept in informal carers of people with cancer, MS, mental illness and dementia (Ybema et al., 2002; Angermeyer et al., 2006; Yilmaz et al., 2009). These studies all used adapted versions of the main burnout measure (translated into other languages or using a different scale of measurement), and thus must be interpreted with caution. For ease of reading, their findings are presented alongside those from the present study in Table 6 of the Results section. Given that professional and family carers are faced with the same task of caring, evidence from studies with professionals will also be used to highlight how caring in this population may be experienced, albeit from a different perspective.

The multi-dimensional theory

The multidimensional theory of burnout is the predominant theory in the field. It identifies three core domains of burnout – high Emotional Exhaustion and Depersonalization and low Personal Accomplishment (Maslach, Jackson & Leiter, 1996, pp. 194).

- Emotional Exhaustion (EE) describes “feelings of being emotionally overextended and exhausted by one’s work”.
- Depersonalisation (DP) describes “unfeeling and impersonal response towards the recipients of one’s care”.

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Person Accomplishment (PA) refers to “feelings of competence and successful achievement in one’s work with people”.

Burnout is identified by high levels of EE and DP and low levels of PA, but adverse scores in any one domain can indicate potential “caseness”.

EE is considered the core component, and is the most commonly reported symptom (Maslach et al., 2001). Within healthcare settings many interactions involve managing difficulties such as the physical, psychological, social or spiritual needs of the patient. Often these problems are charged with emotions such as anger, fear, embarrassment or despair, and frequently solutions are not readily obvious, or even available. This can create further unpleasant feelings. Working in this type of environment over a period of time can be emotionally draining and cause chronic stress (Maslach & Jackson, 1981). A way of managing this stress may be to depersonalise the recipients of one’s care – this involves ignoring the unique human qualities to enable emotional distancing. Such actions are likely to erode one’s sense of effectiveness and achievement in their role which leads to a lack of PA (Leiter & Maslach, 1988). Later research questioned a sequential development of PA, and suggested it developed separately, and in parallel to the others (Leiter, 1993).

Job characteristics such as too much work in a given time, conflict between staff, lack of autonomy and lack of involvement in decision making can all facilitate the development of burnout. Age is the only personal demographic factor shown consistently to be related to burnout - higher levels are found in younger people (Maslach et al., 1996). In family carers, caring for a pwLII can be stressful. However not all carers experience the responsibility or “burden” the same way. Using Maslach’s model, the concept of burnout can be used to assess the subjective emotional, cognitive and behavioural responses to caring.
Prevalence of burnout

Burnout is common to many healthcare professionals. As stated, because of the lack of research with informal carers, it is helpful to turn to the literature on professional carers. Such evidence may shed light on what we might expect in informal carers faced with the similar demands of caring for someone with a LLI. In a UK study of oncology staff, 27 per cent of the overall sample experienced high levels of EE, 19 per cent reported high levels of DP and 31 per cent acknowledged low level of PA (Catt et al., 2005). In a study by Grunfeld and colleagues of cancer professionals in Canada, 53 per cent of doctors displayed high levels of EE compared to 37 per cent of allied health professionals and 30.5 per cent of support staff. Levels of DP were 22.1 per cent, 4.3 per cent and 5.5 per cent respectively. 48 per cent of doctors reported low levels of PA compared to 54.0 per cent of allied health professionals and 31.4 per cent of support staff (Grunfeld et al., 2000). Levels of burnout in support staff are of particular interest as their role is perhaps most similar to that of informal carers in terms of the demands of the task, and the level of education and formal training they receive.

Research suggests that professionals working with pwLLI experience lower levels of burnout that professionals in other caring roles (Ramirez, Addington-Hall & Richards, 1998). Levels of EE and DP appear to be consistently lower in hospice nurses than nurses from other disciplines (Payne, 2001). Within a palliative care setting, both job satisfaction and perceived rewards of working with people and their families at such times are shown to be protective (Fallon & Hanks, 2006). It is also possible that the strong ethos of the hospice movement (which stresses staff support and team cohesiveness) may explain why there are comparatively lower levels of burnout in these groups (Vachon, 1995). However, can we assume that informal carers of pwLLI are at a similar low risk?

Only one previous study (Ybema et al., 2002) explored the level of burnout in family carers of pwLLI. This study compared carers of people with cancer and MS, and
showed similar levels of burnout across all domains. However, this scale used an adapted Dutch version of Maslach’ Burnout Inventory (MBI) which utilised an atypical 7 point rating scale, so the findings of this research therefore cannot easily be compared to those using the standard MBI.

The cost of burnout

Carer burnout can have huge implications at both an individual and organisational level. Burnout in healthcare professionals is associated with an increased probability of marital conflict, a higher prevalence of psychiatric disorders, substance misuse problems and an increased risk of suicide (Blenkin et al., 1995; Wall et al., 1997; Tyssen & Vaglum, 2002). Burnout affects not only the QoL of formal (Souza-Baros, 2007) and informal carers (Ramirez, 1998; van der Heuvel, 2001), but also the quality of care delivered to patients (Cordes & Dougherty, 1993).

It is reasonable to hypothesise that burnout in family carers may lead to comparable consequences for the individual. Indeed family carers may be more susceptible to burnout as they often adopt their role by default, and thus may not have a predetermined motivation to care. Carers are perhaps less likely to have the formal education, training and support to assist them in their role and help them to manage their emotional reactions to their work. They are maybe more likely to have other demands on their time including their chosen career. There may be increased pressure when caring for a pwLLI, as there is no “second chance to get it right” – this may add to the strain of caring (Payne & Ellis-Hill, 2001). Carers may expect very high standards from themselves and strive to be the “perfect” carer. Idealism can increase the risk of burnout, as carers seek to achieve goals which are unrealistic given nature of the illness and the demands on themselves as human-beings (Schaufeli & Enzmann, 1998).
Family carers affected by burnout may feel inadequate, frustrated, overwhelmed and unable to cope. Carer strain is often a key factor in determining if a patient goes into institutional care (Hinton, 1994; Weitzner et al., 2000), which is frequently associated with financial costs to the NHS. The psychological impact of acknowledging that one is unable to manage at home may also be costly - deterioration in self-confidence and self esteem, a sense of being a failure and increased feelings of guilt are common under such circumstances (Nankervis et al., 1997; Kellett, 2001).

**Resilience**

A factor believed to ameliorate the experience of stress is resilience. This relationship can be understood by considering Lazarus & Folkman’s transactional model of stress (1984). The model proposes that there is not a direct link between stressors and stress, but rather the relationship is mediated by an appraisal of the stressful situation and one’s resources to cope with it. Resilience can change how the caring task is perceived (e.g. from one that is overwhelming to one that is challenging), and can also change one’s perception of the resources they have available.

**Definition**

Resilience can be defined in terms of “an individuals’ capacity to maintain competent functioning in the face of major life stressors” (Kaplan et al., 1996, pp. 158). It reflects an ability to adapt to chronic stress or adversity and to manage, or even thrive, *in spite of it*. Resilient individuals have belief in themselves and their capabilities, and are resourceful in times of adversity. They usually have a sense of mastery, determination and independence and are able to find meaning in their circumstances, however challenging (Wagnild & Young, 1993). Resilience can be conceptualised as on a continuum with vulnerability (Rutter, 1985), and arguably its definition is interdependent with adversity or risk - to demonstrate resilience, one must face adversity or risk (Jackson, et al., 2007).
Resilience and coping

The capacity to cope in challenging situations is central to the idea of resilience. In a large American study, Pearlin and Schooler (1982) highlight how different people cope in adverse circumstances. Those who reported “coping well” found meaning in their stressful situation, which reduced the perceived severity of the situation. Their actions also tended to focus on reducing the stress of the situation rather than attempting to alter the situation itself. In a study of older people, greater resilience was associated with an increased use of social resources (Hildon et al., 2008). Most research on resilience has focused on children that thrive despite growing up in adverse circumstances (Werner & Smith, 1992; Cederblad et al., 1994). Such longitudinal studies provide evidence that resilience not only buffers the experience of immediate stress, but also serves to facilitate better long-term outcomes.

Resilience and caring

Resilience is particularly important in mediating the experience of carer burden (Egan, 1993). Anderson (1998) reported that a sense of coherence (as a measure of resilience) was the most important predictor of the impact of an illness on a family. Similarly, in a study of carers of chronically ill elderly people, a sense of coherence was found to be associated with carers utilising healthier coping strategies and “redefining the meaning of the situation” (Wagenfeld et al., 1998, pp. 259). In a review of the resilience literature, Barnard (1994, pp. 139-140) identified 9 phenomena which repeatedly correlate with resilience. Those which may be particularly relevant to family carers of pwLLI are:

1. “A capacity to construct positive meanings for events in their world that enhance their understanding of the events”.

2. “Being able to selectively disengage from the home/task and engage with those outside, and then to engage”.

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Finding meaning in a task can ameliorate the stressful experience. This was highlighted in a group of hospice nurses who reported that finding a sense of meaning and purpose in their work mitigated the effects of the job stress, and enabled them to maintain a sense of well-being (Ablett & Jones, 2007). Resilience is also related to an ability to temporarily detach oneself from the source of stress: to create opportunities away from the caring role that allow carers time to "recharge their batteries". The notion of taking time away from the source of stress underpins the provision of respite care.

Resilience and burnout

Burnout was originally considered an organisational phenomenon that described an attempt to cope with sustained job stress (Maslach, 1997). Until an important study conducted by Egan in 1993, little attention was paid to the role of personality factors. Egan's research highlighted an individual's sense of mastery and self-esteem as important issues associated with a reduced risk of burnout. Subsequent research has identified other factors such as a "hardy" personality and a "sense of coherence" which also impact on burnout (Bakker et al., 2006; Ablett & Jones, 2007).

Traditionally both carers (Harding & Higginson, 2003) and burnout (Rutter, 1985; Albett & Jones, 2007) are topics studied by adopting a problem-focused perspective. Given this, research has focused on identifying shortcomings in resources and the associated psychological morbidities of both caring and burnout. Whilst this has added considerably to our understanding of the topics, it has not been able to explain why people cope differently with similar situations. By considering the antecedent personality factor of resilience, it may be possible to understand burnout from a more solution focused perspective. Adopting such an approach to studying carers of pwLLI is appropriate given that many carers adapt and cope well with their role (Pitceathly & Maguire, 2003; Pakenham, 2005).
The concept of resilience mediating the experience of burnout has been studied previously in other populations (e.g. Howard & Johnson, 2004). In a Brazilian study of carers of the elderly, the inverse of burnout, “work engagement”, was studied alongside the concept on resilience (Menezes de Lucena Carvalho et al., 2006). The authors suggested resilient carers are not immune to burnout but rather develop better engagement skills with their role which in turn made them less vulnerable to burnout.

Wagenfeld and colleagues (1998) suggest that resilience mediates the experience of burnout by enabling carers to find meaning in their role. Resilient people have confidence in their abilities to manage the challenges, and are able to draw on a wider range of coping strategies to deal with chronic stress (Monroe, 2007). Resilience may also be an important factor facilitating efforts to seek resources and sources of emotional and social support (Palattiyil, 2006). Resilience is demonstrated to be a prominent feature in palliative care staff (Vachon, 2000) and the idea of fostering resilience within nurses is emerging (Warelow & Edward, 2007). If resilience is related to lower risk of burnout in family carers, it is possible that similar interventions to foster resilience may be helpful to family carers.

**Political context**

Based on the 2001 Census, the cost of replacing unpaid care provided by family and friends was calculated at close to £87.01 billion pounds per year (Buckner & Yeandle, 2007). Given the large and increasing numbers of carers and the financial cost of replacing their care, the government has prioritised the needs of carers, and has outlined a framework for developing carer support over the next 10 years (DOH, 2008). This strategy recognises the impact of caring on the physical and emotional health of carers, and outlines plans for pilot schemes which aim to identify and address problems experienced by carers at an early stage. Schemes of interest to psychologists include annual mental health checks to detect problems as they emerge and consideration of priority funding for national projects that provide psychological support (such as Improving Access to Psychological Therapies).
The present study

The present study explores burnout and resilience in informal carers of pwLLI, namely carers of people with cancer, multiple sclerosis (MS) and motor neurone disease (MND). Patients and carers affected by these illnesses often use the same generic health, social and palliative care services and thus it is important to understand how, and if, the caring experience is different in terms of burnout.

This research adds to the literature on burnout by looking specifically at the prevalence and extent of the problem in family carers. It seeks to highlight a link between resilience and burnout which can be explained in terms of Lazarus & Folkman’s (1984) model of stress and coping and the role of appraisal of oneself and the resources available. Burnout is the main outcome measure however additional data on quality of life will be collected. This will be used to aid prediction of carers at risk of burnout, and will form the basis of a subsequent paper.

Research Hypotheses

1. **Carers will experience high levels of burnout as indicated by adverse scores on the MBI. This is because caring is normally not a chosen undertaking, and no formal training is provided. The degree of burnout will be higher than seen in professional carers.**

2. **Burnout will be related to resilience.** Carers who score low on resilience will score adversely for burnout.

3. **Burnout will be related to Quality of Life (QoL) in the domains of Physical, Psychological, Social and Spiritual well-being.** Carers who score adversely on the MBI, are likely to have poorer QoL (causality is not inferred).
4. **Burnout may be predicted from carer demographics, care circumstances, resilience scores and QoL measures.**

Further exploratory analysis will determine if there are any significant differences between the level of carer burnout, the degree of carer resilience or the reported levels of QoL depending on the illness of the patient being cared for.
METHODS

Study Design

A quantitative survey design was used. This method was selected as it was the most appropriate way to address the descriptive and predictive goals of the research questions (Shaughnessy et al., 2000). This approach attempts to test hypotheses and theories generated from previous research. It assumes that variables can be identified, numerically measured, manipulated and controlled. It is experimental and deductive, and regards the researcher as detached, impartial and objective. Quantitative studies use formal measures to collect data and seek to find a consensus by identifying the “norm” (Cresswell, 1994).

This study employed a cross-sectional design and each participant was approached once. Despite the limitations of the design (such that results can be overly influenced by recent events, and one cannot make causal inferences from the data), it was considered a good method of collecting data from a large number of participants. It did not involve participants committing a lot of time to the study - which was important given that many were caring for people with short life expectancies. It also allowed data to be collected anonymously which was crucial given the sensitive nature of some of the questions, and powerful social norms which may influence responses.

Study sample and recruitment

Participants were recruited from four main sources: local services for patients, local support groups for carers, internet websites for patients and an internet website for carers. Analyses were conducted on all of the main outcome measures to assess if there were any differences based on the source of the data. One significant difference was found - carers who accessed local services rated their spiritual well-being higher than those who accessed the study online. There were no other significant differences in Emotional Exhaustion, Personalisation, Personal Accomplishment, resilience or in other domains of QoL.
Of 120 questionnaires distributed locally, 73 were returned yielding a response rate of approximately 61 per cent. There is no consensus as to what constitutes a good response. Estimates range from 80 per cent for inoffensive topics to 40 per cent for more sensitive subjects (Breakwell et al., 1995). Although the response rate was deemed acceptable, collecting more data from online participants added to the sample size and facilitated data collection from a wider range of participants. A further 88 participants accessed the study online.

**Inclusion and exclusion criteria**

The inclusion criteria were as follows. All participants were:

- Adults providing unpaid care to other adult family members or friend. (They did not have to live with the person they cared for.

- Carers of people with life-limiting, progressive illnesses. Three specific illnesses were identified - cancer, multiple sclerosis (MS) and motor neurone disease (MND). An “other” category included carers of people with other life-limiting progressive illnesses such as chronic heart failure, chronic obstructive pulmonary disease (COPD) and Parkinson’s disease.

- Carers had adequate English language abilities to meet the demands of the study.  

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6This criterion was deemed necessary due to the nature of the research and reliance on a self-report measure. Using other people (such as the researcher or an interpreter) would have comprised the anonymity and confidentiality of responses, and may have led to more socially desirable responses being reported. Data regarding the psychometric properties for interpreted versions of the scale were also not available.
Exclusion criteria:

- Carers of children or young people (below 18 years) with a life limiting illnesses.
- Carers of people with learning difficulties or dementia.\footnote{This was because the factors affecting the caring experience may be different when caring for someone who is cognitively impaired and possibly presenting behavioural management difficulties.}

**Procedure**

Participants read a Participant Information Sheet (PIS) and completed 1 questionnaire (Appendices 1 and 2 respectively). The PIS and questionnaire were piloted on a group of non university educated associates of the researcher, and feedback was received regarding the presentation and ease of completion – documents were amended accordingly. Flesch readability Statistics were applied to each document and both were deemed appropriate for use in a population of “general” non-technical readers (Heslop et al., 2003). The estimated completion time for the questionnaire was based upon reports of average reading speed. The average reading speed for non-technical material is approximately 200-250 words per minute (Just & Carpenter, 1986). Given the number of words in the questionnaire (2532), an approximate time was 10-13 minutes. As it was likely that participants may hesitate, re-read or think about questions, an estimated time for completion was 15-20 minutes.

Data were collected from a number of sources, as different procedures were followed in each service, they are described separately.

**Local services for patients**

Over a period of 18 months the researcher contacted local services that support pwLLIs. These included a community palliative care team, 6 hospices and a MS therapy centre. All services opted to participate except 3 hospices that were unable to
assist within the timeframe. In each service the researcher discussed the study with a member of the management team and a staff member who had regular contact with patients and their families. Posters indicating how to participate or contact the researcher were displayed in day rooms and waiting areas (Appendix 3). Where appropriate, individual questionnaire packs were left for people to collect. Each pack included a PIS, a Questionnaire and a stamped addressed envelope. In the community palliative care service and 1 hospice, the researcher attended several carer support meetings to discuss the study with carers directly.

Local branches of organisations that support people with MS (n=2) and MND (n=3) were contacted by telephone. The study was discussed, approved by their committees and advertised in their newsletters and on local branch websites: participants were invited to contact the researcher directly or access the study online.

Local services for carers

Telephone contact was made with each service and discussions were held about who was eligible to participate. The researcher posted batches of questionnaire packs to the managers of the services who posted them directly to appropriate carers with a covering letter (Appendix 4). No personal details were passed to the researcher. For this group and those accessing local services (as above), informed consent was assumed when the questionnaire was returned. As all questionnaires were anonymous, it was not possible to withdraw questionnaires once submitted.

Online services for patients

Contact was made with 3 national organisations that offer internet support to pwLLIs. Following approval from each site (1 dedicated to each of the identified illness groups) a link to the online site hosted by the University was posted on the websites. This directed participants to an online version of the study identical to the paper
version. The first page briefly outlined the study (Appendix 5) and offered people the option of being directed to further information (the PIS).

**Online services for carers**

Contact was made with a national organisation that supports carers. Details of the study were discussed and a link to the online version of the study was posted on their website. The procedure for participation was the same as above. Participants were informed that should they wish to withdraw consent mid-way through, they could simply navigate away from the page and their responses would not be used.

**Measures**

Participants completed one multiple choice questionnaire which was divided into four sections. Participants were provided with generic descriptions of each section in order to minimise the risk of their responses being influenced by their knowledge of a particular construct (Manstead & Miles, 1996). This is specifically recommended when using the MBI scale (Maslach *et al*., 1997).

1. **Demographic questionnaire**

This was a non-standard questionnaire developed by the researcher to gather information about the sample. It enquired about the carer’s ethnicity, the age and gender of the carer and patient, how they were related (or not), and if they lived together. It also asked about the patient’s illness, and when they were diagnosed. A second part was at the end of the questionnaire. It asked the carer to think about what they expected to happen to the patient in the next two years (Improve, Remain ill, **

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8 When the patient was diagnosed was taken as a crude but objective measurement of how long the carer had been "caring" for. This was because there is no clear definition of what constitutes caring, and many people have different ideas of when caring begins. In attempt to standardise this, the time of diagnosis was used.
Deteriorate or Die). All questions were multiple choice (except the name of illness) which was consistent with the rest of the questionnaire. Categories for ethnic group were matched with those used in the 2001 Census (Office of National Statistics, 2003).

2. Thoughts about being a carer: Maslach Burnout Inventory (MBI; Maslach & Jackson, 1986).

The MBI was chosen as it is currently the leading measure of burnout (Cordes & Dougherty, 1993). The wording was altered to make it easier for carers to read and apply to their own circumstances. Adaptations included changing the word “work” to “caring”, and changing the word “recipients” to “the person I care for”. The MBI is a 22 item scale divided into 3 subscales. Each subscale measures a component of burnout: emotional exhaustion (EE, 9 items), depersonalisation (DP, 5 items) and reduced personal accomplishment (PA, 8 items). The questionnaire is written in the form of statements about feelings or attitudes (e.g. “I feel like I am at the end of my rope”) and participants are asked to respond by stating how frequently they experience the feeling. Responses range from 0 (“Never”) to 6 (“Every day”) on a 7 point scale.

Previous research has indicated that EE and DP are closely related whereas PA is an independent subscale (Maslach et al., 1997). Given this, each domain is scored separately and not combined into a total score. Maslach and colleagues (1996) suggest using the original numerical scores when performing statistical analyses with the data, although categorical scores of low, moderate and high levels of burnout can be quoted by comparing scores to cut-off points indicated in the manual.

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9 The positioning of these questions was decided following consultation with a NHS Ethics Committee. It was hypothesised that thinking about the death of a family member earlier in the questionnaire may have influenced subsequent responses or perhaps led to some people not wanting to participate.

10 Permission was granted from the author to adapt the scale in this way (Appendix 6)
Items on the MBI were chosen following interviews and collection of questionnaire data from a large sample of healthcare workers (Maslach, 1976, 1982). An original 47 item scale was administered to another large sample, and factor analysis reduced the scale to the 22 item scale used currently. The reliability co-efficients were derived by administering the scale to a further independent sample (N=1316) and internal consistency was estimated by Cronbach’s coefficient (alpha). The co-efficients for the subscales were: EE = 0.90, DP=0.79 AND PA= 0.71 (Maslach et al., 1996). Test-re-test reliability was demonstrated in 5 studies and scores ranged from (0.59-0.82) for EE, (0.50-0.72) for DP and (0.57-0.80) for PA: the delay between testing ranged from 2 weeks to 1 year (Jackson et al., 1986; Leiter, 1990; Lee & Ashforth, 1993, Leiter & Durup, 1996; Maslach et al., 1997).

Good convergent validity was demonstrated by correlating scores with behavioural ratings from people known to the individual, job characteristics related to burnout (e.g. number of clients dealt with), and scores associated with various outcomes related to burnout (satisfaction of growth within job). Good divergent validity was demonstrated by distinguishing the scores from scores obtained on other measures confounded with burnout (e.g. general job satisfaction). The MBI is used widely and considered valid in populations of professional carers (Mallet et al., 1991; Ogus, 1992 & Payne, 2001), however the appropriateness of the scale for family carers has yet to be demonstrated, and thus findings are interpreted with caution.


Resilience was measured using the Resilience Scale (RS). This is a 25-item scale which measures the degree of personal resilience. All items are worded positively and are scored on a 7 point scale. Scores are anchored by qualitative descriptions, and range from 1-7: “Strongly Disagree (1), to “Strongly Agree (7). Total resilience scores range from 25 to 175 with higher scores indicating a higher level of resilience.
The RS was first derived from a 1987 qualitative study of older women who had successfully adapted to a personal loss or major life event (Wagnild & Young, 1993). It originally consisted of 50 items which were verbatim statements made by participants in the 1987 study. After initial analysis, the scale was reduced to 25 items which reflect 5 key aspects of resilience. These key areas are self-reliance, meaning, equanimity, perseverance and existential aloneness. (Wagnild & Young, 1990). Factor analysis revealed that the RS is based upon 2 main factors namely “Acceptance of self and life” (which suggests adaptability, balance and flexibility), and “Personal Competence” (such as self reliance, independence, determination, mastery and resourcefulness) (Wagnild & Young, 1993). It is helpful to acknowledge the conceptual framework underpinning this scale although resilience is reported as a total score.

In 1993, the authors evaluated the RS in a large sample (N=782) of adults. The internal consistency of the scale was good (r=0.91) and concurrent validity was assessed by correlating RS scores with measures of depression (r=−0.41, p<0.001), life satisfaction (r=0.37, p<0.001), morale (r=0.32, p<0.001) and health (r=−0.26, p<0.001) (Wagnild & Young, 1993). Subsequent studies have demonstrated the reliability of the RS in other adult and older adult populations. Cronbach’s alpha coefficients ranged from 0.85–0.94 (Humphreys, 2003; Nygren et al., 2005; Leppert et al., 2005; Wagnild, 2009).

4. Information about your quality of life and how it is affected by caring: Quality of Life Family Version (Ferrell & Grant, 2004)

QoL was assessed using an adapted version of this tool. The original Family version scale stemmed from a tool devised to assess QoL in cancer patients. Factor analysis confirmed 4 subscale domains - Physical, Psychological, Social and Spiritual well-being. The Family version was revised and tested from 1994 – 1998 in a study of 219 family carers of people with cancer (Ferrell, 1996). The original scale was a 37-item
questionnaire. The test-retest reliability score was $r=0.89$, and the internal consistency was $r=0.69$. It was adapted for use in this study for several reasons:

1. To remove cancer specific items (e.g. Are you fearful of a second cancer? Are you fearful of the spreading of the cancer?)

2. To remove items that were worded unclearly and/or not of relevance to this particular study (e.g. How distressing has the time been since your family member’s treatment ended?)

3. To remove items that made assumptions about a person’s spiritual practices (Is the amount of support you receive from religious activities sufficient to meet your needs?)

Each question was scored from 0 (worst outcome) to 10 (best outcome), with a qualitative anchor at each end. Several items were reversed to minimise the risk of acquiescent responding. A subscale score was obtained for each domain by summing the items and calculating a mean. Given that the scale was amended considerably, the psychometric properties of the measure were no longer valid. Careful consideration was given as to whether the scale was still a useful tool.

General QoL measures were not used as the researcher was particularly interested in how carers perceived the task of caring as impacting on their QoL. Most studies assessing the impact of caring on QoL have focused on carers of people with psychiatric difficulties (see Ohaeri, 2003, for a review), or those caring for the elderly, particularly those with dementia (Baillie et al., 1988; Dunckin & Anderson-Hanley,

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11 Answers ranged from 0 (Not at all) to 10 (Completely). The wording of the question could not differentiate between those who did not engage in such activities out of choice, and those who did engage and gained something from them.

12 No items were removed from the Physical well-being section, 5 items were removed from the Psychological well-being section, 2 items were removed from the Social well-being section, and 2 items were removed from the Spiritual well-being section.
1998). Within the palliative care literature, studies exploring QoL have focused predominantly on mapping the patient’s experience (Cohen, 2001), and mostly those with cancer. Despite the adaptation necessary for this scale, it still provides a useful measure of functioning in different domain of QoL.

**Statistical Analyses**

*Sample size calculation*

In order to determine appropriate sample sizes for each statistical test, *a-priori* power calculations were conducted using G-Power 3 software (Faul et al., 2007). Sample size calculations utilise 3 related parameters – effect size, alpha & beta (Field, 2005). In psychological research, it is common to aim for a medium effect size which balances the clinical need to explain a relatively large amount of the variance, with the constraints of recruiting an acceptable sample size. However, to obtain a more meaningful estimate of effect size specific to this study, and linked to the main outcome measure (in this case the MBI, English version), it was helpful to refer to previous research. Previous research (such as Ogus, 1992) achieved a large effect size using a sample of 128 nurses: This indicated that a sample of a similar size was sufficient to elicit meaningful results if they existed. The standard level for alpha is 0.05. Beta represents the power of the test which is its ability to detect an effect (Field, 2005). Cohen (1992) recommends power of 0.8 (that is there is an 80% chance of detecting an effect of one exists). As the research utilised many different statistical tests, the sample size was determined by identifying the minimum number of participants required for the regression analysis which demanded the largest sample. With an expected effect size of 0.15 (medium effect), alpha set at 0.05 and power of 0.8, a minimum sample size of 98 was required.

*Parametric or Non-Parametric tests*

In psychological research, it is helpful to comment upon the findings of the research in relation to the population from which a sample is drawn. To do so, it is advisable to
use parametric tests in which a sample statistic is obtained to estimate the population parameter (Wilcox, 2001). Parametric tests are also generally regarded as more robust and powerful, and better able to efficiently detect real differences and effects if they exist (Freidlin & Gastwirth, 2000; Field, 2005). In order for inferences based upon the research to be valid, it is necessary to ensure the assumptions of parametric tests are met (normally distributed, homogeneity of variance, at the interval level, and independent).

Assessing for assumptions of parametric tests

Data were analysed using the Statistical Package for Social Sciences (SPSS, version 16.0). Initial checks were made to assess for errors in data entry, univariate outliers or missing data: 9 participants were removed as they provided insufficient data to be included in any analysis (N=152). Histograms were plotted for each variable to visually examine the distribution of the data and crudely check for normality. An analysis of skewness and kurtosis for each variable (or each level of variable if split into separate groups) was conducted. For moderate sample sizes, a conventional but conservative alpha level is set for evaluating if the distribution differs significantly from normality. Any z score above the value of 2.58 was deemed significant (p<0.01), and indicated the data were not normally distributed (Munro, 2000). The Kolmogorov-Smirnov test was used to assess for overall normality. If the test was significant (p<0.01), it indicated a significant deviation from normality and thus violated the assumptions of parametric tests. Homogeneity of variance was assessed using Levine’s test. A significant result on this test (p<0.01), indicated there was unequal variance in each group and thus parametric tests could not be used.

13 Although recommended by Munro (2000), statistical tests that check for normality may be biased by sample size. Therefore it is important the distribution is evaluated in combination with other checks of normality such as observing a histogram (Tabachnick & Fidell, 1996).
Transforming data

If data do not meet the assumptions of parametric testing (e.g. the distribution is skewed), it is common for researchers to transform the data to improve the analysis, reduce the impact of outliers and increase statistical power (Tabachnick & Fidell, 1996; Grissom, 2000). Transformation aims to normalise the distribution so that parametric tests can be used without violating the assumption of normality (Bradley, 1978). Despite a suggestion in one text that transformation is always recommended for statistically skewed data (Tabachnick & Fidell, 1996), other researchers suggest transforming data makes little difference to the outcome of certain tests such as Pearson's test of correlation (Norris & Aroian, 2004). In this study, where data were not normally distributed, they were transformed to normality or "near normality" and analysed using parametric tests. If transforming the data was not helpful and the assumption of normality was still not met, the original (non-transformed) data were analysed using non-parametric tests.

Application of statistical analysis to hypotheses

Hypothesis 1: Carers will experience high levels of burnout.

The descriptive statistics function was used to calculate average scores for EE, DP and PA. Percentage of carers falling in each category ("High", "Moderate" and "Low") were computed. To explore how these scores compare to previous reports of burnout in professional carers, a table indicting the mean scores from this study and previous studies was generated.

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14 The robustness of parametric tests mean that they can tolerate data which are "nearly" normally distributed (Tabachnick & Fidell, 1996).
Hypothesis 2: Burnout will be related to resilience

The relationship between resilience and domains of burnout (EE, DP and PA) were explored separately. If data met the assumptions of parametric tests, Pearson’s correlations were computed, if not Spearman’s Correlations were used.

Hypothesis 3: Burnout will be related to Quality of Life (QoL)

The relationships between domains of burnout and aspects of QoL (Physical, Psychological, Social and Spiritual well-being) were explored separately. If data met the assumptions of parametric tests, Pearson’s correlations were computed, if not Spearman’s Correlations were used.

Hypothesis 4: Burnout can be predicted.

Separate analyses were calculated for each domain of burnout EE, DP and PA utilising a stepwise General Linear Model. Predictor variables were chosen based on striking an appropriate balance between simplicity (the smallest number of predictor variables) and predictive power. Green (1991) recommends that to adequately test the overall fit of a model, a sample of 152 participants can accommodate a maximum of 12-13 predictor variables\(^{15}\). To test individual predictors a maximum number of 48 predictors can be used\(^{16}\). Given that the sample size was fixed at 152, a maximum of 12-13 variables were considered.

The model was computed using the General Linear Model command in SPSS as it can easily accommodate categorical data (Howitt & Cramer, 2008)\(^{17}\). This method was

\(^{15}\) Sample size = 50 + 8k where k is the number of predictors.

\(^{16}\) Sample size = 104 + k where k is the number of predictors

\(^{17}\) The reference group for determining the significance of each variable is set by SPSS to the level of the variable that is last alphabetically. In the illness group, this would have been “Other”. However as
selected as it was more efficient than computing dummy variables for each level of each variable as required in multiple regression.

Ethical considerations

Approval for the study was granted by three relevant Committees - NHS Ethics, NHS Research and Development and the University of Surrey (Appendix 7). The researcher worked closely with both the field and research supervisors to uphold the duty to care to protect participants as a principal priority, and to abide by the ethical principles underlying the Declaration of Helsinki (WPA, 1961) and good practice guidelines for conducting research. Excellent field supervision allowed space for the researcher to reflect upon the emotional impact of the work.

Carers were provided with written details about the study and how their results would be used. Various means of contacting the researcher were provided to allow ease of communication. All questionnaire packs were non-identifiable so carers were under no obligation to complete packs if they chose not to do so. Carers were notified that informed consent was inferred when questionnaires were returned, or the full questionnaire was completed online.

The study design (multiple-choice) allowed the researcher to be aware in advance of the range of responses permitted. There was no scope within the questionnaires to disclose criminal or abusive acts. Some carers could identify themselves as experiencing a high degree of burnout, however as the results were anonymous it was not possible to offer direct support specifically to these carers. Carers were asked about the impact of caring on them, which they may not have thought about before. Given that it was about their role in caring for a pwLLI, thoughts about the inevitable loss of the person may have provoked distress. Additionally some questions may have been concerned with illnesses not specifically being studied, the reference group was changed to the largest group of cancer.
triggered their negative thoughts about their role and this may have elicited feelings of
guilt or shame. With these potential issues in mind, all participants were provided with
details of local and/or national support agencies and contact was arranged with these
prior to conducting the research to ensure they were able to support carers if they
chose to contact them. It was not possible to identify if any carers used these services
following participation, although no carers contacted the researcher directly to request
signposting to support services.
RESULTS

Description of the sample

Table 1 - Summary of demographic information

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency</th>
<th>Percentage of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>47</td>
<td>30.9</td>
</tr>
<tr>
<td>Female</td>
<td>105</td>
<td>69.1</td>
</tr>
<tr>
<td>Patient gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>77</td>
<td>50.7</td>
</tr>
<tr>
<td>Female</td>
<td>75</td>
<td>49.3</td>
</tr>
<tr>
<td>Carer age group (mode)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>51-60 years</td>
<td>44</td>
<td>28.9</td>
</tr>
<tr>
<td>Patient age group (mode)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>61-70 years</td>
<td>42</td>
<td>27.6</td>
</tr>
<tr>
<td>Ethnicity(^{18})</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>137</td>
<td>90.1</td>
</tr>
<tr>
<td>White Other</td>
<td>11</td>
<td>7.2</td>
</tr>
<tr>
<td>Mixed Other</td>
<td>1</td>
<td>0.7</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Not stated</td>
<td>1</td>
<td>0.7</td>
</tr>
<tr>
<td>Caring for whom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male Partner</td>
<td>65</td>
<td>42.8</td>
</tr>
<tr>
<td>Female Partner</td>
<td>44</td>
<td>28.9</td>
</tr>
<tr>
<td>Mother</td>
<td>21</td>
<td>13.8</td>
</tr>
<tr>
<td>Father</td>
<td>7</td>
<td>4.6</td>
</tr>
<tr>
<td>Child</td>
<td>11</td>
<td>7.2</td>
</tr>
<tr>
<td>Other(^{19})</td>
<td>4</td>
<td>2.6</td>
</tr>
<tr>
<td>Living arrangements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient living with carer</td>
<td>126</td>
<td>82.9</td>
</tr>
<tr>
<td>Patient living in own home</td>
<td>19</td>
<td>12.5</td>
</tr>
<tr>
<td>Patient living in nursing home</td>
<td>5</td>
<td>3.3</td>
</tr>
<tr>
<td>Patient in hospital/hospice</td>
<td>2</td>
<td>1.32</td>
</tr>
<tr>
<td>Member of a religious group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>52</td>
<td>34.2</td>
</tr>
<tr>
<td>No</td>
<td>100</td>
<td>65.8</td>
</tr>
</tbody>
</table>

(Please see Appendix 8 which divides the sample into those recruited locally and those recruited online).

The sample demographics are described in Tables 1 and 2. The sample consisted of 152 carers. Over two thirds of the carers were female (69.1 per cent), with a more even gender split in patients (50.7 per cent / 49.3 per cent). Age group was normally distributed and the average age of carers (51-60 years) was slightly younger than for

\(^{18}\) Categories from the 2001 Census were provided although only those applicable to the sample are reported.

\(^{19}\) The "Other" group was comprised of 2 friends/ neighbours and 2 sisters.
patients (61-70 years) – in part reflecting the number of people caring for parents (13.8 per cent). The majority of carers selected their ethnicity as White British (90.1 per cent), and just under a third reported being a member of a religious group (34.2 per cent). Carers were mainly living with the person they cared for (82.9 per cent), and most were the ill person’s partner (71.7 per cent).

Table 2 – Summary of information related to the carers’ circumstances

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency</th>
<th>Percentage of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s Illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>61</td>
<td>40.1</td>
</tr>
<tr>
<td>Multiple Sclerosis (MS)</td>
<td>49</td>
<td>32.2</td>
</tr>
<tr>
<td>Motor Neurone Disease (MND)</td>
<td>25</td>
<td>16.4</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>11.2</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the last year</td>
<td>32</td>
<td>21.1</td>
</tr>
<tr>
<td>In the last 2 years</td>
<td>26</td>
<td>17.1</td>
</tr>
<tr>
<td>In the last 5 years</td>
<td>29</td>
<td>19.1</td>
</tr>
<tr>
<td>In the last 10 years</td>
<td>21</td>
<td>13.8</td>
</tr>
<tr>
<td>More than 10 years ago</td>
<td>44</td>
<td>28.9</td>
</tr>
<tr>
<td>Carer’s expectation of the next 2 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve</td>
<td>10</td>
<td>6.6</td>
</tr>
<tr>
<td>Remain Ill</td>
<td>22</td>
<td>14.5</td>
</tr>
<tr>
<td>Deteriorate</td>
<td>57</td>
<td>37.5</td>
</tr>
<tr>
<td>Die</td>
<td>62</td>
<td>40.8</td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td>0.7</td>
</tr>
</tbody>
</table>

Data Screening

Missing data
Initial data screening removed 9 participants (collected from the online study) as they provided insufficient data, and may have withdrawn consent.

Outliers & Distribution
Data in the main burnout domains were checked for outliers and distribution by plotting histograms and using statistical tests. Other variables were screened as
necessary to address the hypotheses. Due to the sample size, alpha was set at 0.01, thus any z scores above 2.58 were considered significant.

**Emotional Exhaustion (EE)**

No significant outliers were noted for EE. An analysis of skewness ($z=1.28, p<0.01$) and kurtosis ($z=2.66^{20}$, $p<0.01$) revealed the histogram was not skewed but was significantly leptokurtic. The Kolmogorov-Smirnov test showed the overall shape differed significantly from normal ($D(152)=0.09, p<0.01$). To assess whether transformation could be helpful, a range of calculations were conducted. All transformations resulted in the data becoming more abnormally distributed so data was not transformed. Given that the z score for kurtosis was only slightly above the critical value, data were analysed using both parametric and non-parametric tests (on untransformed data) and results compared.

**DP**

37 participants (24.3%) scored 0 for DP. The remainder of the sample were approximately normally distributed, with 2 significant outliers [(z=2.74, $p<0.01$) & (z=3.72, $p<0.01$)] and 1 further score on the borderline (z=2.58, $p<0.01$). Outliers were checked against the original data source and found not to be errors in data entry. Although these scores were significantly higher than others in the group, they were legitimate scores (not entered in error), and were also obtained by participants from the intended sample. Given this, they remained in the data set.$^{21}$ The histogram was significantly positively skewed (z=5.44, $p<0.01$) with normal kurtosis (z=2.04, $p<0.01$). The Kolmogorov-Smirnov test showed the overall shape of the distribution differed significantly from normal ($D(152)=1.56$, $p<0.01$). A series of transformations were applied to the data yet it failed to meet the assumptions – all analyses used non-parametric tests.

$^{20}$ Note the z score is marginally above the critical value of 2.58

$^{21}$ It is possible that with a larger sample size, other participants may have scored highly on the measure of DP too.
PA
No significant outliers were noted. An analysis of skewness ($z=2.16$, $p<0.01$) and kurtosis ($z=0.29$, $p<0.01$) revealed the histogram was normally distributed, and this was supported by a non significant result on the Kolmogorov-Smirnov test ($D(152)=0.075$, $p<0.01$). Data utilising PA scores were analysed using parametric tests.

Assessment of the measures
The reliability of the measures in this sample were assessed by calculating Cronbach’s alpha scores for each questionnaire. The MBI burnout tool yielded reliability coefficients of 0.93, 0.74 and 0.73 for the domains of EE, DP and PA respectively. This was comparable to those reported in the original study. The coefficient for the resilience scale was 0.91, as in the original study. The reliability coefficient of the QoL measure was 0.89 which was an improvement on the figure of 0.69 reported by the authors in the original study.
Table 3 – Burnout as a function of demographic factors.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>N</th>
<th>Emotional Exhaustion</th>
<th>Depersonalisation</th>
<th>Personal Accomplishment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Carer gender</td>
<td>Male</td>
<td>47</td>
<td>31.36</td>
<td>14.27</td>
<td>7.34</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>105</td>
<td>29.64</td>
<td>14.49</td>
<td>5.69</td>
</tr>
<tr>
<td>Carer Age</td>
<td>18-40</td>
<td>15</td>
<td>32.67</td>
<td>15.72</td>
<td>8.67</td>
</tr>
<tr>
<td></td>
<td>41-50</td>
<td>35</td>
<td>27.46</td>
<td>13.96</td>
<td>4.97</td>
</tr>
<tr>
<td></td>
<td>51-60</td>
<td>44</td>
<td>28.57</td>
<td>13.99</td>
<td>5.89</td>
</tr>
<tr>
<td></td>
<td>61-70</td>
<td>35</td>
<td>33.86</td>
<td>13.83</td>
<td>7.97</td>
</tr>
<tr>
<td></td>
<td>71+</td>
<td>23</td>
<td>30.13</td>
<td>15.62</td>
<td>4.35</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White British</td>
<td>137</td>
<td>30.35</td>
<td>13.97</td>
<td>6.36</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>15</td>
<td>27.00</td>
<td>18.06</td>
<td>4.00</td>
</tr>
<tr>
<td>Relationship (^{22})</td>
<td>Male Partner</td>
<td>65</td>
<td>27.38</td>
<td>15.77</td>
<td>6.68</td>
</tr>
<tr>
<td></td>
<td>Female Partner</td>
<td>44</td>
<td>32.45</td>
<td>13.32</td>
<td>7.77</td>
</tr>
<tr>
<td></td>
<td>Parent</td>
<td>28</td>
<td>31.14</td>
<td>12.05</td>
<td>4.46</td>
</tr>
<tr>
<td></td>
<td>Child</td>
<td>11</td>
<td>38.73</td>
<td>9.62</td>
<td>3.18</td>
</tr>
<tr>
<td>Living together</td>
<td>Yes</td>
<td>126</td>
<td>30.37</td>
<td>14.79</td>
<td>6.75</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>26</td>
<td>29.23</td>
<td>12.52</td>
<td>3.54</td>
</tr>
<tr>
<td>Religious group member</td>
<td>Yes</td>
<td>52</td>
<td>30.37</td>
<td>15.23</td>
<td>5.33</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>100</td>
<td>30.07</td>
<td>14.03</td>
<td>6.65</td>
</tr>
</tbody>
</table>

SD=Standard deviation.

\(^{22}\) The relationship category was collapsed due to small numbers in some of the groups (mother/father). The “Other” group contained too few participants to be used in any analysis thus was excluded when exploring burnout related to carers’ relationship with patient.
Preliminary Data Analysis

When data were split into groups according to demographic or illness factors, each group was checked to see if it met the assumptions for parametric testing. Independent t-tests and One-Way ANOVAs were used with data that met the assumptions, and Mann-Whitney and Kruskal-Wallis tests were used for data that did not. Table 4 summarises this information. Post-hoc Bonferroni tests were used to determine where significant differences lay.

Table 4 – Significance results for factors involved in Preliminary Data Analysis

<table>
<thead>
<tr>
<th></th>
<th>Emotional Exhaustion (p)</th>
<th>Depersonalisation (p)</th>
<th>Personal Accomplishment (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer gender</td>
<td>0.497</td>
<td>0.093</td>
<td>0.089</td>
</tr>
<tr>
<td>Carer age</td>
<td>0.341</td>
<td>0.052</td>
<td>0.859</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>0.407</td>
<td>0.239</td>
<td>0.080</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td>0.056</td>
<td>0.041*</td>
<td>0.149</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>0.716</td>
<td>0.010*</td>
<td>0.833</td>
</tr>
<tr>
<td>Patient’s Illness</td>
<td>0.026*</td>
<td>0.001*</td>
<td>0.162</td>
</tr>
<tr>
<td>Length of time caring</td>
<td>0.082</td>
<td>0.001*</td>
<td>0.047*</td>
</tr>
<tr>
<td>Expectations for the future</td>
<td>0.001*</td>
<td>0.002*</td>
<td>0.108</td>
</tr>
</tbody>
</table>

* Indicates variable has a significant impact (p<0.05) on EE, DP or PA.

Socio-demographic factors

Carer Gender

Carer gender did not have a significant impact on scores for EE (t=0.68, df=150, p=0.497), DP (U=2049.5 (47,105), p=0.093) or PA (t=-1.71, df=150, p=0.089).

Carer Age

Care age group did not have a significant impact on EE (F(4, 147)=1.34, p=0.341), DP (X²=8.18, df=3, p=0.052) or PA (F(4, 147)=0.33, p=0.859). Despite the p value for

---

23 As different tests were used for each analysis they are indicated in the text rather than Table 4 for ease of reading.
DP being non significant it did suggest that age may still be an important factor accounting for some of the variability in DP scores.

**Ethnicity**

Ethnicity did not have a significant effect on EE ($t=0.83$, df=149, $p=0.407$), DP ($U=777.0$, (137, 14), $p=0.239$) or PA ($t=1.76$, df=149, $p=0.080$).

**Relationship**

The relationship between the carer and patient did not have a significant effect on EE ($F(3,144)=2.63$, $p=0.056$) or PA ($F(3,144)=1.81$, $p=0.149$). However the $p$ value for EE suggests that the relationship between carer and patient may still be an important factor. The relationship did have an effect on DP ($X^2=5.21$, df=1, $p=0.041$), with significantly lower levels reported in those caring for their child (3.18) or parent (4.46) compared to a female partner (7.77).

**Living arrangements**

Whether the ill person and carer lived together did not have a significant impact on EE ($t=0.365$, df=150, $p=0.716$) or PA ($t=-0.212$, df=150, $p=0.833$). It did have an effect on DP ($U=1117.5$, (126,26),$p=0.010$): carers living with the person they cared for reported higher levels of DP (6.75) than those living apart (3.54).

**Religious group member**

Being a member of a religious group did not significantly impact on scores for EE ($t=0.120$, df=150, $p=0.901$), DP ($U=2297$, (52,100), $p=0.235$) or PA ($t=2.00$, df=150, $p=0.106$).
Illness related groups

Patient's illness

The degree of EE differed significantly across illness groups ($F(3,148)=3.17, p=0.026$). Employing the Bonferroni post-hoc test, the level of EE in MND carers was significantly higher than in carers of people with cancer ($p=0.03$). Levels of DP also differed significantly ($X^2=24.00, df=2, p=0.001$): carers of people with MND and MS had significantly higher levels of DP than carers of people with cancer ($p=0.001$). The degree of PA was similar across all groups ($F(3,148)=1.73, p=0.162$). Those caring for people with cancer reported lower levels of burnout across all domains.

Time since diagnosis/Length of time caring

Length of time caring did not have a significant impact on EE ($F(4, 147)=2.11, p=0.082$). Length of time caring had a significant effect on DP ($X^2=18.12, df=4, p=0.001$). Using the Bonferroni post-hoc test, carers of people diagnosed more than 10 years ago were found to report significantly higher levels of DP than those diagnosed in the last year ($p=0.001$). Length of time caring had a significant impact on PA ($F(4, 147)=2.48, p=0.047$). Carers of people diagnosed more than 10 years ago reported significantly lower levels of PA than carers of those diagnosed in the last year ($p=0.046$).
Expectations of the future

The carer's expectation of what would happen to the patient in the next 2 years had a significant impact on EE (F(3,147)=6.88, p=0.001). The Bonferroni test revealed that those who believed the person would improve reported lower levels of EE than those who thought the patient would deteriorate (p=0.007) or die (p=0.002). Similarly, those who believed the patient would remain ill reported lower levels of EE than those who believed the patient would die (p=0.017). Carer's expectations also impacted on levels of DP (X²=14.56, df=3, p=0.002). Those who believed the patient would improve scored significantly lower than those who believed the patient would deteriorate (p=0.045). EE and DP were highest in carers who believed the patient would deteriorate or die. There were no significant differences in PA scores (F(3,147)=0.971, p=0.408).
Table 5 – Burnout as a function of illness factors

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>N</th>
<th>Emotional Exhaustion</th>
<th>Depersonalisation</th>
<th>Personal Accomplishment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Patient’s Illness</td>
<td>Cancer</td>
<td>61</td>
<td>26.87</td>
<td>14.86</td>
<td>3.64</td>
</tr>
<tr>
<td></td>
<td>Multiple Sclerosis (MS)</td>
<td>49</td>
<td>29.78</td>
<td>13.97</td>
<td>7.92</td>
</tr>
<tr>
<td></td>
<td>Motor Neurone Disease (MND)</td>
<td>25</td>
<td>36.40</td>
<td>13.56</td>
<td>9.52</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>17</td>
<td>34.00</td>
<td>12.23</td>
<td>5.53</td>
</tr>
<tr>
<td></td>
<td>In the last year</td>
<td>32</td>
<td>24.50</td>
<td>15.27</td>
<td>3.12</td>
</tr>
<tr>
<td></td>
<td>In the last 2 years</td>
<td>26</td>
<td>29.65</td>
<td>13.47</td>
<td>6.08</td>
</tr>
<tr>
<td></td>
<td>In the last 5 years</td>
<td>29</td>
<td>29.76</td>
<td>14.79</td>
<td>6.45</td>
</tr>
<tr>
<td></td>
<td>In the last 10 years</td>
<td>21</td>
<td>33.52</td>
<td>13.20</td>
<td>4.76</td>
</tr>
<tr>
<td></td>
<td>More than 10 years ago</td>
<td>44</td>
<td>33.27</td>
<td>13.84</td>
<td>9.02</td>
</tr>
<tr>
<td>Expectations of the future (Patient will...)</td>
<td>Improve</td>
<td>10</td>
<td>16.10</td>
<td>11.39</td>
<td>1.60</td>
</tr>
<tr>
<td></td>
<td>Remain ill</td>
<td>22</td>
<td>23.18</td>
<td>15.46</td>
<td>3.64</td>
</tr>
<tr>
<td></td>
<td>Die</td>
<td>62</td>
<td>33.47</td>
<td>12.89</td>
<td>6.95</td>
</tr>
</tbody>
</table>

SD=Standard Deviation.
Hypothesis Testing

Hypothesis 1: Carers will experience high levels of burnout.

Each domain of burnout was explored separately. Using cut-offs provided in the MBI manual (Maslach et al., 1996), scores were classified as Low, Moderate or High. As neither the EE or DP group were normally distributed, median and modal scores are also provided. To facilitate comparison of scores with previous research, mean scores are displayed: however these must be interpreted with caution.

Table 6 – Average categorised scores for burnout

<table>
<thead>
<tr>
<th>Burnout</th>
<th>Median</th>
<th>Mode</th>
<th>Mean</th>
<th>SD</th>
<th>Low (%)</th>
<th>Moderate (%)</th>
<th>High (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Exhaustion</td>
<td>32</td>
<td>44</td>
<td>30.17</td>
<td>14.40</td>
<td>21.1</td>
<td>18.4</td>
<td>60.5</td>
</tr>
<tr>
<td>Depersonalisation</td>
<td>5</td>
<td>0</td>
<td>6.20</td>
<td>6.126</td>
<td>61.2</td>
<td>23.7</td>
<td>15.1</td>
</tr>
<tr>
<td>Personal Accomplishment</td>
<td>32</td>
<td>27 &amp; 34</td>
<td>31.53</td>
<td>8.44</td>
<td>21.7</td>
<td>33.6</td>
<td>44.7</td>
</tr>
</tbody>
</table>

Table 6 shows that although a large proportion of carers experience high levels of EE (60.5 per cent) a relatively small percentage report high levels of DP (15.1 per cent). Just over a fifth of the sample experienced low levels of PA (44.7 per cent). An unusual pattern of scores in the DP category is indicated by the discrepancy in the measures of average. Neither the mean nor median represent the data well, as some people scored low for DP, and others scored much more highly. Overall, 116 participants (76.3 per cent) scored adversely in 1 domain of burnout (i.e. high score for EE or DP or low score for PA). 53 participants (34.9 per cent) scored adversely in 2 domains of burnout, and 14 participants (9.2 per cent) scored adversely in all three domains. To compare the experiences of carers in this study to other family and professional carers, findings from previous research are displayed in Table 7. Carers in the present study showed the showed highest level of EE (30.17). In other studies EE scores ranged from 12.63-24.00.

\[\text{Multiple modes with 11 participants for each score}\]
**Table 7** – Mean scores for burnout in the present and previous studies.

<table>
<thead>
<tr>
<th>Researchers</th>
<th>Sample</th>
<th>N</th>
<th>EE</th>
<th>DP</th>
<th>PA</th>
<th>Methodological Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Maslach’s original study</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maslach &amp; Jackson, 1986</td>
<td>Social workers and child protection workers</td>
<td>1538</td>
<td>21.35</td>
<td>7.46</td>
<td>32.75</td>
<td>MBI scale used in present study was validated on this sample.</td>
</tr>
<tr>
<td><strong>Family Carers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>This study</td>
<td>Family carers</td>
<td>152</td>
<td>30.17</td>
<td>6.20</td>
<td>31.53</td>
<td></td>
</tr>
<tr>
<td>Ybema et al., 2002</td>
<td>Intimate partners</td>
<td>103</td>
<td>23.60</td>
<td>8.25</td>
<td>39.28</td>
<td>Dutch MBI(^2). Used 5 point rather than 7 point scale – provides crude conversion formula for comparisons.</td>
</tr>
<tr>
<td>Angermeyer et al., 2006</td>
<td>Partners of people with schizophrenia or depression</td>
<td>133</td>
<td>12.63</td>
<td>5.09</td>
<td>34.47</td>
<td>German MBI. Only studied partners of people living with the patient.</td>
</tr>
<tr>
<td><strong>Professional carers of people with life-limiting illnesses.</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mallet et al., 1991</td>
<td>Hospice nurses</td>
<td>209</td>
<td>18.50</td>
<td>5.50</td>
<td>61.70</td>
<td>MBI adapted and 7 items added making comparison difficult.</td>
</tr>
<tr>
<td>Hayter, 1999</td>
<td>AIDS Clinical nurse specialists in UK</td>
<td>30</td>
<td>18.75</td>
<td>2.90</td>
<td>30.60</td>
<td>Unusual pattern in DP scores noted by author: 3% of sample within Moderate range for DP, none in High range.</td>
</tr>
<tr>
<td>Payne, 2001</td>
<td>Female nurses from 9 UK hospices</td>
<td>89</td>
<td>17.19</td>
<td>3.91</td>
<td>35.70</td>
<td>Used scale as in present study</td>
</tr>
<tr>
<td>Cocco et al., 2003</td>
<td>Nursing staff</td>
<td>172</td>
<td>15.00</td>
<td>4.00</td>
<td>38.00</td>
<td>Italian MBI</td>
</tr>
<tr>
<td>Italia et al., 2008</td>
<td>Doctors and nurses in an adult oncology unit</td>
<td>32</td>
<td>23.39</td>
<td>8.29</td>
<td>35.07</td>
<td>Italian MBI</td>
</tr>
</tbody>
</table>

\(^2\) The authors of the original scale report the extensive research involved in validating translated versions of the scale (including Dutch and German versions). They acknowledge the psychometric properties of the scales are somewhat similar to American version used in this study (Maslach *et al.*, 2001)
The scores obtained in the present study were most similar to those reported by other informal carers of patients with cancer and MS. DP was comparable to other studies, although higher than reported by professional carers of people with life-limiting illnesses. PA was somewhat similar to other studies, but lower than reported by other family carers, or in professional carers working in hospices on oncology settings.

**Hypothesis 2 - Burnout will be related to resilience.**

*Data screening*

To screen the data relating to resilience, a histogram was drawn. No outliers were noted and statistical tests showed that the distribution was not skewed ($z=1.06$, $p<0.01$) nor leptokurtic ($z=1.86$, $p<0.01$). The Kolmogorov-Smirnov test confirmed the normal distribution ($D(152)=0.059$, $p<0.01$). Scatterplots were drawn to visually assess the relationships between aspects of burnout and resilience. All showed a linear relationship.

*Relationship analysis*

**EE**

The scatterplot showed the relationship between EE and resilience was not unduly affected by significant outliers. Although the data for EE were not strictly normally distributed, the robustness of Pearson’s correlation test can accommodate slight deviations from normally. According to Howitt & Cramer (2008) a Pearson’s parametric test was most appropriate with this data because of its increased power. It showed there was a significantly negative correlation between EE and resilience ($r=-0.50$, $df=150$, $p<0.001$).\(^{26}\)

\(^{26}\) Using the non-parametric equivalent (Spearman’s rho), the relationship was also significant (rho=-0.470, $df=150$, $p<0.001$).
DP
The scatterplot showed there were no significant outliers distorting the size of the correlation coefficient. Data for DP were not normally distributed thus analysed using a Spearman’s rho test. There was a significant negative correlation between DP and resilience (rho= -0.453, df=150, p<0.001).

PA
The scatterplot showed there were no significant outliers distorting the correlation between resilience and PA. Data were normally distributed and analysed using a Pearson’s correlation test. It showed there was a significant positive correlation between PA and resilience (r=0.447, df=150, p<0.001).

Resilience by illness group
To ensure there were no unusual differences in the resilience scores when carers were grouped by illness, a One-Way ANOVA was computed. No significant differences were found (F(3, 148)=0.82, p=0.486).

Hypothesis 3: Burnout will be related to Quality of Life (QoL)

Data screening
To screen the data for QoL, histograms were drawn and statistical analyses computed to check for normality. Although the data were normally distributed within all domains of well-being, there were 3 participants who scored the maximum of 10/10 for Physical well-being. Transforming the data to reduce the impact of these scores was not helpful, therefore the mean scores with and without these participants are included in Table 8.
Table 8 – Mean and Standard deviations of scores for domains of QoL.

<table>
<thead>
<tr>
<th>Domain of wellbeing</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>5.19 (5.09)</td>
<td>1.75 (1.63)</td>
<td>1.00-10.00</td>
</tr>
<tr>
<td>Psychological</td>
<td>4.09</td>
<td>1.49</td>
<td>1.00-8.73</td>
</tr>
<tr>
<td>Social</td>
<td>4.07</td>
<td>1.88</td>
<td>0.14-9.71</td>
</tr>
<tr>
<td>Spiritual</td>
<td>4.32</td>
<td>1.94</td>
<td>0.00-9.80</td>
</tr>
</tbody>
</table>

(Results minus 3 outliers)

Table 8 shows that carers generally rated their Physical well-being as better than their well-being in other domains. This was true even when the 3 carers who reported their Physical well-being at the maximum level were removed.

**Relationship analysis**

Each aspect of burnout was correlated with each domain of QoL.

**EE**

Scatterplots revealed there were negative linear relationships between EE and all domains of QoL. Higher scores for EE were associated with lower scores for Physical, Psychological, Social and Spiritual well-being. The data were analysed using Pearson’s correlations given Howitt & Cramer (2008) statement that “almost” normally distributed data (in the case of EE) can be tolerated within this test.

Table 9 – Correlation co-efficients between aspects of burnout and domains of QoL

<table>
<thead>
<tr>
<th></th>
<th>Physical</th>
<th>Psychological</th>
<th>Social</th>
<th>Spiritual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Exhaustion</td>
<td>-0.451*</td>
<td>-0.455*</td>
<td>-0.558*</td>
<td>-0.396*</td>
</tr>
<tr>
<td>Depersonalisation</td>
<td>-0.192***</td>
<td>-0.208***</td>
<td>-0.234**</td>
<td>-0.193***</td>
</tr>
<tr>
<td>Personal Accomplishment</td>
<td>0.121</td>
<td>0.319*</td>
<td>0.248**</td>
<td>0.283*</td>
</tr>
</tbody>
</table>

(* significant at p<0.001, ** significant at p<0.01, *** significant at p<0.05)
Results

DP

Relationships between DP and domains of QoL were shown on scatterplots to be negative and linear. Higher scores for DP were associated with lower scores for Physical, Psychological, Social and Spiritual well-being. Given that the data for DP were abnormally distributed, the degree of correlation between the variables was computed using a Spearman’s test.

PA

The scatterplot depicting the relationship between PA and Physical well-being indicated the variables were not correlated. This was clarified by a non significant result on the Pearson’s correlation test ($r=0.121$, df=149, $p>0.01$). PA was positively correlated with other domains - Psychological, Spiritual and Social well-being.

QoL by illness group

There were significant differences in the scores for psychological ($F(3,148)=3.512$, $p=0.017$) and spiritual well-being ($F(3,148)=3.153$, $p=0.027$) depending on the illness of the patient being cared for. MS carers scored significantly higher on the measure of psychological well-being than carers of people with MND ($p=0.01$). MND carers scored significantly lower than carers of people with cancer ($p=0.036$, 11) on the spiritual well-being measure. No significant differences were noted in the domains of physical or social well-being.

Hypothesis 4 - Burnout may be predicted.

Which variables?

From this research, we know that resilience, patient’s illness and measures of physical, psychological, social and spiritual well-being all correlate with some aspect of burnout to
some degree. From the literature, it was hypothesised that other relationships may exist between aspects of burnout and:

- Carer age
- Carer gender
- Length of time caring
- Expectations of the future

One method of selecting predictor variables is to compute correlations for all variables with the outcome variables (EE, DP and PA), and include only those that correlate significantly (Field, 2005). However, this is not easily possible for categorical variables and even if partial correlations for continuous variables were found to be statistically significant, it does not mean they are “real” in any sense. Similarly, a variable not significantly correlated with the outcome variable may confound or moderate the impact of another variable in the model (Hayes 2005). Given this and the theoretical indication that the variables listed may be associated, all variables were initially included. These were: Carer age, Carer gender, Length of time caring, Expectations for the future, Patient’s illness, Resilience score, and domains of QoL (Physical, Psychological, Social and Spiritual well-being).

The analyses met the assumptions that the predictor variables were categorical or continuous, the outcome variables were continuous, there was a linear relationship between the variables (with the exception of physical well-being and PA), there was homoscedasticity of variance and the values of the outcome variables were independent (Field, 2005)\textsuperscript{27}. Multivariate normality was further assessed by examining the residual plots of each analysis after computing the model.

\textsuperscript{27} To account for unequal numbers of participants in each group, the regression model was set to "Type III Sum of squares". However, due to the small number of participants in the 18-30 and 81-90 categories, these were collapsed and merged to form 18-40 and 71+ respectively.
As recommended by Kirkwood and Sterne (2003), a stepwise selection procedure was adopted to derive the final regression models for EE, DP and PA:

**Step 1:** The model was fitted with all variables (forward addition) based upon theoretical indications of their importance in predicting the outcome variables.

**Step 2:** A backwards elimination approach was used to omit variables in turn starting with the variable with the largest p value.

**Step 3:** The model was re-fitted and new p values for each variable were automatically computed.

**Step 4:** Steps 2 and 3 were repeated until the p value for each remaining variable was less than a threshold of $p<0.2^{28}$.

At each stage of the elimination, the theoretical and statistical rationale for eliminating variables was considered: I was mindful of the relationship between predictor variables and the outcome variables as determined by this study, and as evidenced in previous literature. I was also aware that some variables may be omitted as a result of shared variance with other predictors. The adoption of a statistical approach to variable selection was used in conjunction with dynamic thinking about the theoretical contributions of each variable.

---

28 It is advisable when adopting a step-wise approach to set the p level much higher than the traditional significance level of 0.05 (Kirkwood & Sterne, 2003). This minimises the likelihood of eliminating variables with may have confounding or moderating effects on other variables, or which may explain an important percentage of the overall variance without reaching the arbitrary threshold for significance of $p=0.05$. 

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EE

EE is a continuous variable which is almost normally distributed, Tabachnick and Fidell (1996), suggest that this data can be accommodated through the robustness of the GLM. All predictor variables were entered into a GLM and stepwise selection procedures were applied to reach the final model. Variables that did not explain a significant amount of the variance (p≤0.2) were omitted in the following order: Carer gender, Spiritual well-being and Length of time caring.

Table 10 – Predictor variables for EE

<table>
<thead>
<tr>
<th>Source</th>
<th>Degrees of Freedom</th>
<th>F</th>
<th>Significance</th>
<th>Partial Eta squared (^{30})</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model</td>
<td>14</td>
<td>14.03</td>
<td>0.001</td>
<td>.591</td>
</tr>
<tr>
<td>Resilience</td>
<td>1</td>
<td>15.77</td>
<td>0.001</td>
<td>.104</td>
</tr>
<tr>
<td>Social well-being</td>
<td>1</td>
<td>18.87</td>
<td>0.001</td>
<td>.122</td>
</tr>
<tr>
<td>Physical Well-being</td>
<td>1</td>
<td>10.40</td>
<td>0.002</td>
<td>.071</td>
</tr>
<tr>
<td>Carer age group</td>
<td>4</td>
<td>4.44</td>
<td>0.002</td>
<td>.115</td>
</tr>
<tr>
<td>Patient’s Illness</td>
<td>3</td>
<td>2.92</td>
<td>0.037</td>
<td>.060</td>
</tr>
<tr>
<td>Expectations of the future</td>
<td>3</td>
<td>1.64</td>
<td>0.184</td>
<td>.035</td>
</tr>
<tr>
<td>Residual</td>
<td>136</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

R\(^2\)=.591, Adjusted R\(^2\)=.549

In the sample studied, the final regression model accounts for 59.1 per cent of the variance in EE. The adjusted R\(^2\) value denotes how well the model generalises: the difference in the values suggests that if the model were derived from the population rather than a sample, it would account for 4.2 per cent less variance in the outcome (54.9 per cent) (Bakeman & Robinson, 2005).

\(^{29}\) Those removed first contributed the least to the overall variance.

\(^{30}\) Partial Eta\(^2\) is a variant of Eta\(^2\) (R\(^2\) change in traditional regression methods), it indicates the percentage of variance in the dependent variable (EE) accounted for by the predictor variable + error. Note that the partial Eta\(^2\) for all significant predictors do not sum to the proportion of total variance R\(^2\). (Tabachnick & Fidell, 1996).
The best predictors of EE were Social well-being (12.2 per cent), Carer age (11.5 per cent) and Resilience (10.4 per cent). Physical well-being and the patient’s illness explained 7.1 per cent and 6 per cent respectively. In the GLM regression technique, it is possible to treat each categorical and continuous variable as separate co-variates. Table 11 shows the effect of each variable on EE when all other variables are controlled.

Table 11 – Mean EE scores by age, illness and future expectation when co-variates are controlled.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>N</th>
<th>Mean</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-40</td>
<td>15</td>
<td>29.42</td>
<td>2.30</td>
<td></td>
</tr>
<tr>
<td>41-50</td>
<td>35</td>
<td>26.96</td>
<td>1.73</td>
<td></td>
</tr>
<tr>
<td>51-60</td>
<td>44</td>
<td>30.94</td>
<td>1.70</td>
<td></td>
</tr>
<tr>
<td>61-70</td>
<td>35</td>
<td>36.00</td>
<td>1.77</td>
<td></td>
</tr>
<tr>
<td>71+</td>
<td>23</td>
<td>35.58</td>
<td>2.12</td>
<td></td>
</tr>
<tr>
<td><strong>Illness Group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>61</td>
<td>27.55</td>
<td>1.36</td>
<td></td>
</tr>
<tr>
<td>MS</td>
<td>49</td>
<td>28.94</td>
<td>1.54</td>
<td></td>
</tr>
<tr>
<td>MND</td>
<td>25</td>
<td>36.59</td>
<td>2.05</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>34.05</td>
<td>2.45</td>
<td></td>
</tr>
<tr>
<td><strong>Expectations of the future</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve</td>
<td>10</td>
<td>24.79</td>
<td>3.52</td>
<td></td>
</tr>
<tr>
<td>Remain ill</td>
<td>22</td>
<td>30.55</td>
<td>2.24</td>
<td></td>
</tr>
<tr>
<td>Deteriorate</td>
<td>57</td>
<td>31.64</td>
<td>1.46</td>
<td></td>
</tr>
<tr>
<td>Die</td>
<td>62</td>
<td>32.75</td>
<td>1.48</td>
<td></td>
</tr>
</tbody>
</table>

Carers aged 61-70 displayed the highest levels of EE (36.00) when all other variables were controlled for. That is, when continuous variables (resilience score, social and physical well-being) and categorical variables (illness group and expectations of the future) remain constant, carers aged 61-70 reported the highest level of EE. (This is unlike in the Preliminary Analysis when age seemingly had no effect). However no general trend linking EE and age could be identified. When all other factors were controlled, carers of people with MND still scored significantly higher (36.59) on EE. The level of EE was significantly lower in carers who expected their family member to improve (24.79), although there was a lot of variation in the scores in this group. Those who anticipated their family member would die in the next 2 years experienced the highest levels of EE (as identified in the Preliminary Analysis).
DP
As the data for DP were not normally distributed, strictly speaking an ANOVA analysis is not appropriate. However Tabachnick and Fidell (1996) suggest computing an ANOVA and examining the residual plot. It is important that the plot displays normally distributed residuals, approximately symmetrical around a mean of 0. This was the case and in the absence of a non-parametric equivalent, the regression is reported31. As for the EE model, a stepwise procedure was followed. The same variables were considered as the literature generally discusses burnout as a whole concept. Given this, it is possible that the same variables for EE may be important in the prediction of DP. In addition, the relationship between the carer and patient was also entered as a variable as this was shown to be important in the Preliminary Analysis section. Variables removed due to their insignificant predictive abilities were: Physical well-being, Social well-being, Expectations of the future and Length of time caring.

Table 12 – Predictor variables for DP

<table>
<thead>
<tr>
<th>Source</th>
<th>Degrees of Freedom</th>
<th>F</th>
<th>Significance</th>
<th>Partial Eta squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model</td>
<td>14</td>
<td>9.66</td>
<td>0.001</td>
<td>.504</td>
</tr>
<tr>
<td>Resilience</td>
<td>1</td>
<td>49.25</td>
<td>0.001</td>
<td>.270</td>
</tr>
<tr>
<td>Carer age group</td>
<td>4</td>
<td>3.35</td>
<td>0.012</td>
<td>.092</td>
</tr>
<tr>
<td>Patient’s Illness</td>
<td>3</td>
<td>11.91</td>
<td>0.001</td>
<td>.212</td>
</tr>
<tr>
<td>Carer gender</td>
<td>1</td>
<td>4.78</td>
<td>0.031</td>
<td>.035</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>1</td>
<td>7.02</td>
<td>0.009</td>
<td>.050</td>
</tr>
<tr>
<td>Spiritual well-being</td>
<td>1</td>
<td>3.64</td>
<td>0.058</td>
<td>.027</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td>3</td>
<td>5.69</td>
<td>0.001</td>
<td>.114</td>
</tr>
<tr>
<td>Residual</td>
<td>133</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

R²=.504, Adjusted R²=.452.

The final regression model accounts for 50.4 per cent of the variance in DP scores in the sample, and is likely to account for approximately 45.2 per cent of the variance in

31 I am aware that this view is not held by everyone and that the practice of examining residuals post-analysis can be controversial (Berry, 1993).
population scores. Resilience was identified as the best individual predictor accounting for 27 per cent, with 21.2 per cent of the variance explained by the patient’s illness. The relationship of the patient to the carer accounted for 11.4 per cent of the variance. Other variables accounted for small proportions each.

Table 13 — Mean DP scores by gender, age and illness when co-variates are controlled.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>N</th>
<th>Mean</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>46</td>
<td></td>
<td>8.55</td>
<td>1.37</td>
</tr>
<tr>
<td>Female</td>
<td>102</td>
<td></td>
<td>4.72</td>
<td>0.71</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-40</td>
<td>15</td>
<td></td>
<td>7.57</td>
<td>1.39</td>
</tr>
<tr>
<td>41-50</td>
<td>32</td>
<td></td>
<td>4.26</td>
<td>0.99</td>
</tr>
<tr>
<td>51-60</td>
<td>44</td>
<td></td>
<td>6.85</td>
<td>0.94</td>
</tr>
<tr>
<td>61-70</td>
<td>34</td>
<td></td>
<td>8.44</td>
<td>0.97</td>
</tr>
<tr>
<td>71+</td>
<td>23</td>
<td></td>
<td>6.06</td>
<td>1.09</td>
</tr>
<tr>
<td>Illness Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>57</td>
<td></td>
<td>3.29</td>
<td>0.79</td>
</tr>
<tr>
<td>MS</td>
<td>49</td>
<td></td>
<td>7.12</td>
<td>0.89</td>
</tr>
<tr>
<td>MND</td>
<td>25</td>
<td></td>
<td>9.89</td>
<td>1.12</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td></td>
<td>6.23</td>
<td>1.27</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male partner</td>
<td>65</td>
<td></td>
<td>9.47</td>
<td>1.09</td>
</tr>
<tr>
<td>Female partner</td>
<td>44</td>
<td></td>
<td>6.39</td>
<td>1.05</td>
</tr>
<tr>
<td>Parent</td>
<td>28</td>
<td></td>
<td>7.43</td>
<td>1.18</td>
</tr>
<tr>
<td>Child</td>
<td>11</td>
<td></td>
<td>3.25</td>
<td>1.62</td>
</tr>
</tbody>
</table>

Male carers reported significantly higher levels of DP (8.55) than females (4.72), although there was more variation in their scores (1.37/0.71). Carers aged 61-70 years displayed the highest level of DP (8.44) (Neither variable was identified as important in the Preliminary Analysis). Carers of people with MND showed the highest level of DP (9.89). These were the same groups of carers (by age and illness) that experienced the highest levels of EE. Those caring for a male partner reported higher levels of DP (9.47) than those caring for a child (3.25). (This is different to in the Preliminary Analysis where those caring for a female partner reported the highest levels of DP (7.77)).
PA

The data for PA were normally distributed and, as previously, the same predictor variables were considered. Variables omitted due to their poor contribution to the model were: Carer age, Spiritual well-being, Patient’s illness, Social well-being and Expectations of the future.

Table 14 – Predictor variables for PA

<table>
<thead>
<tr>
<th>Source</th>
<th>Degrees of Freedom</th>
<th>F</th>
<th>Significance</th>
<th>Partial Eta squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model</td>
<td>8</td>
<td>7.94</td>
<td>0.001</td>
<td>.308</td>
</tr>
<tr>
<td>Resilience</td>
<td>1</td>
<td>21.49</td>
<td>0.001</td>
<td>.131</td>
</tr>
<tr>
<td>Physical Well-being</td>
<td>1</td>
<td>2.361</td>
<td>0.127</td>
<td>.016</td>
</tr>
<tr>
<td>Carer gender</td>
<td>1</td>
<td>2.03</td>
<td>0.156</td>
<td>.014</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>4</td>
<td>10.07</td>
<td>0.002</td>
<td>.066</td>
</tr>
<tr>
<td>Length of time caring</td>
<td>1</td>
<td>2.71</td>
<td>0.032</td>
<td>.071</td>
</tr>
<tr>
<td>Residual</td>
<td>141</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

R²=.308, Adjusted R²=.269.

The final model explains just under a third (30.8 per cent) of the variance in the PA scores in the sample. When generalised to the population, it is estimated to explain only 26.9 per cent. Resilience was identified as a significant predictor (as in the case of EE and DP), and accounted for 13.1 per cent of the variance. The other variables contributed small proportions each. It is important to note that the variables of Carer age and patient illness that were significant predictors of EE and DP were not significant predictors of PA.
Table 15 – Mean PA scores by age and illness when co-varyates are controlled.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>N</th>
<th>Mean</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer gender</td>
<td>Male</td>
<td>47</td>
<td>30.31</td>
<td>1.13</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>105</td>
<td>32.22</td>
<td>0.72</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>In the last year</td>
<td>32</td>
<td>34.45</td>
<td>1.43</td>
</tr>
<tr>
<td></td>
<td>In the last 2 years</td>
<td>26</td>
<td>29.45</td>
<td>1.49</td>
</tr>
<tr>
<td></td>
<td>In the last 5 years</td>
<td>29</td>
<td>32.13</td>
<td>1.36</td>
</tr>
<tr>
<td></td>
<td>In the last 10 years</td>
<td>21</td>
<td>31.17</td>
<td>1.63</td>
</tr>
<tr>
<td></td>
<td>More than 10 years ago</td>
<td>44</td>
<td>29.15</td>
<td>1.12</td>
</tr>
</tbody>
</table>

Females experience marginally higher levels of PA (32.22) compared to males (30.31). Carers of people diagnosed in the last year experience the highest levels of PA (34.45), whereas those caring for more than 10 years experience the lowest levels (29.15); no general trend could be identified.
DISCUSSION

Summary of the findings

Hypothesis 1 - Carers will experience high levels of burnout.

The majority of carers experienced a high level of burnout in at least one domain: burnout was both wide spread and severe.

Prevalence

Over three quarters of the sample scored highly on one domain of burnout. 60.5 per cent of the sample reported high levels of EE. This figure was almost double that reported by support staff in a Canadian oncology team (Grunfeld et al., 2000), and oncology staff in the UK (Catt et al., 2005). The percentage of carers scoring highly on DP was significantly higher than in support staff in a Canadian oncology team (Grunfeld et al., 2000), but comparable with the proportion seen in oncology staff in the UK (Catt et al., 2005). The percentage of carers reporting low levels of PA was less than reported in Canadian support staff working in oncology (Grunfeld et al., 2000), and less than oncology staff in the UK (Catte et al., 2005). No comparable data of the prevalence in informal carers exists.

Extent

The mean score for EE was significantly higher than reported in professional care-givers especially compared to those caring for pwLLIs (Mallett et al., 1991; Payne, 2001). The mean score for DP was less than in previous studies of family carers of people with cancer and MS (Ybema et al., 2002), but higher than reported in most studies of nurses working with dying or elderly people (Mallet et al., 1991; Hayter, 1999; Payne, 2001; Cocco et al., 2003). The mean score for PA was slightly lower than reported in other studies of family carers (Ybema et al., 2002; Angermeyer et al., 2006), but similar to two studies of hospice nurses (Payne, 2001; Italia et al., 2008).
Hypothesis 2 – Burnout will be related to resilience.

Burnout was related to resilience in all 3 domains (EE, DP and PA). A high resilience score was related to low levels of EE and DP and high levels of PA. As expected, carer resilience did not differ depending on the illness of the person being caring for.

Hypothesis 3 – Burnout will be related to Quality of Life (QoL).

There was an inverse relationship between burnout and QoL across the 4 domains of wellbeing measured. In this sample, carers rated their psychological and social well-being as particularly poor. The relationship between EE and all domains of QoL was particularly strong with better QoL associated with less EE - although it was not possible to infer causality. Carers of people with MND reported significantly poorer spiritual well-being than any other carers.

Hypothesis 4- Burnout can be predicted

Models generated to predict the EE and DP components of burnout were good, accounting for 59.1 per cent and 50.4 per cent of the variance respectively. The predictive model for PA was poorer (accounting for just 30.8 per cent), indicating there are other factors not explored in this study which are more important in predicting this domain. Resilience was the only significant predictor of all 3 domains. Carer age, social wellbeing, the patient’s illness, and the relationship between the carer and the patient were all of some predictive value.

When the effect of all other variables was controlled, carer age had a significant impact on EE and DP. In both domains, carers aged 61-70 scored highest for EE and DP indicating an unexpected and unusually high level of burnout in this age group. Carer gender had a significant effect on DP: Males reported higher scores for DP.
The patient’s illness had a significant impact on carer burnout in the domains of EE and DP. Carers of people with MND scored significantly higher for EE and DP indicating increased burnout. Length of time caring was a significant predictor of reduced PA.

Interpretation of results

Formal versus informal caring

In most previous research burnout has been explored in professional carers. Although the context of caring is different, there is likely to be some overlap in the caring experience. Both professional and informal carers are faced with similar demands in terms of caring for pwLLIs, but approach the task from different perspectives. Job characteristics associated with burnout such as having too much work to do in a limited timeframe, a lack of autonomy and a lack of involvement in decision making (Maslach et al., 2001) may all translate into similar issues for informal carers. Carers frequently report that their caring role dominates their life, and they have little time for other responsibilities and activities (Krivickas et al., 1995). I wonder whether not having as much time away from caring could lead carers to cope with the emotional demands of the role by depersonalising the person they are caring for? This could perhaps account for the high levels of depersonalisation in informal carers, particularly those caring for a partner with whom they live.

Carers are less likely to be rewarded, particularly financially for their efforts in their role, and often experience financial hardship as a result (Nijboer et al., 2000; Mockford et al., 2006). Perhaps the financial rewards professionals receive for their role act as a reinforcer for their efforts. (If understood in behavioural terms (e.g. Skinner, 1953)). Positive reinforcement of one’s behaviour is likely to contribute to a greater sense of achievement and thus could explain the comparatively lower levels of personal accomplishment seen in this sample compared to professionals. Carers regularly report that they are not included in decision making (Walker & Dewar, 2001) and feel pressure to care (by professionals and
the patient) with little attention paid to their own needs (Nankervis et al., 1997). Such factors, although not explored in this study, may contribute to the large number of carers experiencing burnout in this sample. Another significant factor may be that informal carers do not have the same level of education, training and support that professional carers have to assist them in their role, and thus are likely to experience higher levels of burnout.

Family carers usually care for one person with whom they have a long-standing relationship. The role of caring within families is not usually boundaried by time and unlike for professional carers, there is not usually an “end to the shift” or sanctuary of home to retreat to. Being in a potentially stressful situation for long periods of time can be emotionally draining and facilitate the development of burnout (Maslach & Jackson, 1981; Cox et al., 1993), and this may go some way in explaining the high levels of emotional exhaustion.

Many carers in the present study were caring for a spouse which often involves prioritising the needs of the ill person over their own (Riley & Fenton, 2007). Caring for a partner can be associated with multiple losses (Cheung & Hocking, 2004), alongside additional roles and responsibilities. People caring for a partner with a LLI may have fears associated with the impending death of the person, worries about how they will cope, and anger at being left behind to cope alone (Riley & Fenton, 2007). Difficulties discussing such issues with the ill person are common (Waldrop & Skretny, 2005), especially so if the patient is the carers partner. Denial is often a factor inhibiting conversations, as is a fear of “making things worse” (Wegner & Jerrome, 1999). Dealing with emotionally difficult situations without an outlet for expressing associated emotions such as anger, fear, sadness or despair is a key factor leading to burnout (Maslach & Jackson, 1981). It is possible that the high levels of depersonalisation, particularly seen in people caring for male partners is a coping strategy for dealing with the emotional challenge of the task in the absence of other methods of emotional expression.
Discussion

Personal demographics of the carer

This study provides further evidence in support of Egan's (1993) findings that personality factors are important when exploring burnout. Resilience was the only significant predictor for all three domains of burnout, and was particularly important when predicting those at risk of depersonalisation. It is possible that resilience is a protective factor for a number of reasons. The more resilient the carer, the more likely they are to find meaning in their role and to adapt to the challenges it presents (Wagnild & Young, 1993). They may also be more likely to enquire about and access resources and sources of support (Hildon et al., 2008). Similarly, they are perhaps more likely to recognise the limitations of their own abilities and to seek help rather than try to manage alone (Barnard, 1994). It is possible that a lack of resilience inhibits carers from drawing on a range of problem solving and coping strategies, and thus makes them more likely to depersonalise the person they are caring for as a way of coping.

In this study, carer age was an important variable in predicting the degree of emotional exhaustion and depersonalisation. However the typical results from other studies of burnout being more common in younger carers (Maslach et al., 1996; Payne et al., 1999) were not found. Carers aged 61-70 reported a significantly higher degree of burnout than other age group. It is possible that the time at which the illness interfaces with the family lifecycle is important in terms of burnout (Rolland, 1987). For many adults, age 61-70 is associated with many major life changes. There are common generational processes which frequently occur at this stage of life including the death of parents, or transition to becoming grandparents (Fennell, 2004). In the UK, retirement is typical at this age and is often a time many families look forward to, and make plans for. For carers, it is possible that the stress of the caring experience is exacerbated by anger and sadness at being deprived of their imagined future. Age related differences are certainly an area worthy of further research. In a study exploring loss in carers of people with MS, the loss of an imagined future and having to postpone or cancel plans such as holidays was linked to anger and resentment towards the person with the illness (Cheung & Hocking, 2004).
Perhaps these negative emotions exacerbate feelings of emotional exhaustion and lead carers to develop an uncaring, resentful attitude which may facilitate the development of burnout?

A general trend of poor QoL associated with greater burnout was identified in this study. However, despite previous research consistently showing this relationship (Ramirez, 1998; van der Heuvel, 2001), aspects of QoL did not explain as much variance in burnout as anticipated. The strongest relationship was identified between poor social well-being and emotional exhaustion (explaining 12.2 per cent of the variance). These findings highlight the benefits of using a scale which splits QoL into different domains. On the basis of these results, it is possible to say that the aspect of QoL most important when exploring its link to burnout is social well-being, as may be expected given previous research identifying the importance of social support for carers (Thoits, 1995; Soothill et al., 2001).

Caring context

Differences in burnout were noted according to the illness of the person being cared for. Carers of people with cancer were least likely to experience high levels of burnout, however the mean level across all domains were still higher than seen in groups of professional carers. It is worth repeating that due to vast differences in how different types of cancers affect patients and their families, there was greater variability in the burnout scores of carers of cancer patients than any other group. Despite this variability, there may be reasons as to why burnout scores were lower in the group of people caring for a relative with cancer than those caring for people with other illnesses. Cancer is the most recognised and financially supported illness of all three studied. It is also the one that commands the most ongoing medical intervention, even in final stages of disease when treatments such as chemotherapy and radiotherapy can be administered for palliative purposes. This may indicate greater involvement with healthcare professionals, and greater support for carers which is known to mediate the experience of burnout (Maslach &
Jackson, 1981; Soothill et al., 2001). For many people with cancer, even in the terminal stages of the illness, it is possible to live relatively independently until very close to death. Conversely, the other illnesses (MS and MND) are characterised by a gradual deterioration in the physical health of the person, and a gradual increase in dependency on the carers. Within this sample, it is possible that increased dependency and less professional support may have been factors explaining why carers of people with other illnesses showed higher rates of burnout than carers of people with cancer. This however would need further investigation as it cannot be inferred currently.

The levels of both emotional exhaustion and depersonalisation were significantly higher in carers of people with MND, indicating that these carers are a particularly vulnerable group. It is possible that the rate at which MND progresses has an impact on how the carer copes with their role. As with all of the illnesses, not only is the carer faced with the demands of their caring role, they are also witnessing the loss of their loved one to illness. Perhaps with MND the rate of deterioration makes this harder to cope with, and leads to greater feelings of being emotionally exhausted in this role? Additionally, the nature of MND “locking in” the person very often leads to the individual being unable to communicate despite being cognitively intact. Carers are likely to be more involved in physical aspects of care than when caring for people with other illnesses, and therefore treating the person “as if they were an impersonal object” may be more likely given how the illness presents. This could go some way in explaining the higher levels of depersonalisation.

Irrespective of the illness, length of time caring was a significant predictor for personal accomplishment but not for other aspects of burnout. Those caring for people diagnosed in the last year reported the highest levels of personal accomplishment. Although it is not possible to conclude on the basis of this research, one could suggest that those who have recently been diagnosed are more likely to be in earlier stages of their disease. Are there more opportunities in early stages of disease for carers to act in ways that elicits feelings of competence and achievement? It is certainly more probable in the early stages for people
to be involved in active interventions. Perhaps the tailing off of these in latter stages contributes to the lower levels of personal accomplishment found in carers who have been caring for more than 10 years. For professional carers, their objective in the latter stages of illnesses often shifts to become geared towards helping a person to have a good death (Fallon & Hanks, 2006). It is possible that the low degree of personal accomplishment reflect caring not adapting to this new goal?

Implications for clinical practice

This research highlights the major problem of burnout for all groups of informal carers regardless of age, gender, illness or length of time caring. It reveals there are certain groups of carers more at risk than others (for example those aged 61-70 years, and those caring for people with MND), which has implications for when or for whom services are needed. It is possible that the needs of carers aged 61-70 are often overlooked as carers of this age usually remain reasonably fit, and are less likely to have other demands such as young children or careers. There may be assumptions about older people being better able to cope (Lazarus & DeLongis, 1983), or the protective benefits of long-term relationships (Revenson & Majerovitz, 2005). Making these assumptions about this group (which are contradicted by the present findings), may lead to services overlooking the needs of these carers and perhaps not offering sufficient support. Similarly, this research highlighted the particular issue of vulnerability in carers of people with MND. This is important as it flags this group as having potentially different needs to carers of people with other illnesses who use the same services.

Health and social services within the UK do not have the capacity to support individuals with LLIs without the assistance of informal carers, and thus it is crucial their needs are addressed. Doing so is likely to improve the quality of life of carers and also the people they care for. Not doing so is likely to result in unsatisfactory levels of care for pwLLIs,
poorer psychological and physical health of carers, and greater demand on already over-stretched services.

Clinical psychologists can play a crucial role in guiding services towards change. There is scope for involvement on a number of levels ranging from direct work with carers to planning and delivering more systemic change. The results of this study suggest that although there are some particularly vulnerable groups of carers, it is not possible to accurately identify who may need additional support. Psychologists have a responsibility to inform staff about the issue and consequences of burnout in family carers, and to offer on-going training and support regarding how to identify it. It would be helpful if psychologists could develop an appropriate screening tool based upon the MBI, but specifically targeted at identifying burnout in family carers. To ensure it is used extensively, it would be important for psychologists to train other professionals to use it as part of their regular assessments with families. On-going training, support and supervision would thus be required to ensure staff were using the tool routinely and correctly, and were taking appropriate action for carers identified as experiencing adverse levels of burnout. Psychologists are well placed to develop appropriate and evidence-based individual and group interventions which specifically address the issue of burnout. To enable greater number of carers to benefit from focused psychological support, creating a stepped-care model of intervention supervising and supporting other professionals delivering preventative, supportive or reparative interventions for burnout would be important.

As psychologists have particular skills in research, it would be useful if a further study could explore whether it is possible to replicate some of the protective factors that professionals have against burnout in order to better support informal carers. Additionally, this research draws attention to the importance of resilience as a protective factor against burnout. It would be useful for psychologists to consider if there are ways to tailor interventions (and measure their effectiveness), which encourage greater resilience in informal carers or prevent resilience being depleting through the role of caring. By
consulting the literature on resilience, it is possible to uncover useful pointers for where interventions may be directed such as assisting carers to find meaning in their task, or uncovering strengths they have developed within their role. Undoubtedly respite services within the UK are invaluable for many families, but for those who are reluctant to be parted from their family member, equipping carers to cope better at home can be very useful, and more cost-effective.

**Critical evaluation**

**Strengths**

This research has gone some way to explore the important issue of burnout in informal carers and the extent of the problem in this client group. It highlights the impact of carer stress on the emotional health of carers, the ways in which carers subsequently interact with the person they care for, and the degree of success and achievement they experience in their role. It is important that psychologists take a lead role in identifying burnout as an issue in carers, just as they have done in professional carers in this context (see the British Psychological Society (2008) document: “The role for psychologists in End of Life Care”). By utilising the same measures in different groups of carers, the similarities and differences between these groups can be identified. This is helpful as various groups of carers access the same generic services and thus are likely to be treated as a homogenous group.

It has been useful in this research to adopt a solution-focused approach which identifies strengths and resilience within carers, as they are usually studied through a lens focusing on the burden of care and associated psychological distress. Taking this approach encourages professionals, carers and PWLIs to view caring as something that can elicit benefits in addition to the challenges and negative experiences usually reported.
Limitations

Data collection

Data were collected from a number of sources to increase the generalisability of the findings. However those who accessed the study were all in touch with either local or online services, which Knight and colleagues (1997) suggest may indicate carers in greater need. Because of self-selection, it is possible that this sample is not representative of all carers of pwLLIs. Additionally, some groups were very small (carers of people with MND, n=25) which may again lead to assumptions being made about all carers based upon a small and perhaps unrepresentative sample.

Although only applicable to a small number of participants (n=10), some carers in this study expected their family member to improve in the next two years. It is common with certain LLIs to have periods of improvement (for example following chemotherapy or radiotherapy for symptom management in cancer, or recovery from a relapse in MS), and thus appropriate that these carers participated. However nine participants were caring for a person with cancer, and it is possible that for these people their cancer was not progressive or life-limiting but rather curable following treatment. This therefore raises the issue of whether they were from the intended sample, and whether the eligibility criteria and recruitment posters were sufficiently clear to target only the intended sample. Furthermore, it highlights the challenges of adopting cross-sectional design methodology. So little is known yet about burnout, for example whether it is long-standing, transient, easily amenable to treatment or self-correcting. It would be helpful to adopt a longitudinal approach in future studies.

Measures

The demographic and care circumstances questionnaire was helpful in many respects but utilised the “time since diagnosis” as a measure of how long a person has been caring. This was because many people have different ideas about what constitutes caring and this benchmark provided a standardised way of measuring how long the person had been in this
role. As previous research is inconclusive about the impact of the extent and nature of caring tasks, and the severity of the person’s illness on the development of burnout, I did not obtain a measure of these factors. However, it is possible that such factors may have a significant impact on burnout and thus are suggested for further research.

With regard to the burnout scale, some questions were phrased in a manner that was perhaps unduly harsh or inappropriate given that people were caring for family members. Indeed, informal feedback from carers participating in the study commented as such. It is possible such responses elicited more socially desirable responding however it is hoped that this was minimised by adopting an anonymous approach to data collection. To consider why so many carers scored 0 on the DP scale of the measure, it is worth revisiting its definition: “being unfeeling and impersonal towards the recipient of one’s care”. Informal carers are likely to have current and pre-existing relationships with the person they care for which may serve to buffer against such extreme reactions to the stress of caring. In the original development of the scale, Maslach and colleagues (1996), removed items on which a large proportion scored 0, as this indicated the item had a poor ability to differentiate between individuals. Given this, it suggests that this particular aspect of the tool may not be sufficiently sensitive for some carers to detect the subtle changes in relationships that may occur under the demands of caring. However, it is worth noting that when a histogram of DP scores was plotted, there was a peak of participants scoring 0, but the remainder of the data was normally distributed. This indicates that although DP, as currently measured, was not relevant to some carers, it was for the majority and thus analysing the results from this scale still provides useful data.

The quality of life tool was significantly adapted and it would be important to explore the validity of this revised measure. On reflection I question whether the information it yields is justified by the length of time it takes to complete. It was used to obtain a measure of how functioning in certain domains may impact on burnout, and revealed that a carer’s perception of their social, physical and to a lesser extent psychological well-being were the
most important predictors of burnout. Given this, it is perhaps more useful to gather information on these specific areas of well-being using other more widely used and better validated tools (such as scaled 28-item version of The General Health Questionnaire, Goldberg & Williams, 1988).

**Future Research**

There is scope for further research to increase our understanding of carer burnout and resilience in a number of ways. Although this was a small scale study, I was impressed with the number of carers who were keen to participate. It would be interesting to explore whether the patterns identified (e.g. in age, illness groups) exist across, and within, larger samples. Furthermore, it is important to look more closely at what appear to be vulnerable groups. Perhaps exploring the role of potential mediating factors such as social and professional support and level of dependency may shed some light on these differences.

It would be useful if further research could develop a more sensitive version of the MBI tool. This could be specifically designed to detect the subtle variations in the relationship between family carers and the person they care for, and may include items different to those developed for professional carers in the original measure. Such a tool could be used for both screening and monitoring purposes to help professionals identify carers at risk burnout.

Adopting a longitudinal approach would enable burnout to be mapped over time. It would be useful to explore if burnout is a stable or variable construct, and if it varies according to any identifiable illness trajectory: such information may indicate particularly times during an illness journey when carers are more vulnerable.
Given the apparent importance of resilience and its association with burnout in this group, developing and evaluating interventions aimed at “building strengths and enhancing resilience” (as proposed by Padesky, 2007) would be a useful way of practically implementing the results of this study.

Conclusions

The aim of the research was to explore the concept of burnout in carers of people with life-limiting illnesses. This study adopted a quantitative methodological design to gain insight into general patterns of how the caring experience is similar or different across different groups of carers – namely those caring for people with cancer, multiple sclerosis (MS) and motor neurone disease (MND). It highlighted that burnout is a common and serious problem for many carers, and that the degree of burnout far exceeds that reported in professional carers working in a similar context.

Carers aged 61-70 years and those caring for people with MND reported the highest degree of burnout. This may indicate these are particularly vulnerable groups of carers, or may highlight current gaps in services that support these individuals. Resilience was identified as an important factor associated with lower levels of burnout. It was the only variable that significantly predicted burnout across all three domains of emotional exhaustion, depersonalisation and a lack of personal accomplishment. As such, it is indicated as a topic worthy of further research to explore the mechanism by which it is protective.

This study contributes to the literature on burnout and provides further evidence in support of the importance of personality factors in mediating its impact. Specifically, it highlights the extent to which burnout is a major problem in carers of pwLLIs, and indicates specific demographic and care circumstances in which burnout is more likely. It provides some indications for further research which will enhance our understanding of this topic broadly and in relation to this group of carers.
References


Norris, A. E. & Aroian, K. J. (2004). To transform or not transform skewed data for psychometric analysis: That is the question! *Nursing Research, 53*(1), 67-71.


Appendices

Appendix 1 – Participant Information Sheet
Appendix 2 – Questionnaire
Appendix 3 – Advertising poster
Appendix 4 – Covering letter to carer organisation
Appendix 5 – Information for online study
Appendix 6 – Authors permission to adapt the MBI
Appendix 7 – Ethical approval documents
Appendix 8 – Demographics of the sample split according to recruitment location.
You are invited to take part in a research study looking at the impact that caring for a relative or friend with a life changing illness has on carers. Before you agree to participate, please read the following information in order to understand why the research is being conducted, and what it will involve. You are under no obligation to take part, and the decision you make about participating will not affect any services you receive. If you have any questions, please feel free to contact me and I will be happy to help.

What is the purpose of this study?
The purpose of this study is to explore some of the factors that may influence how people cope with the task of caring. I am particularly interested in how people view themselves as a carer, and how caring might impact on their physical, psychological, social and spiritual wellbeing. I hope that by identifying patterns in how people cope, I can highlight groups of carers who may benefit from additional support.

Who would I like to participate?
• All participants must be adults (18 years+), and caring for another adult.
• You do not need to live with the person you are caring for.
• Types of life changing illnesses may include:
  o Cancer
  o Motor Neurone Disease (MND)
  o Multiple Sclerosis (MS)
• We are not including carers of people with learning disabilities or dementia. This is because the caring experience is likely to be different when the patient is cognitively impaired.

What would you have to do?
You will be asked to fill in one questionnaire with multiple choice questions. This will take approximately 15-20 minutes to complete. This can be done at your leisure, in your own home. Returning/submitting the questionnaire will be interpreted as giving consent to participate. As all the questionnaires are anonymous, it will not be possible to remove your answers once submitted.

• To access the study online, please go to: www.fahs.surrey.ac.uk/survey/caring. Simply complete the questionnaire and press submit.
If you have a copy of the questionnaire, please follow the instructions on the envelope. These will be transferred back to me either via the internal NHS mail system or, if it has a stamp on it, then please post it in a letter box.

Frequently Asked Questions

Will your participation be confidential?

All your answers are confidential and will only be seen by the research team – no-one involved in your care will have access to your responses.

What will happen to the results?

A report will be written and submitted to The University of Surrey as part of my Postgraduate Doctorate course in Clinical Psychology. Information will be collated from all participants and no individual participants will be identified. The research will also be written up for publication in a scientific journal. A brief summary of the results will be available should you wish to receive a copy. You are asked to contact the researcher using the details provided should you wish to receive a copy.

What support is available to you should you need it?

This research involves asking questions about your role as a carer which you may not have thought about before. After participating, you may wish to talk to someone about being a carer or want to find out how to get additional support. Included in this pack is a list of local support agencies who can be contacted by you should you wish to use them. The support offered varies but ranges from telephone contact, to support groups, to one-to-one contact with an appropriate professional. Of course, I am happy to answer any questions you may have and to signpost you to more specialist/appropriate services. Please contact me using the information provided.

Who is conducting the research?

Principal researcher, Mrs Michelle Conn (Trainee Clinical Psychologist at The University of Surrey).

Supervised by: Nigel Sage (Consultant Clinical Psychologist with a specialist interest in palliative care and working at The Beacon Service in Guildford) & Sue Thorpe (Senior lecturer and Research Tutor at The University of Surrey).
Who has approved this study?

The study has been approved by:

- Surrey Research Ethics Committee.
- Research and Development Committees at Frimley Park Hospital, Royal Surrey Hospital and Surrey Primary Care Trust.
- The Department of Psychology Research Ethics Committee at the University of Surrey.

Who should you contact for further information?

For information about the study, questionnaire packs or a summary of the results, please contact:

Mrs Michelle Conn, Clinical Psychology Department, the University of Surrey, Guildford, GU2 7XH
M.Conn@surrey.ac.uk or 01483 682916

Supervisor contact details:

Nigel Sage, The Beacon Service, Gill Avenue, Guildford, Surrey, GU2 7WW
01483 783400

Alternatively, if you require support in your role as a carer, you may either contact the researcher to be signposted to local agencies or contact directly the following organisations who can provide excellent advice and support

Carers UK  www.carersuk.org  0207 378 4999
Cancer BACUP  www.cancerback.co.uk  0808 800 1234
Multiple Sclerosis (MS) Society  www.mssociety.org.uk  0808 800 8000
Motor neurone Disease Association  www.mndassociation.org  08457 626 262

(Please note that this was spaced across 2 pages not 4 as presented here).
Appendix 2 - Questionnaire

This questionnaire is split into 4 sections, and should take no more than 15-20 minutes to complete. Each section has a different focus. The different topics are:

1. You and the person you care for
2. Your quality of life, and how it is affected by your family member's illness
3. Your feelings about being a carer
4. Your view about yourself in general

Please read the instructions carefully for each section. All responses will be kept strictly confidential, and will be destroyed after analysis.

Section 1 - You and the person you care for

Instructions: Please tick the response which best describes you or your situation.

Your Information

Your Age (years)  
18-30  31-40  41-50  51-60  61-70  71-80  81-90  91+

Your Gender  
 Male  Female

Who do you provide care for?

Husband  Wife  Partner  Mother  Father  Son  Daughter  Friend  Other,

What ethnic group do you belong to?

WHITE

White British  White Irish  Other white

MIXED

White & Black Caribbean  White & Black African  White & Asian  Other mixed

ASIAN or ASIAN BRITISH

Indian  Pakistani  Bangladeshi  Other Asian

BLACK or BLACK BRITISH


### Your family member

#### Their age (years)

<table>
<thead>
<tr>
<th>18-30</th>
<th>31-40</th>
<th>41-50</th>
<th>51-60</th>
<th>61-70</th>
<th>71-80</th>
<th>81-90</th>
<th>91+</th>
</tr>
</thead>
</table>

#### Their Gender

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
</table>

Do you normally live together?  
Is the person you’re caring for living with you now?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If not, where do they live?

<table>
<thead>
<tr>
<th>Own home</th>
<th>Nursing home</th>
<th>Hospital</th>
<th>Hospice</th>
<th>Other, please specify</th>
</tr>
</thead>
</table>

### The Illness

What type of illness does the person you are caring for have?

Please specify:

<table>
<thead>
<tr>
<th>Please specify:</th>
</tr>
</thead>
</table>

When was he/she diagnosed?

<table>
<thead>
<tr>
<th>In the last year</th>
<th>In the last 2</th>
<th>In the last 5</th>
<th>In the last 10</th>
<th>More than 10</th>
<th>Not sure</th>
</tr>
</thead>
</table>
Section 2 - Your quality of life, and how it is affected by your family member’s illness

Instructions: Please select the number (0-10) which best reflects your feelings at this time.

Physical Well-being

<table>
<thead>
<tr>
<th>Fatigue</th>
<th>No problem</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Severe problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appetite Changes</td>
<td>No problem</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Severe problem</td>
</tr>
<tr>
<td>Pain or aches</td>
<td>No problem</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Severe problem</td>
</tr>
<tr>
<td>Sleep Problems</td>
<td>No problem</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Severe problem</td>
</tr>
<tr>
<td>Rate your overall physical health</td>
<td>Extremely Poor</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

Psychological Well-Being

<table>
<thead>
<tr>
<th>How difficult is it to cope as a result of your family member’s illness?</th>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>How good is your overall quality of life?</td>
<td>Extremely Poor</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Excellent</td>
</tr>
<tr>
<td>How much happiness do you feel?</td>
<td>None at all</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Complete</td>
</tr>
<tr>
<td>Do you feel like you are in control with things in your life?</td>
<td>Not at all</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Completely</td>
</tr>
<tr>
<td>How satisfying is your life?</td>
<td>Not at all</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>Completely</td>
</tr>
</tbody>
</table>

235
### How is your current ability to concentrate or remember things?

<table>
<thead>
<tr>
<th>Extremely Poor</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Excellent</th>
</tr>
</thead>
</table>

### How useful do you feel?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extremely</th>
</tr>
</thead>
</table>

### How distressing was your family member’s initial diagnosis for you?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extremely</th>
</tr>
</thead>
</table>

### How much anxiety do you have?

<table>
<thead>
<tr>
<th>None</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Severe</th>
</tr>
</thead>
</table>

### How much depression do you have?

<table>
<thead>
<tr>
<th>None</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Severe</th>
</tr>
</thead>
</table>

### Rate your overall psychological well-being

<table>
<thead>
<tr>
<th>Extremely Poor</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Excellent</th>
</tr>
</thead>
</table>

### Social Well-Being

### How distressing has your family member’s illness been for your family?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extremely</th>
</tr>
</thead>
</table>

### Is the amount of support you receive from others sufficient to meet your needs?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Completely</th>
</tr>
</thead>
</table>

### To what degree has your family member’s illness interfered with your employability?

<table>
<thead>
<tr>
<th>No problem</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Severe problem</th>
</tr>
</thead>
</table>

### To what degree has your family member’s illness interfered with your activities at home?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Severe problem</th>
</tr>
</thead>
</table>

### How much isolation is caused by your family member’s illness?

<table>
<thead>
<tr>
<th>None</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Complete</th>
</tr>
</thead>
</table>

### How much financial burden has resulted from your family member’s illness?

<table>
<thead>
<tr>
<th>None</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extreme</th>
</tr>
</thead>
</table>
### Rate your overall social well-being

<table>
<thead>
<tr>
<th>Rate</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely poor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Excellent</td>
</tr>
</tbody>
</table>

### Spiritual Well-Being

#### How much uncertainty do you feel about your family member’s future?

<table>
<thead>
<tr>
<th>None</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extreme</th>
</tr>
</thead>
</table>

#### Has your family member’s illness made positive changes in your life?

<table>
<thead>
<tr>
<th>None</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extreme</th>
</tr>
</thead>
</table>

#### Do you have a purpose/mission for your life or a reason for being alive?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Completely</th>
</tr>
</thead>
</table>

#### How hopeful do you feel?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extremely</th>
</tr>
</thead>
</table>

#### Rate your overall spiritual well-being

<table>
<thead>
<tr>
<th>Extremely</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Excellent</th>
</tr>
</thead>
</table>

### Are you a member of a religious group?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

#### Please specify

<table>
<thead>
<tr>
<th>Christian</th>
<th>Muslim</th>
<th>Hindu</th>
<th>Sikh</th>
<th>Jewish</th>
<th>Buddhist</th>
<th>Other</th>
</tr>
</thead>
</table>

### How active is your membership?

<table>
<thead>
<tr>
<th>Lapsed</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Very involved</th>
</tr>
</thead>
</table>

#### To what extent do your religious beliefs and actions inform your world view?
Section 3 - Your feelings about being a carer

Instructions: Please tick the answer which best reflects how often you feel this way about being a carer.

The author of the scale does not permit this tool to be included in full. Rather the following information they provided can be used to gain a sense of tool, and how it is used.

SAMPLE ITEMS FOR THE

MASLACH BURNOUT INVENTORY

"Human Services Survey"

by Christina Maslach and Susan E. Jackson

Directions: The purpose of this survey is to discover how various persons in the human services or helping professions view their jobs and the people with whom they work closely. Because persons in a wide variety of occupations will answer this survey, it uses the term "recipients" to refer to the people for whom you provide your service, care, treatment, or instruction. When you answer this survey please think of these people as recipients of the service you provide, even though you may use another term in your work.

Please read each statement carefully and decide if you ever feel this way about your job. If you have never had this feeling, write a "0" (zero) before the statement. If you have had this feeling, indicate how often you feel it by writing the number (from 1 to 6) that best describes how frequently you feel that way.

<table>
<thead>
<tr>
<th>How Often:</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A few times a year or less</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once a month or less</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A few times a month</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once a week</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A few times a week</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Every day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I. Depersonalization

5. I feel I treat some recipients as if they were impersonal objects.

II. Personal Accomplishment

9. I feel I'm positively influencing other people's lives through my work.
### III. Emotional Exhaustion

20. I feel like I'm at the end of my rope.

From the *Maslach Burnout Inventory - Human Services Survey* by Christina Maslach and Susan E. Jackson. Copyright 1988 by CPP, Inc. All rights reserved. Further reproduction is prohibited without the Publisher's consent.

You may change the format of these items to fit your needs, but the wording may not be altered. Please do not present these items to your readers as any kind of "mini-test," but rather as an illustrative sample of items from this instrument. We have provided these items as samples so that we may maintain control over which items appear in published media. This avoids an entire instrument appearing at once or in segments which may be pieced together to form a working instrument, protecting the validity and reliability of the test. Thank you for your cooperation. CPP, Inc., Legal Department.

#### Section 4 - Your general views about yourself

**Instructions:** Please tick the number (0-7) which best describes how you generally feel about yourself.

<table>
<thead>
<tr>
<th>When I make plans, I follow through with them</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I usually manage one way or another</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I am able to depend on myself more than anyone else.</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Keeping interested in things is important to me.</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can be on my own if I have to.</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel proud that I have accomplished things in life.</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I usually take things in my stride.</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I am friends with myself.</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>-------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>----------------</td>
</tr>
</tbody>
</table>

**I feel that I can handle many things at a time**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**I am determined**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**I seldom wonder what the point of it all is**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**I take things one day at a time**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**I can get through difficult times because I've experienced difficulty before**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**I have self-discipline.**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**I keep interested in things.**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**I can usually find something to laugh about.**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**My belief in myself gets me through hard times.**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**In an emergency, I'm someone people can generally rely on.**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**I can usually look at a situation in a number of ways.**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**Sometimes I make myself do things whether I want to or not.**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>
My life has meaning.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

I do not dwell on things that I can’t do anything about.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

When I’m in a difficult situation, I can usually find my way out of it

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

I have enough energy to do what I have to do

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

It's okay if there are people who don't like me.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

I am resilient.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

During the next 6 months, do you expect the person you provide care for to?

<table>
<thead>
<tr>
<th>Improve</th>
<th>Remain ill</th>
<th>Deteriorate</th>
<th>Die</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

During the next 2 years, do you expect the person you provide care for?

<table>
<thead>
<tr>
<th>Improve</th>
<th>Remain ill</th>
<th>Deteriorate</th>
<th>Die</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

One final question...

Where did you hear about this study? Please specify

Thank you for taking the time to complete this questionnaire, your participation is greatly appreciated.
Appendix 3 – Advertising poster

Do you have a family member or friend with a life-limiting illness such as:

- Cancer
- Multiple Sclerosis (MS)
- Motor Neurone Disease (MND)

Can you spare 15-20 minutes to complete a questionnaire to help us understand the impact that caring has on you?

The NHS is changing the way it delivers services. More patients are encouraged to receive treatment and care at home, and much of this is provided by family members. We need to find out how caring affects carers, so we can identify who might need additional support.

For further details on how to take part, simply:

Access the study online from: www.fahs.surrey.ac.uk/survey/caring

Or contact Michelle at: MConn@surrey.ac.uk

01483 682916

All responses are completely confidential.

Thank you.
Appendix 4 – Covering letter to carer organisation

Michelle Conn
Department of Psychology
PsychD Programme
AD Building
Guildford
Surrey
GU2 7XH

Michelle Conn@surrey.ac.uk

Dear Carer,

I hope that you are well. This letter has been sent to you by XXXX branch of XXXXX. XXXX have very kindly posted this pack to people who are caring for a relative or friend with a life changing illness. Your personal details have not been passed to me.

The reason for this correspondence is to invite you to participate in a research project which is looking at the emotional impact of caring for a relative or friend with a life changing illness. Very little is known about the impact of caring and the factors that are associated with successful caring. With the current changes in how the NHS is delivering services, more patients are cared for at home by family and friends. It is essential that we understand the impact of caring on carers so that we can identify which groups of carers may require additional support.

Full details of how to participate are included - it would involve completing 1 questionnaire and posting your responses in the envelope provided. If you would like to contact me about this project, my details are included in the Participant Information Sheet.

Thank you for taking the time to read this letter.

Kind Regards,

Michelle Conn
Trainee Clinical Psychologist
Department of Clinical Psychology
University of Surrey
Appendix 5 – Information for online study

Research study

Are you caring for a person with a life-changing illness such as cancer, multiple sclerosis (MS) or motor neurone disease (MND)?

Are you and the person you care for over 18 years old?

Can you spare 15-20 minutes to complete a multiple-choice questionnaire?

If you can answer YES to the questions above, you are invited to take part in this study which aims to explore some of the factors that may influence how people cope with the task of caring. I am particularly interested in how people view themselves as a carer, and how caring might impact on their physical, psychological, social and spiritual wellbeing.

All your answers will remain completely confidential and you will not be asked to provide any information which may identify you. You may withdraw from the study at anytime by simply closing the page, although only fully completed questionnaires can be included in the study.

Please select the box to indicate that you wish to participate in the study. Completing all questions in the study will automatically register your answers, this process cannot be reversed.

(Unfortunately, people caring for a person with a learning disability or dementia are excluded from this study as the impact of caring for someone with a cognitive impairment is likely to be very different).

Thank you for your time in participating in this study. If you would like a summary of the research upon completion of the study, please include your email address below.

If you have any questions about this study or would like to discuss any issues it has raised, please contact the researcher on:

Michelle Conn, M.Conn@surrey.ac.uk or 01483 682916

Alternatively, if you require support in your role as a carer, you may either contact the researcher to be signposted to local agencies or contact directly the following organisations who can provide excellent advice and support:

Carers UK www.carersuk.org 0207 378 4999
Cancer BACUP www.cancerback.co.uk 0808 800 1234
Multiple Sclerosis (MS) Society www.mssociety.org.uk 0808 800 8000
Motor neurone Disease Association www.mndassociation.org 08457 626 262
Appendix 6 - Authors permission to adapt the MBI

Email correspondence 18th May 2008

Dear Michelle,

Attached please find your fully signed agreement and the sample items.

Best regards,

Sylvia Castañeda
Intellectual Property Rights Manager
CPP, Inc.
1055 Joaquin Road, 2nd Floor
Mountain View, CA 94043
scastaneda@cpp.com
T: 650-969-8901 ext. 133  |  F: 650-623-9273  |

The Leader in Workforce Development

www.cpp.com

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Appendix 7 – Ethical Approval documents (NHS)

Surrey Research Ethics Commi
Education C
Royal Surrey County Ho
Epsom
GuilDF
GU2 7XH

10 December 2008

Mrs Michelle S Conn
Trainee Clinical Psychologist
The University of Surrey
Stag Hill
Guildford
GU2 7XH

Dear Mrs Conn

Full title of study:
Burnout, Resilience and Quality of Life in Informal Carers of Patients with Life-Limiting Illnesses

REC reference number: 08/H1109/157

Thank you for your letter of 23 November 2008, responding to the Committee’s request for further information on the above research.

The further information was considered at the meeting of the Sub-Committee of the REC held on 9 December 2008. A list of the members who were present at the meeting is attached.

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 revised documents, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

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

Management permission at NHS sites (“R&D approval”) should be obtained from the Royal Surrey County Hospital and Frimley Park Hospital in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.
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>Supervisor's CV</td>
<td></td>
<td>01 August 2008</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>1</td>
<td>01 August 2008</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>1</td>
<td>01 August 2008</td>
</tr>
<tr>
<td>Advertisement</td>
<td>1</td>
<td>01 August 2008</td>
</tr>
<tr>
<td>Questionnaire: Non-validated</td>
<td>1</td>
<td>01 August 2008</td>
</tr>
<tr>
<td>Compensation Arrangements</td>
<td></td>
<td>01 August 2008</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>01 August 2008</td>
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<tr>
<td>Investigator CV</td>
<td></td>
<td>01 September 2008</td>
</tr>
<tr>
<td>Application</td>
<td>5.6</td>
<td>03 September 2008</td>
</tr>
<tr>
<td>Online Advertisement</td>
<td>1</td>
<td>23 November 2008</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>23 November 2008</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>2</td>
<td>23 November 2008</td>
</tr>
<tr>
<td>Advertisement</td>
<td>2</td>
<td>23 November 2008</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>2</td>
<td>23 November 2008</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 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.

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
- 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.npsa.nhs.uk.
08/H1109/157  Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Prof David Russell-Jones
Chair

Email: ethics.committee@royalsurrey.nhs.uk

Enclosures:

List of names and professions of members who were present at the meeting

"After ethical review – guidance for researchers"

Copy to:

Ms Aimee Cox
University Ethics Committee
Registry, Senate House
University of Surrey
Guildford
GU2 7XH

Mr Imran Malik
R&D Manager
Royal Surrey County Hospital
Guildford
GU2 7XX

Dr Isaac-John Mary Tourret
R&D Department
Frimley Park Hospital
Portsmouth Road
Frimley
Surrey
GU16 7UJ
University Ethics

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

Michelle Conn
Trainee Clinical Psychologist
Department of Psychology
University of Surrey

13th January 2009

Dear Michelle

Reference: 293-PSY-09
Title of Project: Burnout, Resilience and Quality of Life in Informal Carers of Patients with Life-Limiting Illnesses

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

Dr Adrian Coyle
Research & Development ethics

Sussex NHS Research Consortium

Please reply to: Research Consortium Office
Worthing Hospital
Lynhurst Road
Worthing
West Sussex
BN11 2DH

Mrs. Michelle S. Conn
Trainee Clinical Psychologist
Dep. of Psychology
The University of Surrey
Stag Hill
Guildford
GU2 7XH

08/02/2009

Dear Mrs. Conn,

Our ID: 1171/NOCI/2009
TITLE: Burnout, Resilience and Quality of Life in Informal Carers of Patients with Life-Changing Illnesses

Thank you for your application to the Sussex NHS Research Consortium for research governance approval of the above named study.

The documents considered were as follows:
- NHS REC form parts A and B (unsigned and dated 11/09/2008; lock code: AB/143216/I)
- NHS Site-Specific Information form (signed and dated 07/01/2009)
- Protocol (version 2, dated August 2008)
- Participant Information Form (version 2, date November 2008)
- Questionnaire (version 2, date November 2008)
- Poster (version 1, undated, received 20/01/2009)
- CV for Michelle Conn (signed and dated September 2008)
- Letter from University of Surrey confirming indemnity (signed and dated August 2008)
- Surrey REC approval letter (signed and dated 10/12/2008)
- E-mail from Michelle Conn with clarifications (received 08/02/2009)

I am pleased to tell you that the study has been approved, and so may proceed. This approval is valid in the following Organisations:
- Surrey PCT – The Beacon Cancer and Palliative Care Service

Your research governance approval is valid providing you comply with the conditions set out below:
1. You commence your research within one year of the date of this letter. If you do not begin your work within this time, you will be required to resubmit your application.
2. You notify the Consortium Office should you deviate or make changes to the approved documents.
3. You alert the Consortium Office by contacting me, if significant developments occur as the study progresses, whether in relation to the safety of individuals or to scientific direction.
4. You complete and return the standard annual self-report study monitoring form when requested to do so at the end of each financial year. Failure to do this will result in the suspension of research governance approval.
5. You comply fully with the Department of Health Research Governance Framework, and in particular that you ensure that you are aware of and fully discharge your responsibilities in respect
to Data Protection, Health and Safety, financial probity, ethics and scientific quality. You should refer in particular to Sections 3.5 and 3.6 of the Research Governance Framework.

6. You ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice, Data Protection Act and Human Rights Act. Unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Good luck with your work.

Yours sincerely,

Mrs Helen Vaughan
Senior Research Governance Officer

Email: helen.vaughan@wash.nhs.uk
Tel: 01903 285222 x 4190
Fax: 01903 209884

cc Pam Knott, Quality & Clinical Governance Manager, Surrey PCT
Appendix 8 – Demographics of sample split according to recruitment location

Table 1 – Summary of demographic information

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency in total sample</th>
<th>Percentage of total sample</th>
<th>Sample from local services</th>
<th>Sample from online services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>47</td>
<td>30.9</td>
<td>28</td>
<td>19</td>
</tr>
<tr>
<td>Female</td>
<td>105</td>
<td>69.1</td>
<td>45</td>
<td>60</td>
</tr>
<tr>
<td>Patient gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>77</td>
<td>50.7</td>
<td>36</td>
<td>41</td>
</tr>
<tr>
<td>Female</td>
<td>75</td>
<td>49.3</td>
<td>37</td>
<td>38</td>
</tr>
<tr>
<td>Carer age group (mode)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>51-60 years</td>
<td>44</td>
<td>28.9</td>
<td>61-70</td>
<td>41-50</td>
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<tr>
<td>61-70 years</td>
<td>42</td>
<td>27.6</td>
<td>61-70</td>
<td>61-70</td>
</tr>
<tr>
<td>Patient age group (mode)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicty32</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>137</td>
<td>90.1</td>
<td>70</td>
<td>67</td>
</tr>
<tr>
<td>White Other</td>
<td>11</td>
<td>7.2</td>
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<td>7</td>
</tr>
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<td>Mixed Other</td>
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<td>0.7</td>
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<tr>
<td>Other</td>
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<td>1.3</td>
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<td>1</td>
<td>0.7</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Caring for whom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male Partner</td>
<td>65</td>
<td>42.8</td>
<td>29</td>
<td>36</td>
</tr>
<tr>
<td>Female Partner</td>
<td>44</td>
<td>28.9</td>
<td>26</td>
<td>18</td>
</tr>
<tr>
<td>Mother</td>
<td>21</td>
<td>13.8</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Father</td>
<td>7</td>
<td>4.6</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Child</td>
<td>11</td>
<td>7.2</td>
<td>7</td>
<td>4</td>
</tr>
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<td>Other33</td>
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<td>1</td>
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<tr>
<td>Living arrangements</td>
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<td></td>
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<td></td>
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<tr>
<td>Patient living with carer</td>
<td>126</td>
<td>82.9</td>
<td>64</td>
<td>62</td>
</tr>
<tr>
<td>Patient living in own home</td>
<td>19</td>
<td>12.5</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Patient living in nursing home</td>
<td>5</td>
<td>3.3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Patient in hospital/hospice</td>
<td>2</td>
<td>1.32</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Member of a religious group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>52</td>
<td>34.2</td>
<td>34</td>
<td>18</td>
</tr>
<tr>
<td>No</td>
<td>100</td>
<td>65.8</td>
<td>39</td>
<td>61</td>
</tr>
</tbody>
</table>

32 Categories from the 2001 Census were provided although only those applicable to the sample are reported.

33 The "Other" group was comprised of 2 friends/neighbours and 2 sisters.
- More males accessed the study locally than online.
- The sample accessing the study online was younger than those accessing the study locally.
- More people caring for a male partner accessed the study online.
- The online sample had fewer people stating they were a member of a religious group.

**Table 2 – Summary of information related to the carers’ circumstances**

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency in total sample</th>
<th>Percentage of total sample</th>
<th>Sample from local services</th>
<th>Sample from online services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient’s Illness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>61</td>
<td>40.1</td>
<td>28</td>
<td>33</td>
</tr>
<tr>
<td>Multiple Sclerosis (MS)</td>
<td>49</td>
<td>32.2</td>
<td>20</td>
<td>29</td>
</tr>
<tr>
<td>Motor Neurone Disease (MND)</td>
<td>25</td>
<td>16.4</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>11.2</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the last year</td>
<td>32</td>
<td>21.1</td>
<td>7</td>
<td>25</td>
</tr>
<tr>
<td>In the last 2 years</td>
<td>26</td>
<td>17.1</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>In the last 5 years</td>
<td>29</td>
<td>19.1</td>
<td>12</td>
<td>17</td>
</tr>
<tr>
<td>In the last 10 years</td>
<td>21</td>
<td>13.8</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td>More than 10 years ago</td>
<td>44</td>
<td>28.9</td>
<td>25</td>
<td>19</td>
</tr>
<tr>
<td><strong>Carer’s expectation of the next 2 years</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve</td>
<td>10</td>
<td>6.6</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Remain Ill</td>
<td>22</td>
<td>14.5</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td>Deteriorate</td>
<td>57</td>
<td>37.5</td>
<td>33</td>
<td>24</td>
</tr>
<tr>
<td>Die</td>
<td>62</td>
<td>40.8</td>
<td>24</td>
<td>38</td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td>0.7</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

- There was greater heterogeneity in the illness groups of participants recruited locally.
- A higher number of carers recruited online had relatives diagnosed in the last year.

(There were no significant differences depending on recruitment location for the main outcome measures of the study – Emotional Exhaustion, Depersonalisation, Personal Accomplishment, Resilience Scores or in Physical, Psychological or Social aspects of well-being. However, those who accessed the study locally rated their Spiritual well-being as higher than those who accessed the study online.)