This electronic thesis or dissertation has been downloaded from the King's Research Portal at https://kclpure.kcl.ac.uk/portal/

Older adults with psychosis: carer experiences and relationships Vol 1: Main Research Project & Service Evaluation ProjectVol 2 : Clinical Case Studies

Tehee, Erin

Awarding institution:
King's College London

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without proper acknowledgement.

END USER LICENCE AGREEMENT

Unless another licence is stated on the immediately following page this work is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International licence. https://creativecommons.org/licenses/by-nc-nd/4.0/

You are free to copy, distribute and transmit the work

Under the following conditions:

- Attribution: You must attribute the work in the manner specified by the author (but not in any way that suggests that they endorse you or your use of the work).
- Non Commercial: You may not use this work for commercial purposes.
- No Derivative Works - You may not alter, transform, or build upon this work.

Any of these conditions can be waived if you receive permission from the author. Your fair dealings and other rights are in no way affected by the above.

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Download date: 06. Oct. 2023

Volume 1

Main Research Project & Service Evaluation Project

Erin Tehee

Thesis submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology

Institute of Psychiatry, King's College London
June 2013

MAIN RESEARCH PROJECT

OLDER ADULTS WITH PSYCHOSIS: CARER EXPERIENCES AND RELATIONSHIPS

Erin Tehee

Supervised by Dr Juliana Onwumere

& Professor Elizabeth Kuipers

ACKNOWLEDGEMENTS

The pages of this thesis were written on a raft of kindness, time and support offered by so many, only some of whom I have the space to acknowledge here.

First and foremost, thank you to Juliana Onwumere, the primary supervisor of this project, whose knowledge, dedication, flexibility, patience and compassion are far more than anyone could expect from a supervisor. I feel unduly lucky to have had her as a research and clinical supervisor, as well as a mentor and unfailing source of support.

I would also like to express my sincere and brimming gratitude to Elizabeth Kuipers, for her support, time and kindness in supervising this project, and with whom I feel especially privileged to have worked. Her devotion and contribution to this area of research is inspiring.

Thanks to the carers who took the time to participate in this project, and to the staff and services that have offered their support.

Thank you also to Daniel Stahl for his time and reliability with statistical advice.

Many thanks to Tamatha Ruffell, for her support during the taxing, and seemingly endless, recruitment phase of the project.

My gratitude also extends to Joe Oliver, for his time, support and input during the supervision of my service evaluation project, as well as to Emma Harding and Carmine de Rosa for their help with collating the data.

Thank you to Sue Rutter, a secure base for all trainees, and for whose support I have been particularly grateful this past year.

Thanks also to Patrick Smith for his understanding, support and sage advice during the darker days of the recruitment for this project.

Thank you to Cathy Green, for her containment, advice and encouragement over the past two years.

Thank you to my dear friends, Lorna and Therese, whose emotional and instrumental support (and doctoral thesis empathy) carried me through these last few months.

Thank you to my wonderful fellow coursemates for your support during the tougher times, for the fun we've had, for the laughter we've shared and for the fantastic memories I now take with me. Particular thanks goes to Marc and Sunil, buoys that many times have lightened the load and my heart, keeping me afloat when the water got a bit choppy.

To my beautiful friends Carly, Ger, Mary and Sara-Jane – my boundless source of goodness, kindness, sanctuary and love in this world, my gratitude is unquantifiable here.

Lastly, thank you to my family – my mom, my dad, and my brother, whose support and unwavering belief in me allowed me to believe in myself and tugged me along when I faltered. Mostly, thank you to my mom for her unconditional love, her unquestioning sacrifice, and whose transcendent strength has always been a source of awe and inspiration. It is to her this thesis is dedicated.

ABSTRACT

Background: Based on extensive research, cognitive models of caregiving in psychosis propose the importance of caregiving relationships for patient outcomes and highlight key relationships between carer appraisals of caregiving, the illness and the service user and quality of the relationship. The importance and contribution of coping styles and social networks are emphasised. However, despite the rising numbers of older adults with psychosis, the experiences of carers of older adults with psychosis, including the role of attachment, have been largely ignored in the research literature.

Aims: Firstly, to provide a comprehensive profile of the carers of older people with psychosis in terms of demographics, characteristics and experiences of caregiving relative to carers of working age adults. Secondly, to explore relationships between carer attachment style and coping, expressed emotion and distress and to understand the nature of these relationships in the context of models of caregiving.

Method: A cross-sectional design was employed whereby 23 carers of older adults (≥ 60 years) with non-affective and affective psychosis completed self-report measures of distress, coping, appraisal of caregiving, illness beliefs, social support, time budget and attachment, in addition to a collateral measure of disability of the cared for service users. A five-minute speech sample (FMSS) was taken as a measure of expressed emotion.

Results: The average ages of carers and service users were 58 years and 71 years, respectively. Most carers were the adult offspring of service users (48%) and reported elevated levels of burden and distress. Over half (56.5%) were recorded as high in EE. Avoidant attachment was related to depression, but insecure attachment was not related to ‘avoidant coping’ or EE. EE was related to burden, ‘avoidant coping’, and illness specific beliefs. Distress was related to ‘avoidant coping’, illness beliefs and burden.

Conclusions: Findings support current cognitive models of caregiving (Kuipers et al, 2010) and adjustment to caregiving (Mackay & Pakenham, 2012). Clinical interventions should be mindful of carers’ attachment and the specific needs of this population in relation to caring for older people, as well as qualitative differences in the carer-service user dyad and its influence on caregiving appraisals. Similar to carers of younger groups, carer and family based interventions are indicated.

Table of Contents

Tables

Figures

CHAPTER 1

1. Introduction

1.1 Thesis Overview

This introduction will provide an overview of the definition of psychosis and its presentation in older people. The important role of informal caregivers will be made clear and the extant literature on the impact of caregiving in psychosis, expressed emotion, and illness appraisals will be reviewed. This literature has been integrated into a coherent cognitive model of caregiving in psychosis (Kuipers et al, 2010), which will be summarised. Lastly, the concept of attachment as an additional pathway to considering the caregiving environment will be introduced. Its role in affect regulation and influence on cognitive, behavioural and emotional reactions to stress will be presented and then discussed in terms of its possible implications for carers' psychological well-being, coping style, social support, and interpersonal aspects within the caregiving relationship.

1.2 Psychosis

The term psychosis is commonly used in clinical practice to describe a severe mental illness in which delusions and hallucinations are prominent and may manifest as impaired perceptions and interpretation of the environment, disturbing beliefs, and disorganised patterns of speech and behaviour (Andreasen et al, 1995). In the current diagnostic classification systems of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR; American Psychiatric Association, 2000) and the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10; World Health Organisation, 2010) psychosis is a prominent feature of schizophrenia, schizotypal and delusional disorders, as well as a number of affective disorders (e.g. mania with psychotic symptoms, severe depression with psychotic symptoms, and bipolar affective disorder with psychotic symptoms in the context of severe depression or mania).

The imminent fifth edition of the DSM reflects the evolution in how caseness of psychosis is considered, and proposes presenting subtypes of psychotic disorders on a spectrum according to gradient of psychopathology, referring to these disorders as Schizophrenia Spectrum Disorders (SSDs). This reflects a trend in psychosis research which has moved away from a dichotomous definition of clinical disorders, such as schizophrenia, to the idea that psychotic experiences are best conceptualised on a continuum, with ‘normality’ and clinical cases located at either end (e.g. Freeman et al, 2005; Johns & Van Os, 2001; Van Os, 2003).

The World Health Organisation (WHO) reports the incidence of schizophrenia at a rate of 3 in 10,000 worldwide (WHO, 2010). However, prevalence rates reflect greater impact of psychosis, on account of the long-term nature of the problems it can cause. The DSM-IV (APA, 2000) reports that 1% of people worldwide will be affected by schizophrenia and/or a psychotic disorder at some point in their lives, where more recent estimates of global lifetime prevalence suggest a more conservative figure of 4 in 1,000 (Bhugra, 2005). *Nature* recently published statistics on behalf of the Grand Challenges in Global Mental Health Initiative, which provide even more compelling evidence of the worldwide burden of schizophrenia (Collins et al, 2011). Using a measure of the disability-adjusted life year (DALY; a measure of overall disease burden expressed as the number of years lost due to ill-health, disability or early death) and data from the WHO (*Global Burden of Disease: 2004 update,* 2008), schizophrenia is ranked as the third largest cause of disease burden worldwide (16.8 million DALYs). Bipolar affective disorder, a psychiatric illness in which psychosis may also feature, is ranked fourth. The level of impact at the societal (e.g. economic costs) and individual level (e.g. loss of quality of life and increased mortality) has been well documented (Brown, 1997; Eack & Newhill, 2007; Knapp et al, 2004; Mangalore & Knapp, 2007; Seeman, 2007); thus, the provision of evidence-based interventions that moderate burden is critical.

1.2.1. Psychosis in older people

Scientific and public discourses have positioned psychosis as an illness that mainly affects young people, given its typical onset in late adolescence and early adulthood (DSM-IV; APA, 1994). Though a proportion of people who experience psychosis may only have one episode and fully recover, for the majority it can be episodic and long term, and require on-going treatment. People with psychosis may have a significantly shorter life span, and their mortality rate has been estimated as nearly twice that of the general population owing both to death from natural causes (e.g. diseases of the respiratory system and infectious diseases) and deaths by suicide (Dutta et al, 2012). The development of better pharmacological treatments (e.g. clozapine) may improve mortality rate due to suicide (Meltzer, 1998), but physical morbidity and mortality due to natural causes in this population is pervasive and remains a cause for concern (Dutta et al, 2012). Despite high mortality rates, estimates suggest that by 2030, the number of older people with major psychiatric disorders will be equal to that of those aged 30 to 44 years (Jeste & Lebowitz, 1997). Schizophrenia already makes up the largest proportion of severe mental illnesses in older people (Cohen et al, 2000).

1.2.2. Prevalence of older people with psychosis

The prevalence rate of schizophrenia in the population aged 65 years and over has been estimated at 1% (Cohen et al, 2000), equivalent to that of working age adults. In older adult community samples, the prevalence rates of symptoms of psychosis ranges from 0.2 to 4.7% (Targum & Abbott, 1999), and in a three-year follow-up study of psychotic symptoms in a population-based sample of older people (> 85 years) without dementia, Östling and Skoog (2002) reported a prevalence of 7.1–13.7%.

1.2.3. Heterogeneity in age of onset and aetiology

An onset of psychosis between the ages the 40 and 60 years is typically termed as late-onset psychosis, and that which occurs after the age of 60 years as very late-onset psychosis (Howard et al, 2000). The latter has been viewed as distinct from other presentations of psychosis in terms of its aetiology (Meeks & Jeste, 2008), where it is more likely to be connected to medical or neurobiological abnormalities (DeLisi, 1992; Jeste et al, 1998). Of all older adults with psychosis, it is believed that approximately 25% have late or very late-onset psychosis, with 75% being those who developed the disorder early and have reached old age (Jeste & Twamley, 2003). Late-onset has been noted to occur in females more than males, and is associated with a more paranoid presentation, with less likelihood of disorganised thought, negative symptoms and impact on cognition (Meeks & Jeste, 2008). In those who developed psychosis at a younger age, the severity of positive symptoms is reported to decrease with age (Ciompi, 1980), but negative symptoms are more likely to remain (Harris & Jeste, 1988).

First onset of psychotic symptoms in older adults may be impacted on by a number of factors including: age-related deterioration of frontal and temporal cortices, neurochemical changes associated with aging, social isolation, sensory deficits, cognitive decline, age-related pharmacokinetic and pharmacodynamic changes and polypharmacy (Targum & Abbott, 1999; Targum & Steven, 2001). Thus, older adults may present with psychoses as a result of neurodegenerative disorders (e.g. Alzheimer's disease, vascular dementia, dementia with Lewy bodies and Parkinson's disease) and/or pharmacological treatments (e.g. Parkinson's disease treatments which increase dopamine activity) (Duncan & Taylor, 1996); however, carers of people with psychosis in context of organic conditions are not considered in the present study as their experiences are likely to be different from those caring for a relative with a non-organic psychosis.

Though people with psychosis may later develop dementia, it is viewed as a pathological process distinct from the psychotic disorder. Kurtz (2005) carried out a review of the literature and identified ten longitudinal studies (N = 834) that examined the course of neurocognitive deficits over time in service users with schizophrenia. He found that community-dwelling outpatients did not present with deterioration beyond what would be expected from those without psychopathology, and found that neurocognition remained 'remarkably consistent' despite stage of illness (e.g. first episode or chronic).

1.2.4. Quality of life issues in older people with psychosis

As with working age adults with psychosis, quality of life for older people with psychosis may be compromised by aspects of the illness and its treatment, particularly in the areas of social and cognitive functioning and physical health (Cohen et al, 1997; Cohen et al, 2003; Couture et al, 2006; Dixon et al, 1999; Jeste et al, 2003; Marder et al, 2004; Patterson et al, 1996). The majority of research has focused on working age adults with psychosis, but on account of changes in neuropsychology, social functioning and physical health across the life span it cannot be assumed that the evidence is generalisable to the older population (Cohen et al, 2000). In older adults with psychosis, functioning is likely to be further jeopardised via the process of ageing and cumulative effects of medical treatments (Cohen et al, 2000; Harvey, 1999).

Due to the negative impact psychosis can have on a person's development and cognitive functioning, and the obstacles it presents to the normative acquisition of skills and social roles, social functioning is commonly impaired in people with psychotic disorders (Patterson et al, 1997; Addington & Addington, 2008). These difficulties are likely to continue into old age (Cohen, 1990, 1995) and exacerbate as social networks continue to narrow (Cohen & Kochanowicz, 1989) and where there may be a loss of independence by virtue of cognitive and physical decline leading to higher need for support with activities of daily living (Phelan et al, 1995). Bartels et al (1997) found that, compared to same-age peers, social functioning in older people with psychosis was more impaired, and that cognitive dysfunction in older people with psychosis was the most consistent correlate of poor social functioning in cross-sectional studies (Bartels et al, 1997; Klapow et al, 1997; Patterson et al, 1998). This in turn may have implications for their access to social support. Comparative studies between older and younger people with psychosis have found that older people have smaller social networks that are less likely to include friends, but are more likely to include family members and health professionals, where the relationships are characterised less by reciprocity and emotional support and more by instrumental support (Berry et al, 2006; Meeks & Hammond, 2001; Semple et al, 2007). Loneliness and isolation in non-clinical community-dwelling older people has been shown to be associated with poorer mental health (e.g. Fiori, Antonucci & Cortina, 2006), as well as poorer physical health outcomes (e.g. O'Luanaigh & Lawlor, 2008).

Deficits in functioning may also have implications for the physical health of older people with psychosis making it less likely that they will be able to access healthcare (Altamura & Elliott, 2003). People with psychosis already suffer an increased risk of certain illnesses such as diabetes and heart disease (Schoos & Cohen, 2003), which may be further exacerbated in old age and in the context of poorer functioning. Antipsychotic medications, which are recommended treatments (NICE, 2009), can be associated with serious side effects including metabolic syndrome (Schoos & Cohen, 2003). Age-related biological changes may also leave older people with psychosis more vulnerable to side effects of medication treatments (Bartels et al, 2002). Additionally, older people are more likely to have been prescribed older antipsychotics, which have higher rates of extra-pyramidal side effects, such as tardive dyskinesia and parkinsonism (Jeste et al, 1995). Poor social and physical functioning in this population, further compounded by the biopsychosocial changes inherent to ageing, is likely to have implications for their carers and may present additional challenges compared to those who care for younger adults with psychosis.

1.3 Caregiving in psychosis

SSDs are a significant burden to those affected and to their carers. For schizophrenia alone, the WHO (2010) states that 24 million persons are affected worldwide at present, with only 50% receiving appropriate levels of care (WHO, 2010). The movement from institutional care to community care has meant that in recent decades the family has become increasingly important in supporting relatives with psychosis, with many carers having frequent contact or living with the person for whom they care (Pitschel-Walz et al, 2001).

1.3.1. Definition of caregiving

In general, informal carers can be defined as “someone who without payment provides help or support to a partner, child, relative, friend or neighbour who could not manage without their help” (www.carers.org). The Department of Health (DoH; 1999) defines carers as “people who look after a relative or friend who need support because of age, physical or learning disability or illness, including mental illness”. The term ‘carer’ may not be universally accepted by some relatives who may see caregiving as linked to a sense of responsibility and reciprocity within a longstanding relationship, with a focus on ensuring the well-being and survival of their relative (King, Collins & Liken, 1995). Regardless of terms, relationships and roles are likely to undergo significant changes following the onset of a severe mental illness in a close relative, and adjustment may be characterised by distress and conflict (Martens & Addington, 2001).

Approximately half of those who suffer from psychotic disorders have caregivers, and based on lifetime prevalence of the disorder and the UK population it can thus be estimated that up to 120,000 people are in primary caregiving roles at any one time in the UK (Kuipers, 2010). Carers of working age adults with psychosis are typically first-degree relatives and female (i.e. mothers). They are usually aged in their 50s and are providing care for adult male offspring, reflecting a gender imbalance in these diagnoses (Kuipers et al, 2006; Raune et al, 2004). Spouses and siblings are also commonly represented in this population (e.g. Joyce et al, 2003; Kuipers et al, 2007; Parabiaghi, 2007). A descriptive analysis of carers of older adults with psychosis has yet to be carried out.

Providing care at a community level often depends heavily on the input from informal carers, and thus research that facilitates our understanding of caregiving relationships and strengthens families' resources is important (Czuchta & McCay, 2001; Szmukler et al, 2003).

1.3.2. The importance of studying caregiving

The importance of carers in supporting individuals with psychosis, facilitating their recovery and responding to unmet needs has been widely recognised (Czuchta & McCay, 2001; Szmukler et al, 2003; Tryssenaar et al, 2002). They have a crucial role in improving treatment adherence (Garcia et al, 2006), identifying early signs of relapse (Guest and Burns, 2001) and reducing hospital admissions (Norman et al, 2005). Having a carer may also buffer people with psychosis from the deleterious effects of social isolation (Garety, 2001; White, 2000) and improve their overall quality of life.

In a randomised control trial (RCT) of cognitive behaviour therapy (CBT) and family intervention (FI) for psychosis, Garety et al (2008) found that having a carer improved service users' responses to psychological intervention, irrespective of treatment type, where consistent improvement on general and negative symptoms and social functioning was found.

In terms of optimal service user outcomes, the importance and benefits of having a carer is clear (Magliano et al, 2006; Perlick et al, 1992; Perlick et al, 2004). However, psychological distress and other negative experiences of caregiving may impact on carers' health and well-being and can render them unable to provide care to their affected relatives (Quinn et al, 2003), in addition to fostering a caregiving environment that places their relative at higher risk for distress and relapse (Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998).

1.4 Impact of caregiving in psychosis: defining carer burden

Though the caregiving role can be mutually rewarding (Chen & Greenberg, 2004; Veltman et al, 2002), symptoms and behavioural disturbances resulting from psychotic disorders can have a negative impact, with many carers being significantly affected by their role (Awad &Voruganti, 2008; Kuipers & Bebbington, 2005; Roick et al, 2007). According to Magliano et al (2002), as many as 80% of carers experience carer 'burden'. Increases in disability and morbidity are symptomatic of greying population trends (Carter, 2008; Christensen et al, 2009; Lee, 2011; Vogeli et al, 2007), and burden experienced by carergivers is likely to be compounded by increases in the old age dependency ratio (i.e. the ratio of older dependants, 64 years and over, on the working age population), which is forecasted to double by 2050 and triple by 2100 (Lee, 2011).

The concept of carer burden seeks to capture a broad range of experiences that arise as a result of the process of caregiving and reflects the negative impact of the role. It represents a disruption to existing roles, relationships and lifestyle, as well as the psychological sequelae of such changes (Williams, Dilworth-Anderson & Goodwin, 2003). Negative caregiving experiences are multifaceted, and as a result a breadth of definitions exist for the concept (Jones, 1996; Braithwaite, 1996).

A commonly excepted classification of burden is that put forward by Hoenig and Hamilton (1965), who proposed separate definitions for distinguishing between tangible and observable aspects of burden and affective responses to caregiving. Objective burden has been defined as 'anything that occurs as a disrupting factor in family life owing to the patient's illness,' (Hoenig & Hamilton, 1966) and 'disruption to family/household life which is potentially verifiable and observable,' (Platt, 1985). For example, in carers of people with psychosis, quality of life is often compromised and many experience financial difficulties and restrictions on their leisure activities (Chen et al, 2005; Sanbrook & Harris, 2003). Magliano et al (2002) found that 73% of their sample of carers (n = 709) were not taking part in their usual hobbies and that 68% were unable to go on holiday. Caring may also impact on carers' employment. Stone and Short (1990) examined the competing demands of employment and caregiving in carers of older people and found that those caring for older people with greater care needs were more likely to take unpaid leave, reduce their work hours, or rearrange their work schedules in order to fulfil their caregiving role. Being female, white, and in 'fair to poor' health increased the likelihood of reducing work hours in order facilitate caregiving.

Subjective burden is seen in terms of how a carer appraises objective experiences of caregiving in terms of the sense of 'felt burden' incurred, which may culminate in psychological morbidity. The process of caregiving in psychosis has been likened to bereavement in the literature and many individuals contend with feelings of loss, sadness, pain, anger and upset (Patterson et al, 2005). Burden can also be seen in terms of how a relative's illness impacts on the carer and their social environment. Carers often report experiences of social embarrassment, stigma and conflict as a result of having a relative with psychosis (Angermeyer et al, 2003; Czuchta & McCay, 2001; Ostman & Kjellan, 2002; Struening et al, 2001). Carers may also experience distress, anxiety and confusion when faced with difficult or unusual behaviours (Addington et al, 2003; Jeppesen et al, 2005). In some cases, carers may be fearful of their relative (Barker, Lavender & Morant, 2001).

Poorer physical health outcomes in carers have also been reported. Research has found that carers commonly suffer sleep disturbance (Phillips et al, 2009; Wilcox & King, 1999), poorer immune response (Glaser & Kiecolt-Glaser, 1997), endocrine changes (Kiecolt-Glaser, 1999), are at a higher risk of mortality (Gallagher & Mechanic, 1996; Schulz & Beach, 1999), have more medical hospitalisations and contact with primary care services (Esterling et al, 1994; Gallagher & Mechanic, 1996; Kiecolt-Glaser, 1995; Schulz & Beach, 1999) and report lower levels of perceived health status (Gallagher & Mechanic, 1996). More health complaints have been linked to greater carer burden (Beach et al, 2000; Dyck et al, 1999). A study by Perlick et al (2005) on carers of people with bipolar disorder, mania and schizoaffective disorder reported a similar relationship between burden and use of primary care services. The study found that service use rates by carers were considerably higher than those reported in a general population study (Kessler et al, 1999) for both mental health (29.9% vs. 3.9%) and primary care services (14.4% vs. 5.8%), and were more similar to a sample of respondents with mood disorders in a study of Alzheimer's disease carers (Cohen et al, 1990).

Awad and Wallace (1999) carried out a survey with carers of people with schizophrenia in the community and identified the following as the top ten 'negative impacts' of the illness: a decline in family outings and activities, increase in familial conflicts and arguments, depression in other family members, embarrassment of other family members, economic difficulties, delays/cancellations of holiday plans, loss of self-esteem/confidence in other family members, decline in work/school performance in other family members, increase in alcohol use and separation from a spouse. In terms of top contributing factors to subjective burden, carers identified the following: noncompliance/treatment adherence issues, lack of motivation and poor self-care, comorbid substance misuse, disruptive family dynamics and collective coping styles, insufficient social and economic support, access to crisis care/hospitalisation when required, and access to information and a support network.

Carer burden is also likely to endure. Brown and Birtwistle (1998) reported on fifteen-year outcome data on people with psychosis and their carers, and found that carers showed significant psychological distress at index and at follow-up. More recently, Parabiaghi et al (2007) measured caregiving burden and emotional distress over a three-year period in carers of people with schizophrenia. They found that the majority of carers experienced high levels of burden throughout the three years, but that distress and global burden showed small but significant improvement. Enhanced coping was noted in one-quarter of the carers, with the authors suggesting that changes in coping strategies may alleviate burden as has been shown in other studies (Joyce et al, 2003; Magliano et al, 2000). Barrowclough and Parle (1997) found that carers with longer histories of caregiving reported higher rates of distress.

1.4.2. Predictors of burden

Disruptive behaviour, severe symptoms and disability have routinely been cited as important predictors of burden (Chakrabarti & Gill, 2002; Jiska et al, 2002; Miyamotto et al, 2002; Mueser et al, 1996; Ohaeri, 2001; Roick et al, 2007; Wittmund et al, 2002), in addition to caring for a male relative (Roick et al, 2007), more contact time between the carer and their relative (Canuscio et al, 2002; Roick et al, 2007), higher perceived stigma (Ostman & Kjellin, 2002; Phillips et al, 2002) and psychological vulnerability of the carer (Navaie-Waliser et al, 2002). Lower levels of reported burden have been predicted by better coping abilities (Magliano et al, 2002; Roick et al, 2007) and availability of social support (Ten et al, 2002).

The evidence regarding associations between kinship and burden has been mixed. A number of studies report no relationship (Horwitz & Reinhard, 1995; Schene et al, 1998; Stueve et al, 1997), whereas other studies have found that being a parent of person with psychosis incurs more burden than other kinship types (Lowyck et al, 2004; Magliano et al, 2002; Roick et al, 2007). On the other hand, some studies have found that spouse carers tended to appraise some aspects of caregiving more negatively (Groff et al, 2004; Szmukler et al, 1996). In a cross-national study of prevalence of burden in older carers (50 years and over) of people with physical and mental illness (N = 13,892), Shahly et al (2012) reported the highest levels of burden to exist in those caring for a child or a spouse, with siblings presenting with the lowest levels of burden.

Women were found to report significantly more burden than men in all indicators of burden other than financial.

A limited number of studies have looked at differences in negative caregiving experiences based on ethnicity. One study found that white American family carers were more likely to appraise caregiving as burdensome, as compared to African Americans (Rosenfarb et al, 2006). Other studies point to discrete differences in attitudes towards certain behaviours. For example, one study found that African Americans tended to be less understanding of disruptive behaviours, relative to other ethnicities, and that 'European-Americans' were less understanding of poor social functioning (Tessler et al, 1990).

1.4.3. Summary

Carers provide invaluable support to people with psychosis, as well as an 'healthcare system' which relieves the economic costs of public healthcare (Arno et al, 1999; Shahly et al, 2012); thus, further research into carer outcomes is essential in both supporting carers and those for whom they care. The existing literature on carer burden in psychosis has focused solely on the experiences of carers of working age adults, consequently there is virtually no evidence to account for the profile of carers of older people with psychosis and their experiences.

This section has defined burden and provided a brief overview of the nature of the objective and subjective negative aspects of caregiving, its enduring effect, and its predictors. The following section will expand on the influence of coping and social support on carer burden and distress with reference to the stress-appraisal model proposed by Szmukler et al (1996).

1.5 Coping in carers: the role of appraisal and support

According to Lazarus and Folkman's (1984) transactional model, stress is the result of how a person both appraises a stressor and his/her resources to cope with it. Effective coping requires the accurate appraisal of the situation and selection of coping strategies, as well as the resources available. The same event can be experienced in different ways based on one's appraisals. In the caregiving environment, if the employed coping strategy is not indicated in the circumstance, carer outcomes may be negatively affected (Dyck et al, 1999).

Coping can be classified under two types: emotion-focused coping (i.e. strategies to avoid negative emotions such as engaging in avoidance) and problem-focused coping (i.e. planning or taking action to solve the problem, such as advice-seeking and identifying problems) (Birchwood & Cochrane, 1990). Evidence from the literature suggests that proactive and active coping strategies lend themselves to better carer outcomes in terms of burden (Magliano et al, 2000; Raune et al, 2004; Scazufca & Kuipers, 1999).

Szmukler et al (1996) was one of the first to propose a stress-appraisal model of coping in psychosis, where caregiving experiences are seen not as objective or subjective burden, but dependent on the appraisals of the experience of caregiving. The model posits that the appraisals and coping strategies interact to produce outcomes measured as either psychological or physical well-being. The Experience of Caregiving Inventory (ECI; Szmukler et al, 1996) is a self-report measure developed by the authors to measure carers' appraisals of both negative and positive aspects of caregiving.

Using the ECI, Szmukler et al (1996) found that psychological well-being in carers is strongly related to appraisals of the experience of caregiving. Szmukler et al (1996) also found that carer outcomes on the General Health Questionnaire (GHQ-28; Goldberg & Hillier, 1979) were associated with negative perceptions about the impact of their relative's illness, where coping style predicted 39 to 51% of the variance in the outcome. Raune et al (2004) found avoidant coping was associated with poorer carer functioning and more conflict within the family. Scazufca and Kuipers (1999) found that avoidant coping in carers was strongly associated with carer burden, emotional distress and high EE, both at baseline and nine-month follow-up.

Where there has been recent-onset of psychosis, a 'trial-and-error' approach to coping has been noted in the presence of elevated carer distress and burden (Onwumere et al, 2011). Carers of those with long-term mental illness, on the other hand, have been found to engage in more active and effective coping strategies (Kartalova-O'Doherty & Doherty, 2008), suggesting adjustment over time (Parabiaghi et al, 2007). However, this can vary; Onwumere et al (2011) found that avoidant coping was associated with carer distress independent of length of illness.

1.5.1. The influence of social support

Similar to people with psychosis, carers can also experience a reduction in their informal support network as a result of their caring role and the stigma attached to a diagnosis of psychosis (Chambers et al, 2001; Gutierrez-Maldonado et al, 2005; Magliano et al, 2005). Access to a social support network or reliable confidante may help to moderate distress and encourage more effective coping (Joyce et al, 2003; Magliano et al, 2003). Studies of carers of people with psychosis have consistently found that ineffective coping strategies and higher levels of burden are more common in those with poorer social networks (Birchwood & Cochrane, 1990; Magliano et al, 1998; Struening et al, 1995). In their study of daughters caring for parents with dementia, Bledin et al (1990) also found that maladaptive coping scores were higher in carers who had less access to informal support.

Magliano et al (2003) examined the importance of social support for 709 carers of relatives with psychosis. Results indicated that practical support was more available than psychological support, where 66% felt that they would have access to support in the case of physical illness, as opposed to 31% who felt someone would support them if they were distressed psychologically. Fewer social contacts were available to carers who were spouses or parents, unemployed, older, and who spent more time with service users and cared for those with more severe positive symptoms. Objective and subjective levels of burden were lower in those with a wider and more supportive social network.

Social support is critical in moderating carers' levels of stress (Gore & Colten, 1991; Olstad et al, 1999), which in turn may help them to better manage times of crisis for their relative and prevent hospitalisation (Brugha et al, 1993). Greater access to psychological support from an informal network may also influence carers' attitudes towards service users, decreasing levels of pessimism regarding service user outcomes and fostering more optimistic beliefs (Magliano et al, 2003); thus, carers' access to social support may in turn have implications for service user outcomes by influencing the caregiving environment via the quality of the caregiving relationship and carers' illness appraisals, which are reviewed in more depth in the following sections. To date, no studies have examined relationships between coping, social support and the caregiving environment in the context of caring for an older person with psychosis.

1.5.2. Adjustment to caregiving: a stress and coping model

A recent study by Mackay and Pakenham (2012) examined the use of a stress and coping framework for identifying factors related to adjustment to caregiving in carers of adults with mental health problems (30% of the sample cared for relatives with a psychotic disorder). Based on their findings and Lazarus and Folkman's (1984) theory of stress and coping, the authors propose a model which accounts for background variables, coping resources, coping appraisals and coping strategies that they found to significantly influence the variance in adjustment to caregiving, as measured by benefit finding, positive affect, life satisfaction, health and distress (See Figure 1). One hundred and fourteen participants in the study completed questionnaires eliciting information on salient background factors (e.g. carer demographics, service user demographics and information related to diagnosis and symptoms severity, as well as contextual factors, such as objective burden, duration and frequency of care, choice, co-habitation and kinship). Coping resources, both internal (i.e. optimism) and external (i.e. social support and quality of caregiving relationship), were examined. Primary and secondary coping appraisals were considered, whereby appraisals of threat (i.e. limitations placed on the carer's life and their potential for personal growth) and challenge (i.e. incidental opportunities for personal growth and challenges, development of relationships and skills, and a reorganisation of priorities) were measured, in addition to the extent to which carers felt they had control over their difficulties related to caregiving. Problem-focused and emotional-focused coping strategies were measured. A hierarchical regression analysis found that the background variables of symptom predictability, daily caregiving and objective burden accounted for a significant proportion of the variance in adjustment outcomes. Controlling for these factors, the authors found that better adjustment in carers was related to better coping resources (i.e. social support, optimism and relationship quality), coping appraisal (i.e. fewer threat appraisals and higher challenge appraisals) and 'avoidant coping', where this style of coping was the only significant coping predictor, predicting greater distress in carers.

As previously discussed, many studies have highlighted the importance of the influence coping strategies, appraisals and resources on carer outcomes in the context of psychosis (e.g. Birchwood & Cochrane, 1990; Szmukler et al, 1996; Scazufca &

Kuipers, 1999; Magliano et al, 2000, 2002, 2003; Joyce et al, 2003; Raune et al, 2004). Uniquely, Mackay and Pakenham's model provides a more coherent framework for the application of stress and coping theory (Lazarus & Folkman, 1984) to the process of adjustment to the caregiving role. The model is not only useful for guiding research and the development of hypotheses in this area, but additionally it can be practically applied in clinical interventions with this population (e.g. identifying 'at risk' carers, modifying appraisals, provision of family interventions, improving coping skills and encouraging/facilitating access to better social support).

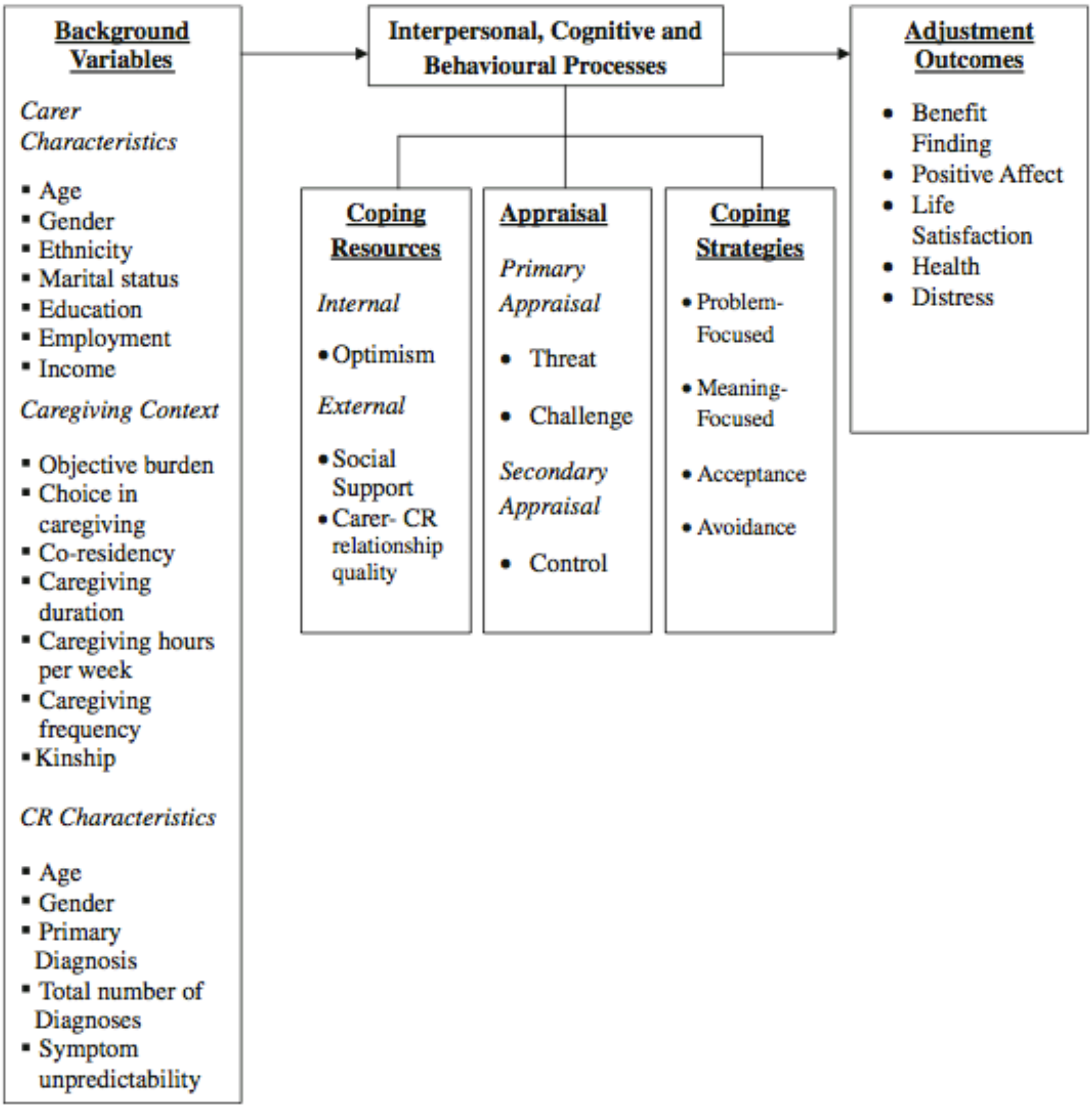


Figure 1. Stress and coping model of adjustment to caring for an adult with mental illness (Mackay & Pakenham, 2012)

1.6 Expressed Emotion (EE)

Expressed emotion (EE) refers to a construct that taps into key aspects of interpersonal relationships in the caregiving environment. It was first introduced in the 1960s as a method of gauging the quality of the relationship between carers and those for whom they care, at a time when researchers first sought to examine the impact of the environment on a service user's progress following their discharge from hospital (Brown & Rutter, 1966).

Carers can be categorised as either 'low' or 'high' EE, with the latter being characterised by high levels of hostility, critical comments and/or emotional over-involvement (EOI) in relation to the person being cared for. Low EE indicates an absence of these characteristics. Criticism presents as negative remarks in reference to either the person's behaviour or personality. Hostility is identified as being rejecting or making a generalised negative comment. EOI is characterised by self-sacrificing and over-protective behaviour, and/or over-identification with the person being cared for (Brown & Rutter, 1966).

High EE is a well-validated predictor of poor clinical outcomes for psychosis; higher levels of relapse are reported in service users living with or in close contact with a relative rated as high EE (Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998). For example, Bebbington and Kuipers (1994) found that relapse rates for those returning to high EE families were significantly higher (50%) than those returning to low EE families (21%).

1.6.1. Measuring EE

EE can be measured by rating the way in which a key relative speaks about the person being cared for in an interview [e.g. Camberwell Family Interview (CFI); Brown & Rutter, 1966]. Ratings are based not only on content of speech but the prosodic aspects (e.g. tone) The CFI (Brown & Rutter, 1996) is widely acknowledged as the gold standard measure of EE. As a measure, however, it is costly and requires a large amount of time in terms of training interviewers, administering the interview and subsequent transcribing and rating of interviews (Hooley & Parker, 2006). The Five Minute Speech Sample (FMSS; Magana et al, 1985) is also an interview-based method of measuring EE, but one that is more economical in terms of time required to deliver and rate speech samples. The FMSS has been employed extensively in research on carers of people with psychosis (e.g. Barrowclough et al, 2001; Lobban et al, 2006; Moore & Kuipers, 1992; Tompson et al, 1995). The psychometric properties of the FMSS are discussed in further detail in Chapter 2.

1.6.2. Factors related to EE

1.6.2.1. Service user symptoms and functioning

Findings regarding the relationship between EE and service user symptoms have been mixed. A number of studies have found EE to be independent of service users' symptoms (Kuipers et al, 2006; Leff & Vaughan, 1985; McCreadie et al, 1994; Rauje et al 2004; Scazufca & Kuipers, 1996), whereas others have found a relationship between positive symptoms (e.g. hallucinations, delusions and unusual behaviour), negative symptoms (e.g. withdrawal and anhedonia), positive and negative symptomatology (e.g. hostility, unusual or difficult behaviour) and high EE (Bentsen et al, 1998; Cochrane & George, 1993; Goldstein et al, 1995; Goldstein & Nuechterlein, 2004; Smith et al, 1993). However, poor social functioning in service users has been more consistently linked to high EE in carers (Barrowclough & Tarrier, 1990; Bentsen et al, 1998; Scazufca & Kuipers, 1996; Scazufca & Kuipers, 1998).

1.6.2.2. High EE in the caregiving relationship: burden, appraisal and coping

Bledin et al (1990) explored the relationships between EE, strain and coping in daughters of people with dementia and found that similar to studies of carers of working age adults with psychosis, lower levels of EE were also associated with less strain and distress, and more effective coping. Further, high and low EE groups did not differ in terms of levels of general impairment observed in service users, but when levels of cognitive impairment were considered, high EE carers reported significantly higher strain and distress. Earlier research has also suggested that the quality of the current and pre-morbid relationship with a parent with dementia may also impact on caregiving experiences and commitment to the caring role (Morris et al, 1988). Bledin et al (1990) found that high EE carers took more frequent respite breaks.

High EE has been positively associated with carer burden (Scazufca & Kuipers, 1996; Wearden et al, 2002). Carers with high levels of EOI may be particularly vulnerable to burden. Raune et al (2004) found that at first-episode psychosis, high EE in carers was associated with higher levels of avoidant coping and subjective burden, and lower perceived service user interpersonal functioning, while factors related to service user symptoms and carers' distress were not associated with EE. Overall, multivariate analyses showed that avoidant coping was the strongest predictor of EE (Raune et al, 2004).

Research has found that carer attributions about a service user's illness may mediate the relationship between EE and burden (Barrowclough et al, 1997; Patterson et al, 2005; Raune et al, 2004). Specifically, beliefs around illness consequences, controllability and course/timeline of illness have been found to be related to carer burden and EE (Barrowclough et al, 2001; Lobban et al, 2005). High EE carers who make more critical comments about service users also tend to attribute more control about the illness and perceive the service user as being responsible for their difficulties compared to low EE carers. They are also more likely to attribute their behaviour to deficits in their personality (Barrowclough & Hooley, 2003; Hooley, 1985; Hooley, 1987). Thus, assigning responsibility to the person rather than the situation may result in more blaming, critical and hostile responses to the person for whom they care. Carers who perceive greater loss are more likely to have high EE and use more avoidant coping strategies (Barrowclough & Parle, 1997; Patterson et al, 2000). Conversely, carers high in EE related to EOI have been found to be more likely to report self-blaming attributions and more controlling behaviours (Peterson & Docherty, 2004). They are similar to low EE carers in that they are less likely to blame the service user for difficult behaviours (Barrowclough et al, 1994). A study by Grice et al (2009) found that low EE relatives were more likely to attribute responsibility of positive events to the person with psychosis significantly more than negative events, whereas high EOI EE relatives did not see the cared for person as responsible for either positive or negative events.

1.6.3. Summary

The extant literature on EE has been primarily borne out of studies of carers of working age adults with psychosis and carers of people with dementia; conceptually, it follows that similar relationships exist between EE, and carer and service user outcomes in caregiving relationships involving older people with psychosis, though research in this area has yet to be carried out. Carers' illness beliefs and appraisals are another way of examining the interplay between the carer role and carer and service user outcomes, which will be reviewed in the next section.

1.7 Illness Appraisals

In health psychology, the study of illness beliefs have been led by the development of social cognition models which help to explain intentions for health-related behaviours (Conner & Norman, 1995), though they have been limited in their predictions of actual health behaviour. Leventhal and colleagues built on this work (Leventhal, Diefenbach & Leventhal, 1992; Leventhal, Nerenz & Steel, 1984) and developed a more comprehensive theory around illness beliefs and related health behaviours referred to as the Self-Regulation Model (SRM).

1.7.1. The Self-Regulation Model

The SRM proposes that self-regulation comes about as a result of the representation of health threats to the person and how these are targeted via continued coping efforts, which in turn are informed by the appraisal of coping outcomes (See Figure 2). The authors posit that there are two parallel, and partially independent, processes occurring, that of cognitive and emotional processing. As part of the cognitive process it is assumed that internal representations of problems are developed before individuals select relevant internal or external resources to solve the issue. Emotional processes may in turn influence practical coping strategies, for example a review by DiMatteo et al (2000) found that depression made medication adherence less likely in physically ill patients. In psychosis emotional processes also play a key role in the maintenance of symptoms (e.g. Birchwood & Iqbal, 1998).

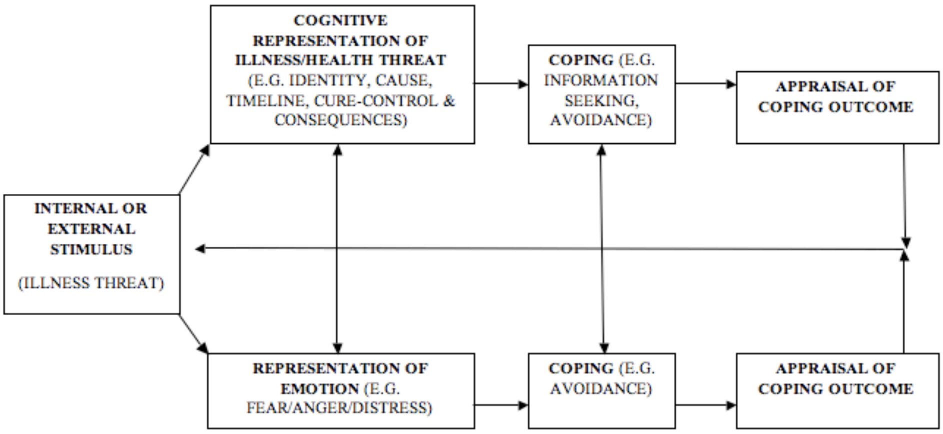


Figure 2. Self Regulation Model (adapted from Leventhal et al, 1984; Leventhal et al, 1992)

As suggested in the model (Figure 2), illness representations determine the choice of coping strategy, and an appraisal of the effectiveness of the coping strategy links back to the illness representation. Through this process, the authors suggest that coping mediates the relationship between the representation of an illness and its outcomes. Leventhal et al (1992) emphasise that the 'coherence' of the system or the 'integration of its parts' is essential for maintaining behaviour change. Representations formed by individuals are guided by the individual's own experience but also influenced by the social environment in which the individual is embedded, ranging from the dominant discourses around disease in the person's culture to what is communicated via the healthcare system (Blumhagen, 1980; Klonoff & Landrine, 1994; Leventhal et al, 1992).

1.7.2. Defining SRM illness constructs

Early work on the model suggested that four inter-related illness constructs informed illness representations, including *identity, cause, consequences* and *timeline* (Leventhal et al, 1980; Leventhal et al, 1984), with later work introducing the fifth construct of *cure-control* (Weinstein, 1988). The five constructs are defined below:

a) Identity – beliefs about the symptoms and labels associated with the illness

b) Cause – beliefs about biological, psychological, social and environmental aetiological factors attributed to the illness

c) Consequences – expectations of the personal (psychological and physical), social and financial consequences of the illness and their severity

d) Cure-control – perception of the illness as curable or amenable to control

e) Timeline – beliefs related to the duration of the illness and its course (e.g. acute, chronic, episodic).

1.7.3. Measurement of Illness Representations

Weinman, Petrie, Moss-Morris, and Horne (1996) developed the Illness Perception Questionnaire (IPQ) based on Leventhal et al's SRM using data from seven physical illness groups. The measure allows for quantitative measurement of the five SRM illness constructs and how they relate to one another. The IPQ has since been revised (IPQ-R; Moss-Morris et al, 2002) and also has a shortened version to allow for quicker administration (Brief IPQ; Broadbent, Petrie, Main & Weinman, 2006). Revision of the IPQ-R by Lobban et al (2005) modified the wording of the questions to allow carers to complete the measure. Details and psychometric properties of the IPQ are discussed further in the Method section in Chapter 2.

1.7.4. SRM in mental health and psychosis

The validity of the five constructs of illness representation have been evidenced across an extensive range of physical conditions (Petrie et al, 2005), ranging from rheumatoid arthritis (Carlisle, John, Fife-Shaw & Lloyd, 2005) to diabetes (Lawson, Bundy, Lyne & Harvey, 2004) to Alzheimer's disease (Roberts & Connell, 2000). More recently, SRM research has been introduced to the mental health literature (e.g. Fortune, Barrowclough & Lobban, 2004; Stockford, Turner & Coopers, 2007), and within the last ten years it has become increasingly important to our understanding of psychosis (e.g. Garety et al, 2001). Lobban and Barrowclough (2005) carried out a study to examine whether illness representations found in physical illnesses could be applied to psychosis in terms of beliefs reported by service users (n = 19) and carers (n = 18). The results showed that overall beliefs around schizophrenia mapped onto most dimensions of IPQ-R (Moss-Morris et al, 2002). As with other areas of carer research in psychosis, studies of illness beliefs have tended to focus on carers of the working age population, consequently what is known about the role of illness beliefs in carers of older people is lacking and requires further attention.

1.7.5. Illness representations in carers of people with psychosis

As Leventhal et al's SRM (1992) suggests, illness beliefs develop from one's own personal experiences but also in the social context in which the individual exists. One such context is the family, thus highlighting the importance of carers' illness beliefs and relevance of the family environment.

Barrowclough et al (2001) used a modified version of the IPQ (Weinman et al, 1996), where carers were given the opportunity to consider illness beliefs for their relative as well as themselves. The authors examined associations between illness perceptions and psychological distress, EE, and carer burden. Results suggested that carers tended to view psychosis as chronic with an episodic trajectory. Carer distress was related to higher levels of negative illness consequences perceived for service users. The perceived consequences for themselves, as carers, were also linked to higher levels of distress and depression, and more negative caregiving experiences. Poorer outcomes for carers were related to beliefs around the illness independent of service users' symptoms and functioning. Carers with higher EE were more likely to perceive themselves as having less control of the illness and that the timeline of the illness would be longer, in addition to perceiving a greater number of symptoms in service users.

Building on their previous work, the same research group found carers' perceptions of the illness consequences and the amount of control attributed to service users for the illness were positively correlated with consequences and control for themselves. Carers who reported higher levels of personal control over the illness also reported more optimistic beliefs about treatment efficacy (Lobban et al, 2005).

In a study of 82 carer-service user dyads in psychosis, Kuipers et al (2007) observed that carers tended to be more pessimistic regarding illness persistence and consequences than service users. In addition, carers with low mood were particularly pessimistic regarding persistence and controllability of the illness by the service user, i.e. they tended to believe the service user's symptoms were less likely to be controlled or modified by treatment and that the duration of symptoms would be longer and more chronic. Lobban et al (2006) examined the relationship between EE and discrepancies in illness beliefs about schizophrenia in family dyads which included carers and service users. When comparing high and low EE dyads they found that discrepancies in illness models of schizophrenia were greater in the high EE dyads.

A cross-sectional study by Fortune et al (2005) examined the relationship between illness perceptions of psychosis, appraisals, coping strategies and distress in 42 carers of relatives with schizophrenia using self-regulation theory. Results indicated that relatives who had higher distress scores tended to hold stronger and more negative beliefs with regard to illness consequences and beliefs that their relative could exert control over their illness, while also tending to report weaker beliefs in treatment control. A number of coping strategies were identified as associated with less distress, including: seeking emotional support, active coping, acceptance, positive reframing, and use of religion/spirituality. Moreover, the study found that illness beliefs and coping contributed significantly to the variance in distress, independent of demographics and primary (e.g. evaluation of personal meaning) and secondary appraisals (e.g. evaluation of coping resources and their likely efficacy). Mediational analyses found that certain coping strategies (acceptance, less self-blame and positive reframing) mediated the relationship between the carers' distress and beliefs around service users' control over their illness and illness identity, though it did not mediate beliefs around treatment control.

1.8 Cognitive model of caregiving in psychosis

Kuipers et al (2010) have recently proposed a cognitive model of caregiving in psychosis that integrates research findings from the literature on expressed emotion, illness perceptions and caregiving experiences including coping and support (See Figure 3). The model suggests that carers' appraisals of service users' behaviour will influence their behaviour towards the service user and impact on carer outcomes.

The authors assert that the model clearly illustrates testable hypotheses, which may in turn inform evidence-based interventions aimed at appraisals and maintaining factors. Based on empirical evidence and clinical experience, Kuipers et al (2010) suggest a typology that identifies three distinct relationship styles arising from the model that may help identify interventions according to need and thus increase the likelihood of sustained change (see Table 1).

As research specific to the caring of older people with psychosis has yet to be undertaken, it is timely and applicable to employ Kuipers et al's (2010) model of caregiving as a basis from which to derive and investigate hypotheses for this population. Guided by the model, hypotheses in the current study have been developed in an attempt to address gaps in the research in this overlooked population. In addition to the typology (Table 1) suggested by Kuipers et al (2010), the current study also seeks to explore the role of attachment style as another possible variable in the caregiving relationship, which will subsequently be reviewed in more depth.

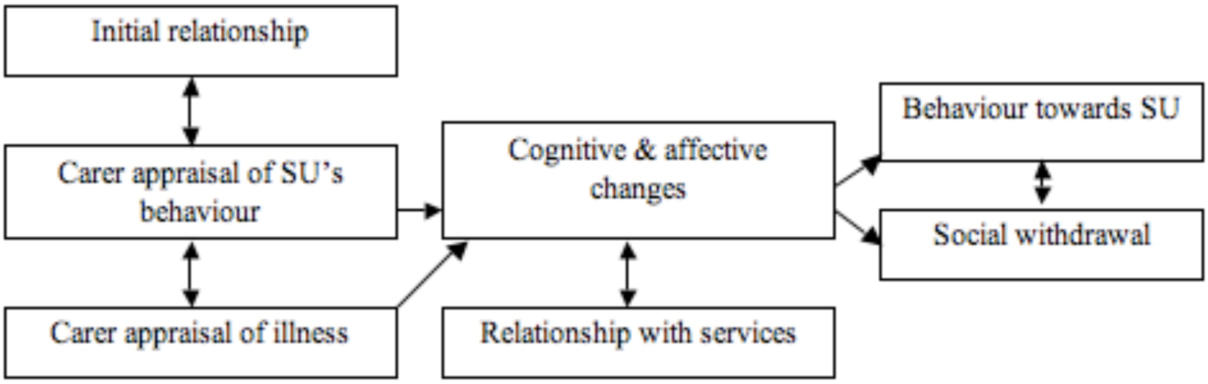


Figure 3. Cognitive model of carer responses in psychosis (Kuipers et al, 2010)

Table 1

Relationship Typology (Kuipers et al, 2010)

	Positive relationship	**Emotional Over Involvement**	**Critical & Hostile relationship**
Initial relationship	Previously positive	Previously positive (when service user is a child; usually a parent), current relationship poor	Previous problems, likely comorbid substance misuse, poor social functioning, long duration of untreated psychosis
Carer Appraisal	Service user not to blame, but has problems that need support	Service user not to blame, carer needs to return to parent role and look after service user	Service user to blame, personality a problem, service user needs to get better and control problems
Carer Reactions	More confident, non-avoidant coping, tries to access support network, high warmth & optimism, low EE, low negative impact of care	High distress & guilt, tries to control situation, tries to do everything, high negative impact of care, loss of social network, takes over responsibilities, exhausted	High distress with anger, loss of social network, avoidant coping, low self-esteem, depression, critical of service user behaviour and pessimistic

1.9 Attachment theory and styles

There is emerging evidence that the literature on attachment offers another way of operationalising the construct of relationship quality in caregiving relationships (e.g. Cooper et al, 2008).

Attachment theory is a lifespan developmental theory which proposes that there is a universal need to form close affectional bonds and that attachment behaviour functions as a mechanism for modulating distress (Bowlby, 1980). A central tenet of attachment theory is that later stressful events, including illness, separation, loss and trauma can lead to a revision of attachment representations (Fraley & Brumbaugh, 2005). Caring for a relative with psychosis can potentially expose the individual to any constellation of these experiences, if not all.

Adult attachment styles can be conceptualised in terms of the two dimensions of attachment anxiety and attachment avoidance, which have been shown to underlie self-report measures of attachment. Hazan and Shaver (1987) found that the distribution of attachment styles in adults was similar to that observed in infancy, where approximately 60% of adults classified themselves as secure, about 20% as avoidant, and about 20% as anxious.

A considerable body of research now exists to support the concept of adult attachment styles and the influence of 'secure' versus 'insecure' attachment styles on interpersonal functioning and relationships (Goodwin, 2003). According to attachment theory, attachment insecurity arises in the absence of a responsive attachment figure during development. When an attachment figure is unavailable, inattentive or unresponsive, an appraisal of the feasibility of achieving proximity with the attachment figure is made, informing the individual's subsequent strategy (i.e. increase promixity-seeking behaviour or abandon attempts at achieving proximity to reduce distress) (Shaver & Mikulincer, 2002). Over time, the responses of caregivers shape the development of attachment, which later manifest as *internal working models* (Bowlby, 1973) that govern individuals' emotions, perceptions and expectations of interpersonal relationships (Bretherton et al, 1999). This complements Beck's (1987) cognitive theory of the development of schemas in early childhood, as shaped by experiences with significant others. Like schemas, IWMs can be seen as the lens by which our perceptions are shaped. Attachment specifically captures the impact of how early life experiences shape our view of interpersonal relationships in the present, and informs the strategies used to manage distress in the face of threat (e.g. proximity-seeking vs. distancing).

In adulthood, *hyperactivating strategies* (Cassidy & Kobak, 1988) are characteristic of individuals with anxious attachment and involve hypervigilance for threat, concern/worry and efforts to achieve security including proximity-seeking, eliciting involvement and controlling and clinging behaviour (Shaver & Hazan, 1993). This process triggers maladaptive cognitive responses such as rumination and worry. Mikulincer et al (2003) suggest that hyperactivating strategies may produce a 'self-amplifying' cycle of distress and preclude participation in nonattachment related activity. In contrast, *deactivating strategies* (Cassidy & Kobak, 1988) are characteristic of individuals with avoidant attachment and develop when attempts at gaining proximity to the attachment figure are futile. Such strategies involve disengaging from proximity-seeking behaviours, relinquishing the search for support and selecting self-reliant coping strategies in an effort to deactivate the attachment system, and thus distress. This in turn leads to avoidance of closeness with others, distancing and increased independence. Avoidant attachment style may lead to 'pre-emptive' avoidance in order to avoid feelings of vulnerability, or 'post-emptive' emotional strategies such as suppression of negative emotions (Mikulincer et al, 2003).

1.9.2. Attachment in the caregiving environment

Feelings of loss are a common aspect of the caregiving experience, and cognitive, emotional and behavioural reactions to the appraisal of loss (e.g. loss of hopes for the future and unfulfilled potential) have been likened to grief experienced in bereavement (Miller et al, 1990; Miller, 1996). Furthermore, the experience of grief may endure for many years after initial onset of the illness. Davis and Schultz (1998) found that grief was present in 43% of older parents caring for adult children with schizophrenia who were diagnosed more than ten-years previous. The cycle of relapse and wellness inherent to SSDs could potentially further complicate and delay the process of grieving and accepting loss.

The role of attachment in mental health outcomes in service users has been evidenced. Separation or death of a parent before the age of 16 has been linked to higher risk of psychosis (Morgan et al, 2007). For service users in inpatient rehabilitation services, extended periods of separation from primary attachment figures may trigger attachment needs and/or interpersonal difficulties and create feelings of loss, insecurity or breakdowns in primary attachments (Schuengel, 2001). Implicit in this is that carers also endure separations and feelings of loss, and security may be similarly compromised.

Perception of loss may be influenced by the pre-existing attachment relationship between the relative and the family caregiver, and may have implications for the subsequent quality of their interactions. In carers of people with psychosis, Birchwood and Spencer (1992) suggest that difficulties in the caregiving relationship (e.g. loss and change) may trigger criticism and EOI. Patterson et al (2000) further elaborate on this to suggest that criticism and coercive behaviour may function as a strategy for coping with feelings of loss, as a way of seeking the return of the person who existed prior to the onset of symptoms (e.g. *hyperactivating* strategies; Cassidy & Kobak, 1988). Patterson et al (2000) also suggest that in a more protracted or poor recovery context, coercive and critical responses from carers may become more pervasive and result in a weakened bond between the relative and the carer and lead to greater hostility. In their study of carers of relatives with a first-episode psychosis, Patterson et al (2000) found that relatives' appraisal of loss resulted in a grief reaction in a significant proportion of key relatives, with the authors further noting that relatives with very high levels of grief may be at increased risk of 'sealing over' and shutting down to the affective aspects of the caregiving relationship, and thus more likely to become distant. From an attachment perspective, high levels of grief and loss may be indicative of beliefs that the attachment figure is now beyond reach, thus a *deactivating* strategy (Cassidy & Kobak, 1988) is selected. In a sample of people with psychosis, Tait et al (2004) found that avoidant coping styles ('sealing over') were associated with insecure adult attachment. Markiewicz et al (1997) observed that family carers with avoidant attachment were more likely to have service users looked after in residential settings.

1.9.3. Attachment and psychological well-being

Attachment has been conceptualised as a working model for affect regulation (e.g. Mikulincer & Florian, 2001), where attachment style may result in different cognitive, emotional and behavioural reactions to stress. In the general population, individuals with insecure attachment have been shown to perform less well on measures of well-being, such as depression, anxiety, loneliness, hostility and psychosomatic illness compared with the individuals rated as secure (e.g. Carnelly et al, 1994; Hazan & Shaver, 1990; Kobak et al, 1991). Poorer well-being has been found to have a stronger association with anxious attachment styles compared to avoidant attachment styles (Kafetsios & Sideridis, 2006; Magai & Passman, 1997; Mikulincer & Florian, 2001); however, in studies where coping styles are considered, avoidant coping tended to result in poorer well-being either similarly or to a greater extent than anxiously attached individuals (Birnbaum et al, 1997; Kettler et al, 1994).

In the Alzheimer's disease literature, securely attached adult children who are caring for a parent with dementia report lower levels of burden whether their parents are living in the home (Carpenter, 2001) or in care homes (Crispi et al, 1997). Crispi et al (1997) found that carers who reported an insecure attachment style also reported higher levels of psychological morbidity. A more recent study by Cooper et al (2008) examined the relationship of attachment style to coping strategy use and psychological morbidity in carers of people with Alzheimer's disease. They found that carers who were more avoidantly attached were more likely to use less adaptive ways of coping. These strategies significantly predicted greater vulnerability to anxiety. Additionally, caring for someone with greater impairment in activities of living predicted greater anxiety.

1.9.4. The relationship between attachment and social support

Cognitive, emotional and behavioural reactions to stress shaped by attachment style may also impact on a person's social support networks. In the general population, attachment and social support have been empirically linked (Davis et al, 1998); better psychological well-being has been associated with greater levels of perceived social support (Cohen, 2004; Sarason et al, 1992). A study of a student sample by Davis et al (1998), found that insecurely attached (anxious and avoidant) students described lower levels of global social support. Individuals with avoidant attachment styles may be particularly affected, as they are more likely to employ emotional-distancing strategies (Mikulincer & Florian, 1995) and less likely to seek out support (Collins & Feeney, 2000). Individuals with insecure attachments may also perceive key sources of support as less supportive, compared to secure individuals (Collins & Feeney, 2000).

Secure attachment may be even more important as people age, when social networks begin to narrow, making the quality of relationships more important (Cartenson, 1999).

Grossman et al (1993) found that older people with secure attachment had better quality social networks with more support and also gave more support themselves, compared with their more insecurely attached counterparts.

Attachment style may also have implications for engagement with formal supports, such as mental health services. In a sample of people with psychosis and formal carers, Berry et al (2008a) found that attachment avoidance in service users was related to poorer therapeutic alliance from both service user and care staff perspectives. The findings from a recent study by Blackburn et al (2010) suggest that services may find it more difficult to meet the attachment needs of service users with a more insecure fattachment style. The authors suggest that service users who are anxious in attachment relationships and whose self-worth depends on the need to gain approval from others may perceive staff as rejecting whether or not they are able to attend to their needs immediately. Service users who are avoidant in attachment relationships and who dismiss the importance of close relationships or deny feelings of distress may not engage in potentially helpful relationships and impact carers' appraisal of their relative.

Berry et al (2008b) also found significant positive correlations between attachment styles and interpersonal problems. Specifically, they found that higher staff avoidance was associated with greater discrepancies in staff and service user ratings of service users' interpersonal problems as well as poor staff psychological mindedness. This could have implications for the caregiving relationship in terms of the development a more collaborative dynamic, rather than using coercive or avoidant strategies to manage relatives' care. Carer attachment could also conceptually influence their engagement with mental health services, both in terms of seeking their own support and acting as an advocate for their relative.

1.9.5. Attachment in carers of people with psychosis

The relationship between avoidant attachment and avoidant coping can be predicted based on the literature, but this has not yet been established in research with carers of older people with psychosis. Research investigating the relationship of carer attachment style in relation to coping style, psychological morbidity, and use of informal and formal supports has yet to be examined. Less secure attachment styles may impact on the caregiving environment and affective reactions towards service users, (high EE), as well as contributing to increased vulnerability to psychological morbidity and burden, which have been consistently linked to high EE in the psychosis literature (Kuipers et al, 2010). Thus, identifying key attachment styles in carers could highlight an additional pathway to understanding the caregiving environment, quality of caregiving relationships and carer outcomes in psychosis.

1.10 Study Aims

Carers of people with psychosis have been identified as a critically neglected group (Kuipers, 2010). The position of carers of older people with psychosis may be even more precarious given the 'double stigma' of ageing and psychosis faced by those for whom they care, leaving carers at greater risk of falling off the healthcare agenda (Palmer et al, 1999). Family interventions are a key feature of the NICE Schizophrenia Guideline (National Institute for Clinical Excellence, 2003; Updated 2009); however, research informing clinical practice in schizophrenia has focused almost exclusively on carers of working age adults. Kuipers et al's (2010) cognitive model of caregiving in psychosis offers a coherent evidence based framework from which to study the caregiving environment. However, due to the lack of research carried out with carers of older adults with psychosis it cannot be reliably generalised to this population and more research focusing exclusively on this group of carers is warranted.

This study seeks to address part of this gap in the literature. Given the paucity of literature, this research offers the opportunity to identify the demographics of carers of older adults with psychosis population, particularly in terms of the relationship to the person who is cared for and relationship quality. Differences in service user and carer characteristics could potentially lend themselves to different experiences of caregiving.

In the context of the cognitive model of caregiving in psychosis (Kuipers et al, 2010), and the theoretical framework underpinning attachment theories (e.g. Hazan & Shaver, 1990; Mikulincer & Florian, 2001), this study seeks to explore hypothesised relationships between EE, illness specific appraisals, affect, burden and attachment styles in carers of older adults with psychosis. Due to the age and clinical profile of older adults with psychosis, it is predicted that carers will be more likely to be demographically different to carers of working age adults. The role of social support and coping style on carer outcomes is also explored.

1.10.1. Hypotheses

Primary hypotheses

In carers of older adults with psychosis:

a) Carers who are higher on avoidant attachment will report greater use of ‘avoidant coping’ strategies.

b) Carers who are more insecurely attached (i.e. higher on avoidant and/or anxious attachment) will (a) report higher rates of psychological distress and (b) have higher rates of EE.

c) High EE in carers will be positively associated with (a) negative illness appraisals, (b) avoidant coping and (c) negative caregiving experiences.

Secondary hypotheses

In carers of older adults with psychosis:

a) Carer distress will be positively associated with (a) avoidant coping, (b) illness appraisals and (c) negative caregiving experiences.

b) Avoidant coping will be positively associated with negative caregiving experiences.

CHAPTER 2

Method

2.1 Introduction

This chapter describes the methodology of the study. A description of participant characteristics and the design of the study is provided. The chapter also outlines details of ethical approval and considerations of the study, followed by details of the procedure used for recruitment of participants and data collection. A description of the statistical analysis plan concludes the chapter.

2.2 Design

A cross-sectional within subjects design was employed for the current study.

2.2.1. Power analysis and sample size

Power analyses were carried out using G*Power 3 for Mac OS X (Faul et al, 2007). Power analyses were two-sided based on the exploratory nature of the study. Ideally an alpha level of 0.01 would have been assumed in order to correct for multiple correlations; however, due to the limited potential for recruitment in this study an alpha level of 0.05 was used. Implications for this will be discussed in more detail in the Discussion.

As research in the area of caregiving experiences and attachment has not yet been carried out in carers of older adults with psychosis, the current power analysis was based on correlations from a study by Cooper et al (2008) who found that more avoidant attachment styles were associated with 'dysfunctional coping' ($r = 0.39$, $p < 0.001$) in a sample of family carers of older adults with Alzheimer's Disease. For the current study, a power analysis was carried out in order to detect a relationship between less secure attachment styles and avoidant coping in carers. For the current study, a sample size of 47 was required to have an 80% chance to detect a ρ of 0.39.

For the other primary hypothesis, to detect a relationship between insecure attachment and distress, another correlation from Cooper et al (2008) was used ($r = - 0.45$, $p < 0.01$), who found that secure attachment was inversely related to anxiety. Results indicated that in the current study a sample size of 36 was required in order to have 80% power to detect a ρ of 0.56.

2.3 Participants

2.3.1. Inclusion criteria

Carers were defined as informal carers and included relatives, spouses, partners, or children of the service user who were identified by either the service provider, service user and/or themselves as being in a caregiving role. Carers had to have regular contact with service users, including face-to-face contact and phone contact for at least ten hours per week. Similar criteria have been applied to studies of carers in the past (e.g. Barrowclough et al, 2001b; Kuipers et al, 2006; Onwumere et al, 2008). Only those aged 18 years or older and who were able to provide informed consent were included.

2.3.2. Exclusion criteria

Those with an insufficient grasp of the English language required to respond to the questionnaires and interview were excluded. Translated and validated questionnaires were not available and the provison of interpreting services was not possible within the budget allocated to the project.

2.3.3. Source of participants

The following avenues were explored with regard to participant recruitment:

a) Community Mental Health Teams (CMHTs) for older adults from the South London and the Maudsley (SLaM), and Oxleas NHS Foundation Trusts.
b) Older adult SLaM inpatient treatment teams at the Maudsley and Bethlem Royal Hospitals
c) Working age adult recovery teams within the Oxleas and SLaM NHS Foundation Trusts
d) Carer support groups run in affiliation with the Princess Royal Trust for Carers and Rethink Mental Illness.
e) Distribution and email lists, social networking sites and the website of Rethink Mental Illness.

2.4 Materials

2.4.1. Social and demographic information (Appendix A)

For each participant, social and demographic details including the type of caregiving relationship they had with the service user (e.g. spouse, son/daughter), was obtained.

2.4.2. Five Minute Speech Sample (FMSS; Magana et al, 1985; Appendix B)

The FMSS is a direct measure of expressed emotion (EE) conducted by a brief interview. As part of the interview, the carer is asked to speak freely and uninterrupted for five minutes about the person for whom they care. The interview is recorded transcribed and subsequently rated on four dimensions: 1) quality of the initial statement, 2) quality of the relationship, 3) criticism, and 4) emotional over involvement (EOI). Based on the ratings, the recording is classified as being either high or low for EE.

High EE is assigned to those who are high on the critical dimension and/or EOI dimension. On the critical dimension, high EE is assigned if the carer makes one or more critical comments, or if the quality of the initial statement is negative. On the EOI dimension, a carer can be classified as high EE if responses indicate one or more of the following: 1) self-sacrificing or devoted behaviour, 2) emotional display during the interview, *or* two or more of the following characteristics: 1) excessive details from the past, 2) one or more statements of attitude or five or more positive remarks (Magana et al, 1985).

Magana et al (1986) found the FMSS to be reliable and to produce ratings comparable to those derived from the Camberwell Family Interview (CFI; Vaughan and Leff, 1976). Moore and Kuipers (1999) found 89.7% agreement between FMSS and CFI ratings. The utility of the FMSS has been established in a variety of populations including psychosis (Magana et al, 1986; Hahlweg et al, 1987; Hahlweg et al, 1989) and Alzheimer's Disease (Vitaliano et al, 1988; Vitaliano et al, 1993). It has been widely used in carer research in psychosis, as a more time efficient equivalent to the CFI (Bachmann et al, 2001; Barrowclough et al, 2001; Heikkila et al, 2002; Lobban et al, 2006). As a construct, EE may not necessarily be stable but one that is liable to fluctuate over time (e.g. McCreadie, Robertson, Hall, & Berry, 1993; Treanor, Lobban & Barrowclough, 2011). Scazufca and Kuipers (1998) found a 63.9% stability rate after a period of nine months.

The speech samples were transcribed by the author. To establish inter-rater reliability, each sample was rated independently by the author, a research worker and the primary supervisor of the project (JO), using the manual scoring guidelines. Ratings were subsequently compared until a consensus for each sample was reached.

2.4.3. Time Budget Measure – Adapted (TBM; Jolley et al, 2005; Appendix C)

The TBM is a measure of social functioning. The original use of the measure elicits a comprehensive record of the service user's activity over the last week via interview and an activity diary. As the current study focused on carers' social functioning, the interview was adjusted to be completed with the carer. The responses to the interview provide a retrospective account of a typical day in the previous week. The activities throughout the day are recorded in four time blocks each day (morning, midday, afternoon and evening). Each block is rated on a scale from 0 (doing nothing, such as sleeping, thinking, sitting) to 4 (time period filled with demanding activities requiring motivation, planning and variation in tasks), with the activity receiving the highest rating forming the score for that individual block. There are 4 blocks with total scores ranging 0 – 16; higher scores indicate high levels of purposeful activity. The measure allows for the collection of information on work, leisure, domestic and social activities and has good reliability and validity (Jolley et al, 2005; Jolley et al, 2006b). Intraclass correlations have shown very good inter-rater reliability ($r = 0.83$, $p < 0.0001$). The TBM also has concurrent validity with the widely used Social Functioning Scale (SFS; Birchwood et al, 1990). The TBM has been used in the past to assess patient functioning in psychosis (e.g. Garety et al, 2008; Onwumere et al, 2009; Favrod et al, 2010; Waller et al, 2012).

2.4.4. Hospital Anxiety and Depression Questionnaire (HADS; Zigmond & Snaith, 1983; Appendix D)

The HADS is a 14-item self report scale designed to detect the presence and severity of depression and anxiety, with seven items relating to anxiety and seven items relating to depression. Responses are given on a four point scale (0 – 3) and pertain to the frequency at which the item is experienced in the previous week. Each scale has a total which can range from 0 – 21, with scores of 11 and above indicating clinical levels of distress. High internal consistency has been found for the anxiety (0.80 – 0.93) and depression (0.81 – 0.90) subscales.

The HADS has been widely used in a range of clinical settings and research studies, including somatic, psychiatric and primary care patients, as well as the general population (Bjelland, 2002). The tool was selected for the current study as it provides a valid and reliable measure of distress, yet is brief (taking 5 – 10 minutes to complete), and therefore minimises the burden of participation. The HADS has been previously used in psychosis carer research (e.g. Lobban et al, 2004; Fortune et al, 2008).

2.4.5. Independent Activities of Daily Living (IADL) & Physical Self Maintenance Scale (PSMS; Lawton & Brody, 1969; Appendix E)

Lawton and Brody's (1969) measure of IADL is an eight item scale that measures daily self-care activities within an individual's place of residence, in outdoor environments, or both, and is a measure of a person's functional status. The scale comprises items querying functioning in the following areas: use of telephone, shopping, food preparation, responsibility for medication, housekeeping, laundry, transport, and managing finances.

The PSMS is a six item measure that assesses independence of physical functioning in the areas of toileting, bathing, feeding, dressing, grooming and physical ambulation. Lawton and Brody (1969) demonstrated the usefulness of these measures. The PSMS and IADL are widely used tools to check functioning in activities of daily living in older adults and have been noted to be simple and efficient assessment instruments (Barberger-Gateau et al, 1992; Katz, 1963).

For the current study, carers were asked to complete the IADL and PSMS as measures of current levels of functioning of the person for whom they care. Scoring was adapted, where responses were on a scale from highest level to lowest level of functioning. Sums of items on each measure provided total scores; thus, higher total scores indicated lower levels of functioning.

2.4.6. Experience of Caregiving Inventory (ECI; Szmukler et al, 1996; Appendix F)

The ECI is a 66-item self report questionnaire which measures caregivers' appraisals of their caregiving experience. There are ten subscales, eight of which are related to negative aspects of caregiving, such as negative symptoms, stigma, effects on family, the need to provide backup, dependency, problems with services, difficult behaviours and loss. The remaining two subscales are related to positive aspects of caregiving, such as positive personal experiences and good aspects of the relationship. Items are scored on a 5 point Likert scale (0 – 4). Scores on the negative subscales range from 0 to 208, with higher scores indicating more negative caregiving appraisals. In the current study, the total score for the negative subscales is used as a measure of carer burden. Positive subscale scores range from 0 to 56, with higher scores indicating more positive caregiving appraisals. All subscales have been shown to demonstrate good reliability, with the negative subscales yielding reliability scores between 0.74 and 0.91, and between 0.82 and 0.86 for the positive scales (Szmukler et al, 1996). The ECI has been used in several studies of carers of individuals with psychosis (Kuipers et al 2006; Harvey et al, 2001; Joyce et al, 2003; Raune et al., 2004; Addington et al, 2005), and thus allows for comparisons with previous studies.

2.4.7. Social Support Questionnaire – Six item version (SSQ6; Sarason, Sarason, Shearin & Pierce, 1987; Appendix G)

The SSQ6 is a 6-item measure of appraisal of social support. It is abbreviated from the original 27-item Social Support Questionnaire (SSQ; Sarason et al, 1983). Each item has two parts. The first part assesses the number of available others the respondent perceives they can turn to in times of need for each situation presented (i.e. number of perceived availability score). The second part of each item assesses the respondent's degree of satisfaction with the support available (satisfaction score). Responses are presented on a six-point Likert scale (ranging from 'dissatisfied' to 'very satisified'). Sarason et al (1983) report acceptable psychometric properties for abbreviated versions. The short form version of the questionnaire was selected in order to minimise the length of participation time.

2.4.8. Psychosis Attachment Measure – Revised (PAM-R; Berry et al, 2006; Appendix H)

The PAM-R is a 16-item measure of attachment. Eight items assess the contruct of attachment anxiety and the other eight items assess the construct of attachment avoidance. Responses to questions about how the person relates to others in a variety of situations are given on a 4-point Likert scale, ranging from 0 (not at all) to 3 (very much). Scores are calculated by totaling the scores for each dimension and then calculating the average. Higher scores reflect greater attachment anxiety and avoidance. The PAM-R has demonstrated good psychometric properties including construct validity in non-clinical samples (Berry et al, 2006; Berry et al, 2007). The scale was derived from previous self report measures (e.g. Brennan et al, 2006), and has the advantage of not requiring the respondent to currently be or recently have been in a romantic relationship. One-month test-retest estimates on subscales were comparable to existing measures (e.g. Fraley & Brumbaugh, 2005), where intraclass correlation efficients were 0.71 for attachment anxiety and 0.56 for attachment avoidance. The measure has been used in studies of individuals with psychosis (Berry et al, 2008a; Berry et al, 2009) and formal care staff in mental health settings (Berry et al, 2008b) and thus was deemed suitable for use in the current study.

2.4.9. Brief Illness Perception Questionnaire (BrIPQ; Broadbent et al 2006; Appendix I)

The BrIPQ is a nine-item scale that measures patients' cognitive and emotional representations of their illness. The nine items refer to each of the dimensions of the model of illness representation (Leventhal, Meyer & Nerenz, 1980). Eight of the dimensions are rated on a scale from 0 – 10. The items elicit the respondents' perceptions of each of the following: the consequences of the illness (how much the illness affects their life); timeline (how long the illness will last); personal control (how much the person feels they have control of the illness); treatment control (how much the person thinks treatment can help); identity (how much the person reports experiencing symptoms from the illness); concern (how much the person is concerned about the illness); illness coherence (how much the person feels they understand the illness); emotional representation (how much the illness affects them emotionally). Causal beliefs are examined by the respondent listing the three most important factors they think caused the illness. The measure has been shown to have good reliability and validity across a wide range of illnesses (Broadbent et al, 2006).

2.4.9.1. Adaptations for the current study The original and unabridged version of the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris & Horne, 1996) was modified to form the Illness Perception Questionnaire for Schizophrenia (IPQ-S), which also included an informant version for carers (IPQ-R; Lobban et al, 2005). The

IPQ-R questionnaire has 38 items, and is thus more time-consuming to complete. For the purpose of this study it was considered that the BrIPQ would provide sufficient information. The BrIPQ has been used to assess psychiatric staff's perceptions of service users with psychosis (Berry et al, 2008b), so was considered to be appropriate to use with relatives and a timely alternative to the IPQ-R.

Similar to revisions made by Lobban et al (2005) for the IPQ-R, the wording of the version of the BrIPQ used in this study was altered to say "problems/illness" rather than just "illness". The wording of the questions was also modified to read appropriately as an informant, e.g. "How much do you think his/her problems/illness affect your life" and "How much control do you feel he/she has over his problems/illness?" The adapted version has been used with carers of service users with psychosis (Tomlinson et al, in submission).

2.4.10. Brief COPE (Carver, 1997; Appendix J)

The Brief COPE is a 28-item self-report questionnaire that assesses coping styles on 14 subscales made up of two items each. The subscales include: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Responses are given on a scale (1 – 4) which pertains to the frequency in which the respondent engages in the presented method of coping. In order to provide a measure of 'avoidant coping' in the current study, responses on the following scales were tallied: behavioural disengagement, self-distraction, substance use and denial. These behaviours can be defined as ones which function as distraction from the problem rather than attempts to deal with the problem via practical or emotional means and is consistent with previous studies using the Brief COPE (e.g. Raune et al, 2004; Kuipers et al, 2006; Onwumere et al, 2011).

The Brief COPE has satisfactory psychometric properties. The authors report an internal consistency of all subscales ($\alpha > 0.50$) (Carver, 1997). It has been used previously in research in patients with psychosis (e.g. Meyer, 2001), research on carers of individuals with psychosis (e.g. Onwumere et al, 2011; Fortune et al, 2005) and in studies of carers of individuals with dementia (e.g. Crespo et al, 2005).

2.5 Ethical approval

Ethical approval was granted by the NHS National Research Ethics Service Committee London at London Bridge (Ref No. 11/LO/0655). Please see Appendix K for the letter of approval.

Research and development approval was granted from:

a) South London and the Maudsley NHS Foundation Trust – the Mental Health of Older Adults Clinical Academic Group (MHOA CAG) and the Psychosis CAG (Appendix L)
b) Oxleas NHS Foundation Trust – Mental health services for working age adults and for older people (Appendix M)
c) North-East London NHS Foundation Trust - Mental health services for working age adults (Appendix N)

The project was also approved by Rethink Mental Illness*,* subsequent to a review of the study by a panel including carers and service users (Appendix O). The project was also approved by the Princess Royal Trust for Carers.

2.5.1. Ethical considerations

One of the main ethical issues concerning this project was the method of recruitment, which involved seeking direct consent from carers rather than first seeking the consent of service users to contact carers. One of the guiding principles of this research was the importance of acknowledging that carers are a vulnerable group in their own right and have needs separate to those of their respective service user, which may not be met by existing mental health services (Kuipers, 2010). The recent publication of "No Health without Mental Health" (Department of Health, 2011) highlights the importance of supporting carers via the expansion of care to improve mental health outcomes and enhance quality of life for all carers. According to the publication, families and carers of all ages often receive limited help and they report that they are neglected by health professionals on the grounds that they need to protect the confidentiality of the service user. Research that is accurately representative of carers' experiences needs to be as inclusive as possible; therefore, the aim of the current study was to recruit all carers, not just those whose respective service users had consented to their carer being contacted. When considering seeking service user consent, it was necessary to take into account that service users may have a number of reasons for refusing consent. It was important to be mindful of the possible reasons for this, such as the individual experiencing more active and severe psychotic symptoms, having a poor relationship with the carer and/or service provider. A carer in such circumstances may theoretically experience more negative caregiving, more isolation and greater psychological distress. If excluded on the grounds that their service user has not provided consent for the carer to be approached, such carers' needs may have remained unexamined and thus unmet in the long term. Consequently, it was felt that directly seeking consent from carers was the most ethical and relevant approach given the ethos guiding this research. This approach was also consistent with published research programmes with carers (e.g. Onwumere et al, 2008). The implications for the recruitment procedure will be outlined in later sections of this chapter and the Discussion.

2.6 Procedure

2.6.1. Recruitment

Due to difficulties in recruiting carers from the originally identified source (MHOA CAG, SLaM), permission to recruit from other services and NHS Trusts was sought at different time points during the recruitment phase in an effort to achieve a large enough sample. The recruitment strategy differed across sources of participants due to the nature of the services and the agreed site-specific procedures. Recruitment from each source is described in detail, below.

2.6.1.1. MHOA CAG (SLaM) An audit identifying service users with carers who fit the study inclusion criteria was carried out as part of another study running concurrent to the present study, and which shared the same inclusion criteria for carers. Permission to contact carers identified by the audit was granted by the MHOA CAG and the research team of the other study, which was headed by the primary supervisor of the current study. Carers were invited to participate in both studies, and participation in one study did not preclude participation in the other. Care coordinators were provided with Professional Information Sheets, with information about the study (see Appendix P). Carers were initially informed about the research by care coordinators assigned to the service user. Carers were contacted by the researcher once they had consented to their contact information being shared for this purpose. Participation in both studies involved completing the BrIPQ, ECI, TBM and FMSS. To minimise the burden of participation on carers, once the participant had completed these measures in one study they were not asked to complete them again, with consent to share responses on these measures between studies being sought beforehand.

2.6.1.2. Psychosis CAG (SLaM) Carers recruited to another project running parallel to the present study and who met the current study's inclusion criteria were asked by the researcher of the other study if they would be interested in being contacted about further research. If they indicated interest, carers were then contacted about the present study. Participation in both studies involved completing the HADS, ECI and FMSS. As per the affformentioned procedure, to minimise the burden of participation on carers they were not asked to complete these measures again and consent was obtained to share the previously collected data.

2.6.1.3. Older adult mental health teams (Oxleas NHS Foundation Trust) A lead psychologist at the Trust agreed to support the project and to disseminate project information (Professional Information Sheet; see Appendix Q) to professionals working with eligible carers, who would then pass on information about the project to carers (Participant Information Sheet and study flyer; see Appendix R and S, respectively). Professionals making initial contact with carers did not seek their consent to being contacted by the researcher, thus it was left to carers to contact the researcher in order to indicate their interest in participation.

2.6.1.4. Recovery teams (Oxleas NHS Foundation Trust) An audit of eligible carers was carried out by Recovery Team managers across three sites of the Trust. Care coordinators who were in contact with identified carers were asked to provide carers with information on the study (as above) and seek their consent for participation in the research study. This was also outlined in the Professional Information Sheet provided (Appendix P).

2.6.1.5. Carer support workers and groups Carer support groups and carer support workers (organised under Princess Royal Trust for Carers and Rethink Mental Illness) were contacted by e-mail and telephone. Group coordinators were provided with information about the study and asked to identify potential carers within their support groups and to provide them with information about the study and an invitation for participation. Those who were interested in participating were requested to contact the researcher using the contact details outlined in the study information sheet.

2.6.1.6. Rethink Mental Illness Rethink Mental Illness provided assistance in the advertising and promotion of the study through the following media:

a. The Rethink website – on the research webpages, under 'Get involved'.
b. Twitter – placing a brief advert on their Twitter site.
c. Involvement and Activist Mailing – Circulating an advert for the study in their monthly Involvement and Activist Mail.
d. Rethink services – Emailing PAs to service managers about the study with the researcher's contact details and study information/posters.
e. Rethink groups – Emailing group coordinators about the study with the researcher's contact details and study information/posters.

2.6.2. Scheduling Appointments Once carers agreed to participation, they were offered the choice to be seen in their own home, at the site of the service provider (if available) or in a private space at the Institute of Psychiatry. The scheduling of appointments aimed at being as flexible as possible and early evening appointments were offered to carers who were unable to take time off during the day to participate.

2.6.3. Reimbursement

Participants were reimbursed £25 for time taken to participate.

2.6.4. Assessment and Interview Procedure

2.6.4.1. Consent process Before the assessment and interviewing procedure began, participants were provided with and asked to read the study information sheet which outlined the purpose of the study, what participation would involve and other details related to the nature of participation (please see Appendix T). Participants were given the opportunity to ask questions about the study before being asked to read through the consent form with the researcher and provide written consent (please see Appendix U).

2.6.4.2. Order of Assessment and Interview Participants completed all measures in one appointment which lasted approximately 80 minutes. The assessment began with the demographic information. Carers then completed the questionnaires (HADS, PAM-

R, ECI, BrIPQ, Brief COPE, SSQ6, IADL, and PSMS) which were read aloud by the researcher unless the participant indicated a preference to complete the questionnaires by pen and paper. Participants were encouraged to ask questions throughout and to request breaks as needed. Following the questionnaires, carers were interviewed using the protocol for the the FMSS, followed by the TBM interview.

2.6.4.3. Debriefing Procedures Following the assessment, participants were prompted to reflect on their experience of participation and were provided with an opportunity to raise any questions or concerns arising from their participation. Participants were offered information on www.mentalhealthcare.org, a website which provides information to family and friends of individuals with psychosis. For carers presenting with concerns for their own mental health, the researcher provided information on how to contact mental health services and local carer support services and organisations. All participants were asked if they would like a lay summary of the findings of the research, and if interested they were asked if they would prefer to be contacted by e-mail or post, for which contact details were requested.

2.6.4.4. Follow-up Phone Calls In order to monitor participants' welfare following participation, participants were offered a follow-up phone call scheduled for a week following participation, which would provide an opportunity for the researcher to address any questions, concerns or feelings of distress which may arise following participation. If participants declined this offer, they were not followed up after participation.

2.7 Statistical Analysis

Descriptive and statistical analyses were carried out using SPSS 20 for Mac OS X (Version 20). To compare data from the current sample to published data of studies on carers of working age adults with psychosis t-tests were carried out using an online t-test calculator (http://www.quantitativeskills.com/sisa/statistics/t-test.htm).

Descriptive statistics (including mean, standard deviation, range, frequency and percentages) were used to provide a summary of the data and to allow for comparisons between studies. Spearman's Rank Order Correlations (rho) were used to examine the relationship between variables in the primary, secondary and exploratory hypotheses.

CHAPTER 3

3. Results

3.1 Overview

This chapter presents a summary of the main findings. It begins with a breakdown of the recruitment pathways, and is followed by a description of the sample. A detailed summary of the descriptive data of the measures is presented. The chapter ends with the results of statistical analyses of the primary and secondary hypotheses.

3.2 Recruitment: pathways and challenges

Twenty-three carers were recruited in total. Recruitment into this study faced several challenges. The main challenge, however, was the process of establishing initial contact with prospective participants which required care-coordinators, clinicians and group facilitators to facilitate carers' consent to being contacted before the initial contact by the researcher could be made, which was in accordance with the ethical guidance and approval.

Other methods of recruitment (e.g. email invitations, social media) were self-selecting in nature, which precluded the ability to follow-up with possible participants unless they had made the first contact. Given poor levels of recruitment and rates of participation it was agreed mid-way through recruitment to extend the geographical area from which to recruit, and Research and Development approval was sought from Oxleas NHS Foundation Trust and North East London NHS Foundation Trust (NELFT).

Figures 4, 5 and 6 summarise the recruitment pathways for SLaM, Oxleas, and mental health charity carer groups, respectively. Complete participation data was available for the SLaM pathway, where the participation rate was approximately 27% (14 agreed out of the 51 carers contacted). This recruitment pathway was the most successful, whilst some pathways yielded few or no participants. For those recruited through MHOA Oxleas teams and carer support groups, data on the number of carers approached by the care coordinator was not available to the researcher.

Of those who did agree to the study (N = 25), one person did not respond to subsequent efforts to make an appointment for participation, whilst another withdrew their participation on health grounds. Consequently, the final sample comprises 23 carers.

Recruitment through NELFT was unsuccessful, the details for which will be outlined as part of the discussion section alongside other difficulties encountered in recruitment. Implications for the sample size will also be reviewed.

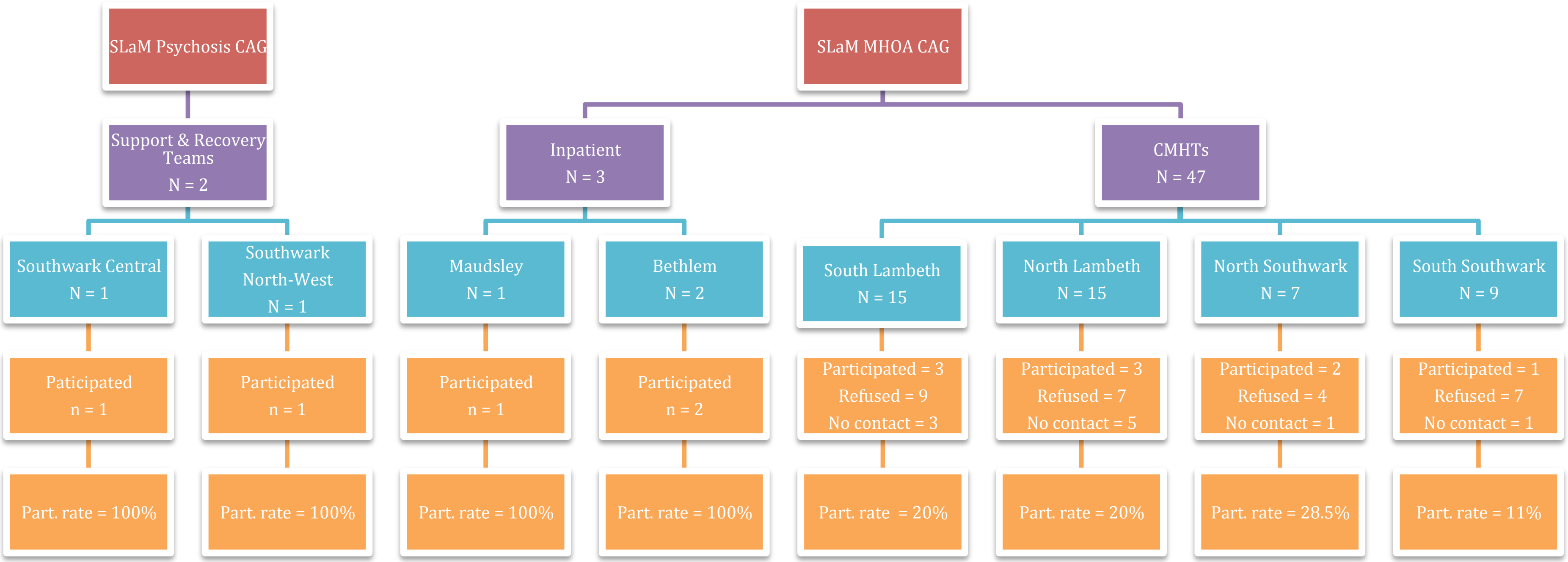


Figure 4. Flowchart showing recruitment through SLaM Psychosis and MHOA CAGs

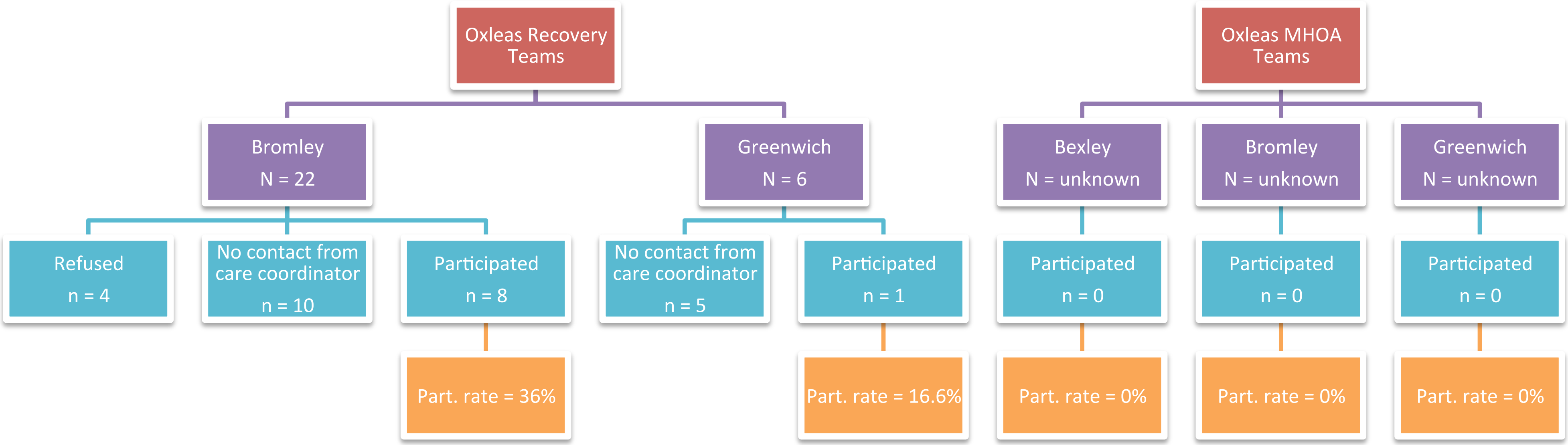


Figure 5. Flowchart showing recruitment through Oxleas Recovery and MHOA teams

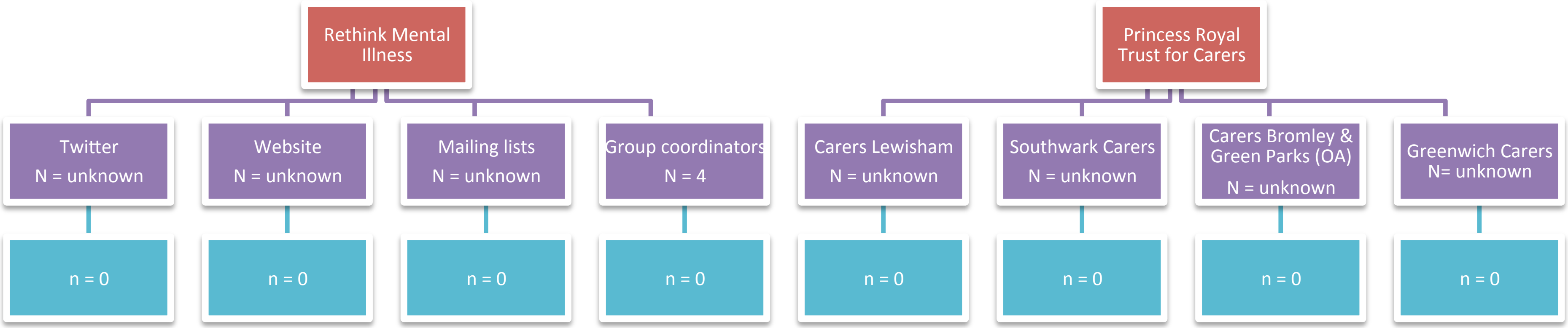


Figure 6. Flowchart showing recruitment through charities/carer groups

3.3 Data preparation

Data were explored to establish whether assumptions of a normal distribution had been met using Kolmogorov-Smirnov test of normality and visual analyses of histograms, normal quantile-quantile (Q-Q) plots and boxplots. A number of variables were not normally distributed. On account of this, and the sample size, a non-parametric statistic, Spearman's Rank Order Correlation (rho), was used for all correlational analyses, including for those that were normally distributed in order to allow for consistency in comparisons. A comparison of the 5% Trimmed Mean with the overall mean for each variable ensured that the presence of the small number of outliers had not distorted mean values used in the analyses; thus, no further action was required to eliminate or transform these data points. The dataset had no missing data points.

3.4 Considerations for power, multiple testing and level of significance

All findings are reported as two-tailed in significance. In order to detect a relationship between avoidant attachment and 'avoidant coping' (primary hypothesis I), the required sample size of 47 was not met on account of recruitment difficulties. The achieved sample size of 23 provided 50% power to detect a ρ of 0.39 (with an alpha value of 0.05). Previous research into this relationship has reported medium effect sizes (e.g. Cooper et al, 2008), which this study is underpowered to detect. In order to detect a relationship between attachment and distress (primary hypothesis II), the sample size of 23 had 64% power to detect a ρ of 0.45 (with an alpha value of 0.05).

3.5 Sample demographics

3.5.1. Carers

The mean age of carers was 58 years (SD = 16.9, range 23 – 87). Most were female (61%) and of White (47.8%) or Black (30.4%) self-reported ethnicity. For the majority (78.3%), English was their first language. In terms of their relationship status, 60.8% of carers were either married or cohabiting. Carers were more likely to be retired (34.8%) or in employment (26%). Most carers did not care for any children under the age of 18 years (95.6%, n = 22). Two carers (8.6%) cared for one or more other relatives. See Table 2 for a more detailed breakdown of demographic information.

Table 2

Characteristics and demographics of carers (N = 23)

Demographic categories	
Female Gender	14 (61%)
Age Mean (SD)	58 (16.9)
Occupation n (%)	
Employed full-time	3 (13%)
Employed part-time	2 (8.7%)
Self-employed	1 (4.3%)
Full-time student	1 (4.3%)
Unemployed	5 (21.7%)
Retired	8 (34.8%)
Homemaker	3 (13%)
Relationship status n (%)	
Single	6 (26.1%)
Divorced	1 (4.3%)
Widowed	1 (4.3%)
Married	13 (56.5%)
Cohabitating	1 (4.3%)
Separated	1 (4.3%)
Ethnic Group n (%)	
White	11 (47.8%)
Mixed	1 (4.3%)
Asian or Asian British	2 (8.7%)
Black or Black British	7 (30.4%)
Chinese or other ethnic group	2 (8.7%)
First Language English n (%)	18 (78.3%)

3.5.2. Service users with psychosis

Service users' mean age was 71.4 years (SD = 7.1 years, range 62 – 82). Most service users were female (65.2%). The length of time since service users' diagnosis ranged between 5 months to 54 years (M = 28 years, SD = 18 years). All service users presented with symptoms of psychosis and included those with non-affective psychosis (n = 18) (e.g. schizophrenia) and affective psychosis (n = 5) (e.g. bipolar affective disorder with psychotic symptoms). (See Figure 7).

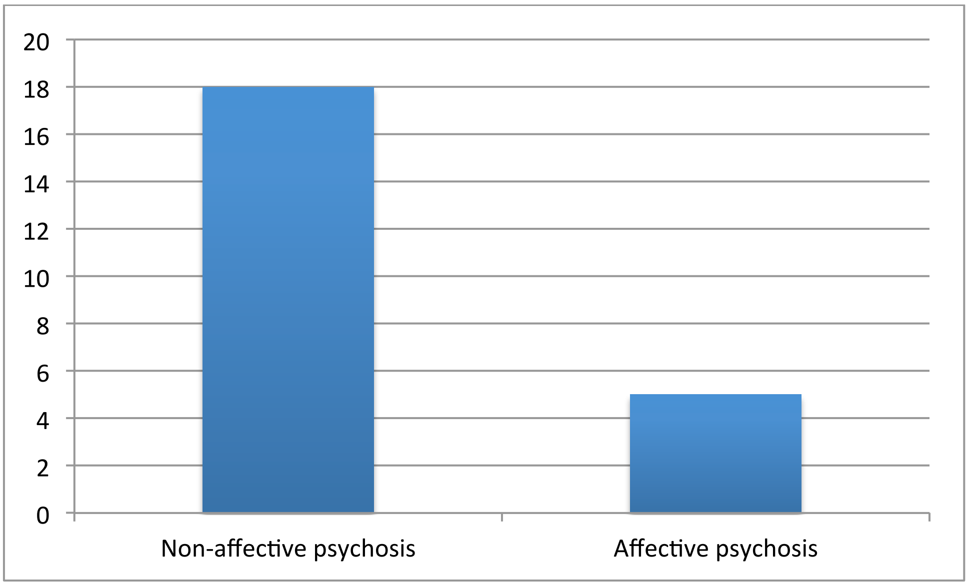


Figure 7. Type of presentation of psychosis in service users

3.5.3. Relationship between carers and service users

Most carers were the adult children of the person for whom they cared (47.8%) or their spouses or partners (34.3%). The largest subgroup of carers was daughters (34.8%). Figure 8 provides a summary of relationship types. Sixty-five percent (n = 15) of carers were living with the service user, with the remainder of service users residing in either sheltered accommodation (n = 4), privately owned or rented accommodation (n = 1), or local authority accommodation (n = 3).

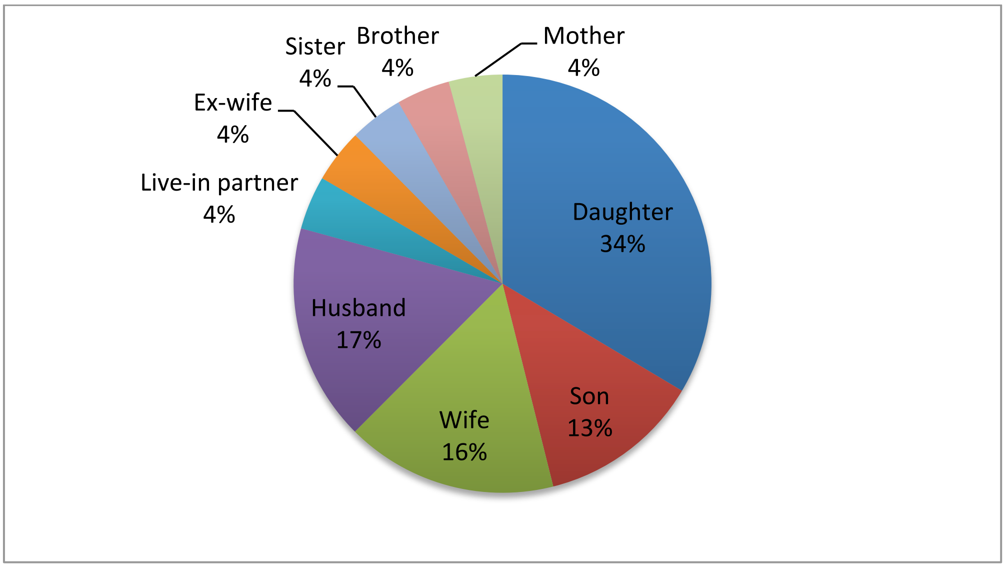


Figure 8. Relationship of carer to service user

3.6 Descriptives of data

3.6.1. Attachment (PAM-R; Berry et al, 2006)

As this is the first time the PAM-R has been used with informal carers of people with psychosis, reliability of the scale was analysed. A Cronbach alpha coefficient of .74 indicated good internal consistency of the measure. Avoidant and anxious attachment were measured on a continuum with secure attachment, where higher scores on these subscales indicated more attachment avoidance and anxiety, respectively. Descriptives of participants' scores are presented in Table 3, below.

For descriptive purposes, responses on the attachment scale were dichotomised, and frequency of responses below the scale's midpoint (1.5 on a scale of 0 – 3) on the attachment and avoidance subscales was calculated. Four percent of carers scored above the midpoint for attachment anxiety. Forty-three percent of carers scored above the midpoint for attachment avoidance. Those who scored above 1.5 on the attachment anxiety scale also scored above 1.5 on the attachment avoidance scale. Attachment avoidance was thus more prevalent than attachment anxiety, though percentages indicate that most of the sample reported a more secure attachment style (57%).

Table 3

Mean, SD, and range for PAM-R subscale scores (N = 23)

PAM-R subscales	***M***	***SD***	***Range***
Attachment avoidance	1.53	0.60	0.13 – 2.63
Attachment anxiety	0.61	0.51	0 – 2.25

3.6.2. Anxiety & Depression (HADS; Zigmond & Snaith, 1983)

A score of equal to or greater than eleven on subscales of the HADS is indicative of probable clinical levels of distress (Zigmond & Snaith, 1983). For the subscale of anxiety, 17.4% (n = 4) of carers scored above the clinical cut-off, and 13% (n = 3) scored above clinical cut-off for depression, with 13% scoring above the cut-off for co-morbid anxiety and depression (n = 3). To contextualise these figures, a comparison with data from Fortune et al (2005) was undertaken. Fortune et al also employed the HADS to assess levels of anxiety and depression in a sample of carers of working age adults with psychosis (N = 42). See Table 4 for a summary of mean scores as compared their sample.

Table 4

Mean and SD for HADS and HADS subscales for current sample (N = 23) and Fortune et al (2005) (N = 42)

	Current Study (N = 23)		Fortune et al (N = 42)	
HADS	***M***	***SD***	***M***	***SD***
Anxiety	7.35	4.16	11.24	4.80
Depression	6.39	4.44	8.50	4.11

Independent sample t-tests were carried out to compare differences between anxiety and depression mean scores of the current study and those reported by Fortune et al (2005). A statistical difference was found between studies for the anxiety subscale, where carers in the current the sample reported significantly lower levels of anxiety, t (63) = -3.41, $p < 0.001$ (two-tailed). The mean difference was 3.89, 95% CI [1.65 to 6.12]. A statistically significant difference was not found between studies for the depression subscale.

3.6.3. Caregiving experiences (ECI; Szmukler et al, 1996)

Table 5 reports the individual subscales and total scores of the ECI in order of the strength of their relationship with the total score for negative and positive caregiving experiences, respectively. Need for back up (rho = .829, $p < 0.0001$), difficult behaviours (rho = .807, $p < 0.0001$), effects on the family (rho = .713, $p < 0.0001$) and stigma (rho = .655, $p < 0.001$), correlated most highly with overall negative caregiving experiences. Positive personal experiences (rho = .849, $p < 0.0001$) were more related to the positive caregiving total, relative to good aspects of the relationship (rho = .623, $p < 0.01$). Results of independent sample t-tests indicated that the current sample reported significantly fewer caregiving appraisals of loss, effects on the family, and problems with services than those reported by Szmukler et al (1996) in a sample of working age adults (Table 6).

Table 5

Mean and SD for ECI scores (N = 23)

	Current Study (N = 23)		Szmukler et al (N = 32)	
ECI subscale	***M***	***SD***	***M***	***SD***
Negative caregiving subscales				
Need for backup	7.35	4.74	8.9	5.7
Difficult behaviours	15.35	7.57	11.2	6.4
Stigma	5.17	4.13	5.5	4.4
Effects on family	6.87	5.51	10.4	6.6
Loss	8.39	5.77	12.5	6.9
Problems with services	10.17	6.28	13.3	7.3
Negative symptoms	11.21	5.23	10.6	5.6
Dependency	12.65	4.26	10.1	4.7
Negative experience of caregiving total	77.17	29.36	-----	-----
Positive caregiving subscales				
Positive personal experiences	14.3	6.85	16.3	7.1
Good aspects of the relationship	13.7	4.4	12.8	4.4
Positive experience of caregiving total	28	8.66	-----	-----

Table 6

ECI: significant differences between current sample and Szmukler et al (1996)

Subscale	**Mean difference**	**df**	**t**	**95% CI**	**P**
Loss	4.11	63	-2.56	0.96 – 7.26	< 0.01
Problems with services	3.13	63	-1.8	0.26 – 6.5	< 0.05
Effects on the family	3.53	63	-2.29	0.52 – 6.5	< 0.05

3.6.4. Expressed emotion (FMSS; Magana et al, 1985)

Over half (56.5%, n = 13) of carers were rated as high in EE. Descriptive data of EE categories (high and low EE classification) are presented in Table 7, and a breakdown of the rating dimensions in each category is provided in Table 8.

Table 7

Summary of expressed emotion (FMSS) categories (N = 23)

EE Category	***n* (%)**
Low EE ratings	**8 (34.8%)**
Borderline ratings	**2 (8.7%)**
Borderline EOI	0 (0%)
Borderline critical	1 (4.3%)
Borderline EOI & borderline critical	0 (0%)
High EE ratings	**13 (56.5%)**
Critical	5 (21.7%)
EOI	1 (4.3%)
Critical & EOI	6 (26.1%)
EOI & borderline critical	1 (4.3%)

Table 8

High and Low EE classifications on the FMSS (N =23)

EE Dimension	High EE *n* = 13	Low *n* = 10
Initial statement		
Positive	2 (15.4%)	4 (40%)
Neutral	6 (46.2%)	6 (60%)
Negative	5 (38.5%)	0 (0%)
Relationship		
Positive	1 (7.7%)	5 (50%)
Neutral	3 (23.1%)	5 (50%)
Negative	9 (69.2%)	0 (0%)
Critical comments		
0	5 (38.5%)	15 (100%)
1	5 (38.5%)	0 (0%)
2	1 (7.7%)	0 (0%)
4	2 (15.4%)	0 (0%)
Dissatisfaction		
Present	12 (92.3%)	1 (10%)
Absent	1 (7.7%)	9 (90%)
Emotional Overinvolvement		
Presence of self-sacrifice	3 (23.1%)	0 (0%)
Presence of lack of objectivity	0 (0%)	0 (0%)
Presence of emotional display	5 (38.5%)	0 (0%)
Presence of excessive detail about past	0 (0%)	0 (0%)
Positive comments		
0 - 4	12 (92.3%)	10 (100%)
≥5	1 (7.7%)	
Statement of attitude		
Present	0 (0%)	0 (0%)
Absent	10 (100%)	10 (100%)

3.6.5. Illness appraisals (BrIPQ; Broadbent et al 2006)

Broadbent et al (2006) suggests that an overall score for the BrIPQ can be computed which represents the degree to which an illness is perceived as benign or threatening. In order to compute this score, items 3, 4, and 7 are reverse scored and added to items 1, 2, 5, 6, and 8. Higher scores reflect a more threatening view of the illness. Carers' mean score on the BrIPQ was 47.7 (SD = 12.1) out of a highest possible score of 80. Table 9 provides details of mean scores for each item in descending order of their mean endorsement.

Table 9

Mean and SD for BrIPQ subscales and total (N =23)

BrIPQ	***M***	***SD***
Timeline	8.3	2.75
Concern	7.35	2.82
Treatment control*	7	2.6
Emotional representation	6.87	2.47
Illness coherence*	6.65	2.58
Identity	6.65	2.67
Consequences	6.52	2.68
Personal control*	4.3	2.89
Total	47.74	12.14

*These items were reversed scored when summed for the total scores

The top three factors identified by carers as having caused service users' illnesses were: stress, genetics, and difficult childhood experiences (including abuse and violence). Table 10 summarises categories and frequency of responses for the three causal factors identified by the twenty-three carers in the sample (number of responses = 69). See Appendix V for a transcription of responses.

Table 10

Categories of causal beliefs: 69 responses for top three causal factors of service users' illness reported by carers (N = 23) on the BrIPQ

Causal belief categories	**Percent (*n*)**
Stress (overall)	**21.7% (*15*)**
Stressful life events (not incl. bereavement)	14.5% (*10*)
Stress related to caring/childcare	1.4% (*1*)
Stress related to money	2.9% (*2*)
Stressful environment	1.4% (*1*)
Genetics	**13% (*9*)**
Childhood (overall)	**11.6% (*8*)**
Childhood – difficulties experiences	7.2% (*5*)
Childhood – abuse and violence	4.3% (*3*)
Do not know	8.7% (*6*)
Loss and bereavement	7.2% (*5*)
Being alone – fear and loneliness	7.2% (*5*)
Service user's personality/attitudes	4.3% (*3*)
Violence experienced as an adult	4.3% (*3*)
Mistrust of others	2.9% (*2*)
Physical/sensory disability	2.9% (*2*)
Organic	2.9% (*2*)
Boredom/Poor social functioning	2.9% (*2)*
Conflict in family	2.9% (*2*)
Anxiety/mood	2.9% (*2*)
Medication	1.4% (*1*)
Alcohol abuse	1.4% (*1*)
Superstition	1.4% (*1*)
Religion	1.4% (*1*)

3.6.6. Coping (Brief COPE; Carver, 1997)

Carers' mean score for 'avoidant coping' was 11.87 (SD = 2.5). This was out of a highest possible score of 24. Table 11 provides details of mean scores for the 14 subscales of the Brief COPE in descending order of their mean endorsement by carers, and alongside comparative findings reported by Fortune et al (2005) who also used the measure with their sample of carers of working age adults with psychosis (N = 42). Table 12 presents significant differences between mean scores on the Brief COPE subscales between the two studies. Onwumere et al (2011) reported mean 'avoidant coping' in their sample of carers of working age people with psychosis as 14.3 (SD = 4.6), which was significantly higher than that found in the current sample, *t* (102) = -3.28, $p < 0.001$ (two-tailed), CI [0.85 to 3.4].

Table 11

Mean and SD for subscales of the Brief COPE for current sample (N = 23) and Fortune et al (2005) (N = 42)

	Current Study (N = 23)		Fortune et al (N = 42)	
Brief COPE subscales	***M***	***SD***	***M***	***SD***
Acceptance	7.17	1.11	6.02	1.25
Active coping	5.04	1.46	---**	---**
Planning	4.96	1.96	6.69	1.17
Venting	4.74	2.2	4.40	1.51
Emotional support	4.43	2.19	5.00	1.65
Instrumental support	4.30	1.82	6.07	1.27
Religion	4.22	2.61	4.47	2.15
Self-distraction*	4.04	1.22	5.95	1.60
Positive reframing	3.96	2.12	4.26	1.82
Humour	3.48	2.04	2.42	0.59
Self-blame	3.09	1.56	4.76	2.09
Substance use*	2.83	1.4	3.02	1.31
Behavioural disengagement*	2.74	1.21	3.54	1.85
Denial*	2.26	.619	3.14	1.33

*These items were tallied to create a the 'avoidant coping' subscale for the current study, **Comparison data unavailable

Table 12

Brief COPE: significant differences between current sample and Fortune et al (2005)

Subscale	**Mean difference**	**df**	**t**	**95% CI**	**P**
Self blame	1.67	63	3.65	0.77 – 2.56	< 0.001
Denial	0.88	63	-3.63	0.41 – 1.32	< 0.001
Planning	1.73	63	-3.87	0.85 – 2.6	< 0.001
Self-distraction	1.91	63	-5.38	1.2 – 2.6	< 0.01
Instrumental support	1.77	63	4.1	0.93 – 2.6	< 0.001

3.6.7. Social functioning (Time Budget Measure; Jolley et al, 2005)

Carers' mean social functioning score for an 'average day' was 10.52 (SD = 2.64, range = 5 – 16) out of a highest possible score of 16. On a scale of 1 – 5, mean satisfaction with their current routine score was 3 (SD = 1, range = 1 – 5), with 34.8% indicating they were not satisfied (score of 1 or 2).

3.6.8. Activities of daily living and physical self-maintenance (IADL & PSMS; Lawton & Brody, 1969).

Higher scores on the IADL and PSMS indicate greater disability and dependence. Carers' means score for ratings of service users' independence in activities of daily living was 18.65 (SD = 6.47) out of a maximum of 31. Their mean rating of service users' physical self-maintenance was 11.04 (SD = 4.44) out of a maximum of 28. Higher scores indicate greater disability and dependence. Nearly half (47.8%) of service users required support with ambulation, with 43.5% (n = 10) requiring either a walker or a cane, and 4.3% (n = 1) requiring a wheelchair.

Further exploratory analyses were carried out to examine the relationship between the measures and carer outcome variables (appraisals of caregiving and distress) and negative illness appraisals. No significant relationships were identified between the IADL and PSMS and appraisals of caregiving or distress (HADS). See Table 13 for relationships between the IADL and PSMS and the BrIPQ.

Table 13

Significant correlations between service user functioning (IADL & PSMS) and BrIPQ

Scale	**Variable**	**IADL**	**PSMS**
BrIPQ	Consequences	.453*	.533**
	Timeline	-.043	-.042
	Personal control	-.276	-.194
	Treatment control	-.432*	-.576**
	Identity	.309	.111
	Concern	.487*	.535*
	Coherence	.006	-.324
	Emotional representation	.387	.334
	BrIPQ total score	.406	.542**

**p* < .05, two-tailed. ** *p* < .01, two-tailed

3.6.9. Social support (SSQ6; Sarason et al, 1987)

The average number of individuals available to carers for social support was reported as 2.19 (SD = 1.78, range 0 – 6.5). One person reported having no supports. On a scale of 1 to 6, where higher responses indicated more satisfaction with social support, the mean rating of satisfaction was 4.5 (SD = 1.4, range 1 – 6). In response to the question 'whom can you really count on to be dependable when you need help?', the majority (69.6%) reported having between 1 to 3 people they could turn to for support, whereas the remainder (26.1%) reported having 4 to 9 people in their social network that they felt would be 'dependable' when they needed help. See Table 14 for a summary of significant relationships between the SSQ6 and coping and attachment.

Table 14

Significant correlations between the number of supports and satisfaction with support (SSQ6) and the Brief COPE and PAM-R

Scale	**Variable**	**No. of supports**	**Satisfaction**
Brief COPE	Acceptance	.250	.337
	Planning	.185	.257
	Active coping	.453*	.452*
	Venting	.246	.163
	Emotional support	.667**	.727**
	Instrumental support	.344	.584**
	Religion	.190	.156
	Positive reframing	.199	.108
	Self-distraction	.176	.485*
	Humour	.185	-.114
	Self-blame	.161	.294
	Substance use	-.299	-.108
	Behavioural disengagement	.154	.012
	Denial	.121	.266
PAM-R	Attachment avoidance	-.554*	-.344
	Attachment anxiety	-.120	.185

*$p < .05$, two-tailed. ** $p < .01$, two-tailed

3.7 Demographic comparisons with studies of carers of working age adults

Demographics from the current study were compared to studies involving carers of working age adults (Kuipers et al, 2006) using descriptive data. See Table 15 for a summary of the comparisons. Table 16 summarises the carers' relationships to service users and compares them to studies of carers of working age adults (Kuipers et al, 2007; Lobban et al, 2005).

Comparisons between the current study and Kuipers et al (2006) showed similarities in terms of carer age and gender, where carers were more likely to be female and aged in their 50s. Differences were noted between service users' gender, where the current study noted a preponderance of female service users, which differed from Kuipers et al (2006) who found that service users were mostly male. Service users' duration of illness was notably longer in the current study than that found by Kuipers et al (2006).

Table 15

Demographics of current study compared to Kuipers et al (2006)

Demographic categories	**Current study**	**Kuipers et al (2006)**
Carer female gender %	61%	70. 2%
Service user female gender %	65.2%	27.9%
Carer age Mean (range)	58 (23 - 87)	52.9 (26 – 86)
Service user age Mean (range)	71.4 (62 – 82)	36.3 (18 – 46)
Living with %	65%	23.8%
Length of illness (years) Mean (range)	28 (0.4 - 54)	11.2 (<1 – 44)
Carer Occupation %		
Employed	26%	39.2%
Unemployed	21.7%	36.7%
Retired	34.8%	unreported
Ethnic Group %		
White	47.8%	83.7%
Black or Black British	30.4%	7%
All other	21.8%	9.3%

**Comparison data unavailable

Table 16

Relationship of carers to service users in current study and studies of carers of working age adults

Relationship to service user (%)	**Current study**	**Kuipers et al (2006)**	**Lobban et al (2005)**
Adult children	47.8%	Nil	1.7%
Spouses/partner	34.3%	34%	26%
Siblings	8.6%	---**	14%
Parent	4.3%	50%	64%

**Comparison data unavailable

Difference in the carer relationship to the service user was most apparent. Carers in the current study were mostly adult children, where the other studies reported no or only one relationship of this type (Kuipers et al, 2006; Lobban et al, 2005). Kuipers et al (2006) and Lobban et al (2005) found that the majority of carers were parents of those for whom they cared, whereas in the current study there was only one parent. All three studies reflected similar proportions of spouse/partner carers. The number of sibling carers was similarly low in all three studies relative to other kinship types. Compared to Lobban et al (2005), carers in the current study were more likely to be living with the person for whom they care

3.8 Results of statistical analyses of primary hypotheses

3.8.1. Primary hypothesis 1: Carers who are higher on avoidant attachment will report greater use of 'avoidant coping' strategies.

There was a non-significant relationship between avoidant attachment and 'avoidant coping' (see Table 17). Exploratory analyses between coping subscales and avoidant attachment identified a medium positive association between avoidant attachment and emotional support (Spearman's rho = - 0.44, $p < 0.05$). However, the analyses are underpowered, thus subsequent analyses remain exploratory.

3.8.2. Primary hypothesis 2: Carers who are more insecurely attached (i.e. higher on avoidant and/or anxious attachment) will (a) report higher rates of psychological distress and (b) have higher rates of EE.

Results of the analyses of relationships between attachment (PAM-R), 'avoidant coping' (Brief COPE), psychological distress (HADS) and EE (FMSS) are summarised in Table 17.

Table 17

Correlations between attachment (PAM-R), 'avoidant coping' (Brief COPE), distress and High EE (FMSS)

Attachment style	**Avoidant coping**	**Anxiety**	**Depression**	**EE Rating**
Anxious	0.193	0.242	0.077	.027
Avoidant	0.193	0.562**	0.606*	.159

**p* < .05, two-tailed, ** *p* < .01, two-tailed

Results indicated that the relationship between anxious attachment and psychological distress was not significant. However, avoidant attachment had large positive associations with both depression and anxiety. No relationship was found between EE and anxious or avoidant attachment.

3.8.3. Primary hypothesis 3: High EE in carers will be positively associated with (a) illness appraisals, (b) 'avoidant coping' and (c) negative caregiving experiences

Results for the relationships found between high EE (FMSS), negative illness appraisals (BrIPQ), 'avoidant coping' (Brief COPE) are summarised in Table 18.

Table 18

Correlations between EE, 'avoidant coping', negative illness appraisals and burden

	Avoidant coping (Brief COPE)	**Negative illness appraisals (BrIPQ)**	**Negative caregiving experiences (ECI)**
EE	0.427*	0.728**	0.503*

**p* < .05, two-tailed, ** *p* < .01, two-tailed

Large positive relationships were found between EE and both negative illness appraisals (BrIPQ) and negative caregiving experiences (ECI). A medium positive relationship was found between EE ‘avoidant coping. Table 19 provides details of mean rank scores for each variable by EE category.

Table 19

Mean rank scores for dependent variables according to according to EE category

Variable	**EE category**	**Mean Rank**
Negative illness appraisals (BrIPQ)	Low EE	6.50
	High EE	16.23
‘Avoidant coping’ (Brief COPE)	Low EE	8.80
	High EE	14.46
Negative caregiving appraisals (ECI)	Low EE	8.20
	High EE	14.92

To understand the nature of the significant relationship observed between EE and negative caregiving experiences, further exploratory analyses were undertaken and found that high EE showed large positive correlations with appraisals of service users’ negative symptoms (rho = .617, $p < 0.01$), difficult behaviours (rho = .583, $p < 0.01$), and with need to provide [service] backup (rho = .511, $p < 0.01$). Carers with low EE tended to report significantly more good aspects in the caregiving relationship than those with high EE (rho = .465, $p < 0.01$), but positive personal experiences and overall positive caregiving ratings were not found to be related to low EE.

On ‘avoidant coping’ subscales, high EE showed a medium positive relationship with self-distraction (rho = .430, $p < 0.05$).

Regarding the subscales of the BrIPQ, higher EE was strongly related to more negative beliefs about consequences (i.e. the affect of the illness on the carers’ life; rho = .626, $p < 0.01$), and had medium relationships with perceptions of a longer illness timeline (rho = .424, $p < 0.05$), less treatment control (rho = -.443, $p < 0.05$) and the amount of symptoms experienced by the service user (rho = .421, $p < 0.05$).

3.9 Results of statistical analyses of secondary hypotheses

3.9.1. Secondary hypothesis 1: Carer distress will be positively associated with (a) 'avoidant coping', (b) negative illness appraisals and (c) negative caregiving experiences

Results are summarised in Table 20. Anxiety had a medium relationship with 'avoidant coping' and negative caregiving appraisals, and a strong relationship with negative illness appraisals. Depression had strong relationships with both negative caregiving appraisals and negative illness appraisals, but was not significantly related to 'avoidant coping'.

Table 20

Correlations between distress and 'avoidant coping', illness appraisals and negative caregiving

HADS	**Avoidant coping**	**Illness appraisals**	**Negative caregiving**
Anxiety	.480*	.631**	.436**
Depression	.341	.631**	.603**

**p* < .05, two-tailed. ** *p* < .01, two-tailed

In order the to look at specific relationships between distress and negative caregiving experiences, further analyses between the anxiety and depression and the negative caregiving subscales were carried out. A medium positive relationship was found between anxiety and needing to provide [service] back-up (rho = .421, $p < 0.05$). Medium positive associations were found between depression and effects on the family (rho = .433, $p < 0.05$), difficult behaviours (rho = .465, $p < 0.05$) and stigma (rho = .453, $p < 0.05$). Depression was strongly associated with needing to provide [service] back up (rho = .580, $p < 0.01$). Relationships between specific illness appraisals (BrIPQ) and anxiety and depression (HADS) are summarised in Table 21, below.

Table 21

Relationships between illness appraisals and anxiety and depression

Illness appraisal	**Anxiety**	**Depression**
Consequences	.572*	.521*
Timeline	.488*	.392
Personal control	-.374	-.582**
Treatment control	-.219	-.2.85
Identity (symptoms)	.291	.183
Concern	.533*	.371
Coherence	.120	.144
Emotional representation	.580**	.436*

*$p < .05$, two-tailed. ** $p < .01$, two-tailed

3.9.2. Secondary hypothesis 2: 'Avoidant coping' will be positively associated with negative caregiving experiences

A significant relationship was not found between 'avoidant coping' and the total score on negative caregiving scale of the ECI (rho = - 0.353, $p = 0.09$).

CHAPTER 4

4. Discussion

4.1 Overview of chapter

This chapter begins with a summary of the aims of the study. The findings regarding the demographics and experiences of carers of older adults with psychosis are first discussed in relation to the existing literature on carers of working age adults. Next, interpretations of the findings for each hypothesis are presented, followed by the proposed theoretical and clinical implications. A considered analysis of the limitations and strengths of the study are then offered before the chapter concludes with recommendations for future research.

4.2 Summary of study aims

The aim of the current study was to provide a descriptive analysis of carers of older adults with psychosis and to explore relationships between key factors in the experience of caregiving. Research into the experiences of carers has consistently identified a number of cognitive, behavioural and emotional interrelated factors that influence the caregiving environment and carer and patient outcomes, including EE (e.g. Bebbington & Kuipers, 1994; Wearden et al 2002; Scazufca & Kuipers, 1996; Raune et al, 2004), illness specific appraisals, (e.g. Lobban et al, 2006; Kuipers et al, 2007), avoidant coping (e.g Scazufca & Kuipers, 1999; Raune et al, 2004; Onwumere et al, 2011), and appraisals of caregiving (e.g. Szmukler et al, 1996). Research on caregiving in psychosis has begun to consider the role of attachment in formal caregiving relationships with a focus on service user outcomes and therapeutic alliance (e.g. Berry et al, 2008a; 2008b), but has not yet explicitly looked at the impact of attachment in informal carers on carer outcomes. Studies of carers of people with dementia however, have recently included attachment as a variable hypothesised to predict coping strategies and psychological morbidity (Cooper et al, 2008), with the emergent data suggesting that attachment may also be an important variable to consider in carer studies.

The current study focused specifically on carers of older people with psychosis, as to date there have been no studies that have attempted to extend our existing knowledge of carer experiences and characteristics to this population. Carer outcomes are important, not only because carers constitute a group 'in need' in their own right (Kuipers, 2010), but also because informal carers have a crucial role in supporting better outcomes in people with psychosis, both instrumentally (e.g. Czuchta & McCay, 2001; Tryssenaar et al, 2002) and via the quality of the caregiving relationship (e.g. Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998).

The study proposed that carers of older adults with psychosis would be demographically distinct from those caring for working age adults with psychosis, with potential to present with a characteristically different profile in terms of their caregiving experiences. In order to improve on the generalisability of existing research on carers, the study sought to examine the relationships between expressed emotion, illness appraisals, negative caregiving experiences, coping and distress based on the findings established in the literature and integrated in the recent cognitive model of caregiving (Kuipers et al, 2010), which has thus far only considered the experiences of carers of working age adults with psychosis. Carer attachment style was put forward as another variable in the caregiving environment that might influence coping, quality of the caregiving environment, and carers' distress.

4.3 Summary of findings

4.3.1. Demographics and characteristics of carers

Similar to studies of carers of working age adults, carers in the current sample tended to be female and in their 50s. As the majority of carers were children of those for whom they cared, daughters tended to make up the largest group of carers, followed by wives, sons and husbands. This differs from working age adult studies that tended to find that carers were parents, mostly mothers, caring for their adult children with psychosis (e.g. Raune et al, 2004; Kuipers et al, 2006; Onwumere et al, 2011). This difference may have implications for the nature of the caregiving relationship between carer and service user, which will be discussed in more detail in later sections.

Though the carers in the current study were slightly older (average age = 58 years) compared to Kuipers et al's (2006) carers of working age adults (average age = 52.9

years), the range of ages in the studies were notably similar (i.e. 23 to 87 years and 26 to 86 years, respectively). The range in age is likely to reflect the fact that the responsibility of caring can occur any time during the life course and also the diversity in the nature of caregiving relationships (e.g. offspring, spouse and sibling carers). It may be more common to see people in their 50s in a caregiving role, as they have the potential to be caring for young adult offspring as well older parents with psychosis. This portion of the population may become increasingly burdened along with aging population trends, which will see marked increases in the old age dependency ratio in the coming decades (Lee, 2011). It is also important to note that 43% of the sample was comprised of carers who themselves were older (65 years and over). Trends for an increasingly older profile of carers across caring contexts has been noted by the literature (Levine et al, 2010; Kakuma et al, 2011; Lee, 2011; Shahly et al, 2012). Older carers may be more vulnerable to certain aspects of burden, such as physical morbidity and financial strain (Vitaliano et al, 2003; Kusano et al, 2011), by virtue of their age and likely economic inactivity.

In terms of sample gender, a preponderance of female carers has been consistent across carer studies, including carers of those with psychosis (e.g Kuipers et al, 2006; Onwumere et al, 2011; Parabiaghi et al, 2007; Magliano et al, 2000; Szmukler et al, 1996) and dementia (Bledin et al, 1990; Cooper et al, 2008). The higher proportion of women in caring roles may be borne out by wider discourses and beliefs around the responsibilities of women in society. The Office of National Statistics (ONS, 2004) found that in a survey of division of household tasks, women were more likely to be viewed as responsible for caring tasks from the point of view of both male and female respondents.

In the current sample, service users with psychosis were older than those typically recorded in working age adult studies (e.g. 71.4 vs. 36 years; Kuipers et al, 2006) and also more likely to have longer illness durations (28 vs 11.2 years; Kuipers et al, 2006). Unlike working age adult carer studies, the current service users were more likely to be female (65.2% vs. 27.9%; Kuipers et al, 2006). The differences in gender (older adults vs. working age adults) could be explained by higher mortality rates in men (Barford et al, 2006), and the dissimilarity in illness profiles and incidence rates between women and men for psychosis. For example, Canuso and Pandina (2007) reported that women with psychosis tend to have better premorbid functioning, later age of onset, and a more favourable illness course, including a better response to antipsychotic medication. This may attenuate physical morbidity related to psychosis and its treatment compared to men, enhancing women's life-expectancy and by implication their increased numbers in clinical services and studies. Furthermore, better functioning and illness course in women with psychosis may lend itself to better psychosocial functioning in terms of interpersonal relationships, increasing the likelihood of access to a social support network that includes a carer. For example, wider and more satisfying social networks have been found in women relative to men (Antonucci & Akiyama, 1987). Later illness onset of psychosis both in young adulthood and middle to late ages (i.e. late onset psychosis and very late onset psychosis) will often mean that females are more likely to have raised a family of their own children who may subsequently act as carers.

The majority of carers in the current sample lived with the person for whom they cared (65%). The figures were in line with those reported by Parabiaghi et al (2007), who looked at burden in carers of working age adults in Italy. Onwumere et al (2011) reported 70% of carer-service user dyads as cohabiting. In the current study, over a third of carers were live-in partners, which suggests that the remaining 30% was largely made up of adult offspring living with a parent.

4.3.2. The experience of caregiving: descriptive and exploratory analyses of carers' scores on measures

4.3.2.1. Attachment

Most carers reported higher attachment security on the attachment measure (PAM-R, Berry et al, 2006). For attachment anxiety, 95.7% scored below the scale's midpoint of 1.5 (scale of 0 to 3). For attachment avoidance, 56.5% of carers scored below the midpoint on the scale, indicating that avoidant attachment was more common than anxious attachment in this sample. Using a different measure of attachment (The Attachment Questionnaire; Hazan & Shaver, 1987; 1990), Cooper et al (2008) also found that their sample of carers of people with Alzheimer's disease tended to be securely attached. We know that secure attachment is also more prevalent in the general population (Hazan & Shaver, 1987); the current study indicates that secure attachment in carers is comparable to that of non-carers.

Exploratory analyses of differences in attachment based on relationship type found that carers who were the adult offspring of the service users reported significantly more anxious attachment than other carer sub-groups (e.g. spouses, siblings and parents). An early study by Naslund et al (1984) examined attachment in the one-year old offspring of mothers with non-organic schizophrenia, compared to controls similar in demographics, and found a significantly higher rate of anxious attachment in the offspring of mothers with schizophrenia. Attachment security that is compromised through early parent-child interaction in the context of a parent's mental illness is likely to persist to adulthood (Bretherton, 1992). This could have implications for the well-being of offspring who subsequently come to care for their parents.

4.3.2.2. Coping styles

Coping via acceptance, actively tackling issues and planning were the most highly endorsed coping strategies by carers in this study. The least endorsed strategies were substance use, behavioural disengagement, and denial, which make up three out the four subscales of the 'avoidant' coping subscale. Research has consistently found that active and proactive strategies are linked to better outcomes in terms of carer burden and that 'avoidant coping' is particularly linked to poorer outcomes (Mackay & Pakenham, 2012; Scazufca & Kuipers, 1999; Magliano et al, 2000; Raune et al, 2004; Onwumere et al 2011). The results indicate that carers in this study may be utilising more adaptive coping strategies. Kartalova-O'Doherty and Doherty (2008) have found active (more adaptive) coping strategies are more prevalent in families of those with enduring mental illness. These results would make sense in the context of the average illness of service users in the current study (28 years). Over the years, carers may have identified the importance and the merits of not avoiding problems and leaving them to escalate. Indeed anecdotal feedback from several participants also suggested that carers have learned to respond in a timely fashion to any issues arising with their relatives' mental health.

Compared to Fortune et al's (2005) study on carers of working age adults, there were significant differences between two out of the four constructs that make up 'avoidant coping', where the current sample was less likely to engage in self-distraction and denial. The current sample was also less likely to use coping strategies characterised by self-blame. As most carers were adult offspring caring for a parent, differences in self-blame may reflect qualitative differences in appraisals based on relationship to the service user. For example, parent carers may be more likely to report issues of guilt and self blame around the relationship and their child's illness (Bentsen et al, 1998).

Studies have shown that carers' coping styles can change and become more adaptive over time, and positively influence burden outcomes (Parabiaghi et al, 2007; Magliano et al, 2000; Joyce et al, 2003). Conversely, a recent study by Onwumere et al (2011) found that service-users' illness duration was unrelated to changes in carer 'avoidant coping'. However, the current study is the first to look at the experiences of carers of older adults, and illness duration (mean = 28 years, SD = 18) was significantly longer in this study than those reported in other studies (e.g. mean = 7.03 years, SD = 9.29; Onwumere et al, 2011), which may have allowed for a longer period in which carers could adjust their ways of coping over time. Onwumere's et al (2011) also reported significantly greater use of 'avoidant coping' strategies.

4.3.2.3. Distress

Levels of distress in carers were raised above what would be expected based on normative data. Seventeen percent of the sample scored above cut-off for a probable clinical disorder of anxiety, compared to 12.6% noted in a study using the same measure (i.e. HADS) in a non-clinical sample (Crawford et al, 2001). Thirteen percent also scored above cut-off for depression. This differed markedly from Crawford et al's (2001) sample where only 3.6% of people scored above clinical cut-off, suggesting that the carers in this sample presented with a higher rate of mood disturbance than would be expected in the general population. The results are consistent with the wider literature undertaken with working age adults, which commonly reports elevated levels of psychological distress and mood disturbance (Kuipers et al, 2010; Lowenstein et al, 2010; Dyck et al, 1999).

Scores for anxiety and depression in the current sample were compared to findings reported by Fortune et al (2005) who also used the HADS with a sample of carers of working age adults with psychosis. The authors reported that 54% and 38% of their participants scored above cut-off for probable clinical disorder of anxiety and depression, respectively. The cross-sectional design of the study precluded an examination of the relationship between time and carer distress to investigate whether longer experiences of caregiving could be related to less distress. Previous findings, however, have not found significant improvement in distress over time. For example, Brown and Birtwistle (1998) reported no significant change in psychological distress in primary carers of people with schizophrenia over a 15-year period on distress items of the Social Behaviour Assessment Schedule (SBAS; Platt et al, 1980) and the GHQ (Goldberg & Hillier, 1979). Three-year follow-up data from Parabiaghi et al (2007) observed improvement in 39.2% carers' distress based on mean GHQ-12; however, 37.3% showed no improvement and 23.5% had worsened.

The differences in reported levels of distress in this sample compared to others could be attributed to several factors. In Fortune et al's study, carers were recruited through carer information and support groups, which may have meant that the sample was particularly distressed and seeking additional support. This contrasts with the current sample where all carers were recruited through service users' community and inpatient mental health services. In addition, Parabiaghi et al (2007) used a different measurement of distress (GHQ-12), which may pick up on different experiences (e.g. the GHQ-12 includes items on lost sleep over worry, feeling useful, capability in making decisions, strain, feeling unable to overcome difficulties, facing up to problems, confidence, and worthlessness, which are not included in the HADS). Though both are comparable in their ability to detect probable clinical disorders (Lewis & Wessely, 1990), they may tap into qualitatively different experiences of distress.

4.3.2.4. Caregiving experiences

Caregiving experiences as measured by the ECI were compared to Szmukler et al's (2006b) study of carers of working age adults using the reported pre-intervention scores of their sample. Caregiving experiences for carers in the current study were similar to those found by Szmukler et al (2006b) in the areas of difficult behaviours, dependency, negative symptoms, need for back-up, and stigma on the negative subscales, and both positive personal experiences and good aspects of the relationship in the positive caregiving subscales. Carers in the current sample, however, reported significantly fewer appraisals of loss, fewer effects on the family and fewer problems with services. It is possible that appraisals of loss may differ on account of the different carer-service user relationship profile in this study. In Szmukler et al's study, 53% of carers were parents, whereas in the current study the same proportion were adult children of the person for whom they cared. This could potentially affect appraisals of loss in terms of lost opportunities and hopes for the future due to the qualitative difference in role types. Furthermore, as previously discussed, feelings of responsibility for causing the illness may be accentuated in parent carers (Patterson et al, 2000).

Fewer negative appraisals of effects on the family may be a reflection of the fact that carers were less likely to have children under the age of 18 years (n =2), and therefore having a family member with psychosis would be less likely to impact on other dependants. Additionally, in families of service users with a longer duration of illness, carers may experience less perceived burden in terms of explaining the illness to other family members over time. These results also exist in contrast to the findings of Awad and Wallace (1999), who found that the most reported 'negative impacts' of caring for a working age relative with psychosis were related to disruptions of family life and the compromised well-being of other family members.

Carers' tendency to report fewer problems with services could indicate that those who have longer caring histories have learned to navigate services over time by way of experience, for example in relation to finding out how hospitals and services work, dealing with mental health professionals and psychiatrists, and knowing what services are available to them and the person whom they care. Additionally, with time they may also require less information about their relatives' illness.

Findings also showed that carers responses on the subscales for need to provide service back up, difficult behaviours and stigma correlated most highly with total negative caregiving scores, relative to other aspects of negative caregiving. The need to provide back up may demonstrate a disruption to carers' lives, where their input is required to bridge the gap between what formal services can provide and the needs of their relatives. Hence, it is important to continue to recognise informal carers as an ‘invisible healthcare’ system (Arno et al, 1999), but that it is a role that is not without its costs to the carer. These results extend these findings to carers of older people with psychosis, and support the need for the development and provision of services and supports that will allow carers of an older population with psychosis to continue caregiving whilst minimising the negative impact inherent to the role.

Difficult behaviours also correlated highly in terms of overall negative caregiving experiences and suggests that carers of older people with psychosis, similar to carers of working age adults (Addington et al, 2003; Jeppesen et al, 2005), continue to endure burden related to service users’ mood and unusual and unpredictable behaviours, which may be source of distress and worry (Roick et al, 2007).

The experience of stigma related to caring for someone with a mental illness has been reported consistently in the literature (Ostman & Kjellin, 2002; Angermeyer et al, 2003; Struening et al 2001; Czuchta & McKay, 2001; Rose, 1996) and can be particularly felt by some carer subgroups (e.g. BME groups; Knifton et al, 2010; Shefer et al, 2012). This may have implications for carers’ psychological well-being, their beliefs about their relative and their access to social support. In a study by Ostman & Kjellin (2002), carers reporting stigma found it difficult to be around others and felt that stigma negatively influenced their relationships with other people. They also felt that it significantly impacted on their own mental health, with some reporting suicidal ideation, and a number of carers reported feeling that their relative might be better off dead. The amount of symptoms experienced by service users has also been linked to distress and burden in other carer studies (Czuchta & McKay, 2001; Phillips et al, 2002; Addington et al, 2003; Mackay & Pakenham, 2012). Given the longer illness duration of service users, carers may have had many years experience of coping with the stigma of having a family member, particularly a parent with psychosis. This stigma may be particularly difficult for carers who have their own children. Negative appraisals of unusual and difficult behaviour have been linked to higher rates of carer distress (e.g. Roick et al, 2007), and may potentially lead to embarrassment or stigma as perceived by the carer. Stigma may hinder help-seeking behaviour by carers (Czuchta & McKay, 2001; Rose, 1996), effectively narrowing their options for informal and formal supports, which can often leave them at greater risk for distress and burden and potentially impact on the quality of the caregiving environment via high EE (Bebbington & Kuipers, 1994). Appraisals of stigma may make it more difficult for carers to approach formal supports, such as mental health services, and undermine carers' confidence in dealing with professionals and in seeking information about their relatives' illness and how mental health services operate. If carers perceive that they are not being heard or taken seriously by services this may further compound poor carer outcomes in terms of subjective burden. Given that 78.3% of carers in this study had been caring for a relative for ten years or longer, and 60.9% were caring for their relative for 25 years and longer, it is interesting to note the persistence of felt stigma in this sample. Stigma may be particularly significant in prolonged caregiving histories given its potential to exacerbate poorer carer outcomes, impact on beliefs about the patient, and obstruct access to informal and formal social supports. As a large proportion of the sample was older, it could also be an artefact of cohort beliefs around mental illness. For example, a study by Segal et al (2005) found that older people were more likely to perceive people with mental illness as embarrassing or as having poor social skills. The study also found that negative views of mental illness were related to less willingness to engage in psychological services. Further research in this area is required in order to build on our knowledge of how this might relate to older carers of people with psychosis.

Positive caregiving experiences were also reported by carers in the study, where positive personal experiences were more highly correlated to the total positive caregiving score, relative to good aspects of the relationship. Onwumere et al (2008) reported more positive caregiving appraisals in carers of service users with longer illness histories. Positive personal experiences can reflect aspects of psychosocial growth, including personal growth (e.g. learning more about oneself, discovering strengths in oneself and improved confidence), interpersonal growth (e.g. feeling closer to family and friends and becoming more understanding of others) and feeling that one has given back (e.g. contributing to others' understanding). The majority of research has focused on negative aspects of caregiving as they have been found to be a predictor of outcome in carers (Szmukler et al, 1996). Positive experiences have been less thoroughly examined, though from a qualitative perspective their importance is intuitive, as many relationships can be mutually rewarding, especially in the context of care and fondness of a close relative (Chen & Greenberg, 2004; Veltman et al, 2002). Chen and Greenberg (2004) reported on positive experiences of carers caring for relatives with psychosis, and found that informal and formal support were associated with perceived positive gains in the caregiving relationship. This possibly highlights the importance of facilitating access to social supports in this sample.

4.3.2.5. Expressed emotion

Over half of the sample was recorded as high EE (56.5%). These findings show that the prevalence of critical and over-involved relationships in caregiving relationships in the current sample was similar, and sometimes higher, than those reported in carers of working age adults [e.g. 28.6% (Lobban et al, 2006), 36% (Kuipers et al, 2006), 44% (Raune et al, 2004), and 60% (Patterson et al, 2005)]. A high rate of high EE in this sample is likely to have important implications for both patient (e.g. Bebbington & Kuipers, 1994) and carer outcomes (e.g. Scazufca & Kuipers; 1996 Wearden et al 2002; Raune et al, 2004). Mackay & Pakenham (2012) found carer adjustment was related to better quality relationships between carers and the person being cared for in a sample of carers of adults with mental illness. The prevalence of high EE may be an important target for psychological interventions in this population, such as family interventions for psychosis (NICE Schizophrenia Guideline; 2009 Update; The Schizophrenia Patient Outcomes Research Team: Updated Treatment Recommendations, 2009), given the link between high EE and poor patient and carer outcomes (e.g. Bebbington & Kuipers, 1994; Scazufca & Kuipers, 1999).

4.3.2.6. Illness specific appraisals

The most highly endorsed negative illness beliefs by carers in the sample were timeline of service users' difficulties and their concern about their relatives' difficulties. Carers rated treatment control highly (i.e. beliefs around how much treatment helped their relatives' problems/illness).

Relative to other illness belief dimensions, carers' low rating of personal control indicates that they were less likely to see the service user as having control over their problems/illness. Attributions around personal control have been highlighted as an important predictor of high EE (Hooley, 1985; Hooley, 1987; Barrowclough & Hooley, 2003). Lobban et al's (2005) study (using the IPQS-R; Lobban et al, 2005) of carers of working age adults with psychosis also found that their sample tended to appraise their relatives' illness as chronic and cyclical, but were more likely to rate it as amenable to cure/control. For carers of older adults with psychosis, beliefs in a more chronic timeline (how long they believe service users' illness will continue) may reflect a more realistic observation of the difficulties faced by their relative who have endured a prolonged illness course.

The top causal beliefs reported by carers were stress (21.7%), genetics or heredity (13%), and childhood difficulties or abuse (11.6%). This is in keeping with the well-established and widely accepted stress-vulnerability model of psychosis (Zubin & Spring, 1977). Carers of working age adults in the Lobban et al (2005) study also endorsed similar illness beliefs including, 'stress and worry', 'chemical imbalance in the brain', 'thinking about things too much', and 'trauma'. Similarly, Brewin et al (1991) reported a range of causal beliefs of carers of people with psychosis, which are similar to those reported in the current study and included "stress, genetic influences, losses and separations, taking recreational drugs, unemployment, insensitive behaviour by other people, misinterpretations of a situation, failure to take medication, conscious and subconscious attitudes, bad company, rebelliousness, the menstrual cycle, childishness, attention seeking, current stress, aspects of personality, and the relative's own behaviour towards the patient". Previous researchers have emphasised the need for a quantitative analysis of causal attributions using a dimensional framework that would allow them to be compared with other variables (Lobban et al, 2005). At present, the extent of their value in this research and others is descriptive.

4.3.2.7. Time budget

The scores from the Time Budget Measure (TBM; Jolley et al, 2005) suggested that carers were generally busy each day and were satisfied with their level of activity and daily routines. However, over a third of carers (34.8%) reported their satisfaction as being below 3, indicating that most carers were satisfied with their daily routine.

4.3.2.8. Social support

All carers, apart from one person, reported having at least one source of social support across a range of six contexts, where the average number of supports was 2.19 and carers were mainly satisfied with their support network (4.5 on a scale of 1 to 6). All carers, except one, reported that they had someone they could confide in.

Further exploratory analyses of this measure confirmed that the number of and satisfaction with supports showed medium and strong positive relationships with coping styles characterised by active coping and seeking emotional support, respectively. These findings are consistent with existing studies, which found that access to a social support network or a reliable confidante may help to encourage more effective coping (Joyce et al, 2003; Magliano et al, 2003).

Avoidant attachment was strongly and inversely related to the number of supports reported by carers. This relationship has also been reported in the attachment literature, where less securely attached individuals reported lower levels of social support (Davis et al, 1998). Mikulincer and Florian (1995) have suggested that social networks of avoidantly attached individuals may be more affected because of their tendency to use emotional-distancing strategies, making them less likely to seek out support (Collins & Feeney, 2000). These results are likely to have implications for carers' willingness to access more formal support networks; for example, offering support via carer support groups and psychological support services. Mackay and Pakenham (2012) found that better carer adjustment was related to greater levels of social support in carers of people with mental illness.

4.3.1.9. Service user functioning

The findings indicated that nearly half of service users required support with ambulation, with 43.5% using a walker or a cane, and 4.3% using a wheelchair. Carers reported more service user disability in activities of daily living than physical self-maintenance.

Greater disability in activities of daily living and physical self-maintenance showed medium and large positive relationships with more negative illness beliefs regarding the extent to which the illness/problem affects the carer (consequences), and the amount of concern reported by the carer. Greater disability was inversely related to beliefs about treatment control. It could be argued that greater disability may erode carers' expectations for treatment.

Though these findings remain exploratory, it is possible that measures that account for additional aspects of service user disability may be indicated in studies of older people with psychosis and their carers, as disability in older service users may serve as an additional an concern for carers of older people with psychosis and impact on illness appraisals.

4.4 Hypotheses and interpretation of findings

4.4.1. Primary Hypthotheses: Attachment

4.4.1.1. Attachment and coping

The current study proposed attachment as an additional variable that might influence the caregiving environment. The primary hypothesis predicted that carers who were higher on avoidant attachment would report greater use of 'avoidant coping' strategies. A relationship was not found between these variables. As reported in the previous chapter, the analysis for this hypothesis was underpowered to detect the medium relationship found in a previous study of carers of people with dementia (i.e. Cooper et al, 2008). However, the correlation found in the current study was particularly small (Spearman's rho = .19), suggesting that a meaningful relationship between 'avoidant coping' and avoidant attachment was unlikely to be found in this study regardless of sample size.

As measurement of attachment and less adaptive 'dysfunctional coping' varied between the studies, it warrants further discussion. Cooper et al (2008) also employed the Brief COPE (Carver, 1997) to measure coping; however, the construction of their 'dysfunctional coping' scale diverged from the 'avoidant coping' scale used in the current study, which was selected for comparability with other psychosis studies (e.g. Raune et al, 2004; Onwumere et al, 2011). Cooper et al's scale employed six subscales (self blame, venting, behavioural disengagement, denial, self distraction and substance use), whereas the current study employed four subscales (behavioural disengagement, denial, self distraction and substance use). A retrospective analysis including the additional scales of self-blame and venting, however, found that no relationships were evident between these variables and avoidant attachment, suggesting that measurement of 'avoidant coping' did not account for the difference in findings.

Cooper et al (2008) employed the Attachment Questionnaire (AQ; Hazan & Shaver, 1987; 1990), whereas the current study used Berry et al's (2006) PAM-R. The PAM-R was selected for the current study because of its sound psychometric properties and to allow for comparisons between the developing attachment evidence-base in psychosis (e.g. Berry et al, 2007, 2008a, 2008b, 2009; Blackburn et al, 2010, Berry & Drake, 2010). Though the measures are different, they measure the same constructs (attachment security, avoidance, and anxiety) on a continuum. The PAM-R and the AQ have not been directly compared, but Berry et al (2008) reported satisfactory concurrent validity of the PAM with the Relationship Questionnaire (RQ; Bartholomew & Horowitz, 1991; anxiety and model of self: $r = -.59$, $p < .001$; avoidance and model of other: $r = -.54$; $p < .001$), and an analysis by Brennan, Shaver and Tobey (1991) found that classifications obtained from the AQ (Hazan & Shaver, 1987; 1990) and the RQ (Bartholomew & Horowitz, 1991) were significantly related. Consequently, it is unlikely that the use of different measures of attachment between studies would account for the opposing findings.

As the analysis for this hypothesis was underpowered, it is not possible to draw conclusions from the findings. However, the small size of the correlation suggests a likely difference in findings between this study and Cooper et al (2008); thus, the relationship between avoidant attachment and 'avoidant coping' requires further investigation to inform the evidence base.

4.4.1.2. Carer attachment and distress

The study also sought to examine the relationship between attachment style and distress. The hypothesis predicted that carers who were more insecurely attached (i.e. higher on avoidant and/or anxious attachment) would report higher rates of psychological distress. Findings confirmed a relationship between distress and avoidant attachment, but not between distress and anxious attachment. Results indicated that avoidant attachment had a strong and medium relationship with anxiety and depression, respectively. Cooper et al (2008) reported the same pattern of results in their sample of carers of people with Alzheimer's disease. The results are also supported by a strong evidence-base, which has consistently found relationships between psychological well-being and attachment both in the general population (e.g. Hazan & Shaver, 1990; Kobak et al, 1991; Carnelly et al, 1994) and in those caring for a relative with dementia (e.g. Crispi et al, 1997; Carpenter, 2001). However, some studies have found poorer well-being to have a stronger association with anxious attachment styles compared to avoidant attachment styles (Mikulincer & Florian, 2001; Kafetsios & Sideridis, 2006; Magai & Passman, 1997), which was not found in this study or by Cooper et al (2008). The literature has suggested that this difference is likely to be mediated by avoidant coping (Birnbaum et al, 1997; Ketler et al, 1994); however, this is unlikely to be the case in the current study, which did not find a relationship between 'avoidant coping' and attachment.

Theoretically, attachment insecurity is a stable construct shaped throughout the early years of development, thus it likely pre-dates caregiving roles, but it may present as a risk factor for poorer carer outcomes in terms of psychological morbidity. In the current study the majority of carers were daughters caring for parents, mostly mothers, and this may have particular relevance for the role of attachment in the caregiving environment. A subset of these carers are almost certainly likely to have grown up with a parent with psychosis, which may have influenced their attachment style through fluctuations in continuity of care in terms of physical and emotional availability of the parent, due to symptoms of the illness, hospitalisations and cyclical illness trajectories (Naslund et al, 1984). For these carers, attachment and their experience of caregiving are likely to be closely intertwined, and some of these carers may have assumed the caring role in childhood or adolescence. Most young carers care for mothers in lone-parent families (Dearden & Becker, 2004). In such situations the child would lack another care-figure, which could moderate attachment anxiety. Being a young carer for a parent can negatively impact on psychosocial functioning. Dearden and Becker (2004) reported statistics of young carers in the UK (across a range of caring contexts, including mental illness) and found that a significant proportion had missed school or were experiencing educational difficulties. Poor school attendance and performance may also obstruct other informal sources of support (e.g. peer relationships) and narrow future opportunities in terms of education and employment. Thus, long-term offspring carers may be particularly vulnerable to distress as a result of insecure attachment and possible disruptions in their psychosocial development.

4.4.1.3. Attachment and expressed emotion

The relationship between carer attachment and the quality of carer-service user interactions (EE) in caring for older people with psychosis was also examined. Previous studies have not looked directly at the relationship between attachment and EE in carers. However, Patterson et al (2000) have suggested that criticism and coercive behaviour may function as a strategy for coping with feelings of loss by way of activation of the attachment system, and that such responses from carers may become more pervasive and result in greater hostility and a weakened bond between the relative and the carer over time. High levels of grief have been linked to ‘shutting down’ or ‘sealing over’ coping styles in carers of people with psychosis (Patterson et al, 2000), and ‘sealing over’ recovery style has been linked to insecure attachment style in people with psychosis (Tait et al, 2004).

The hypothesis for the current study predicted that carers who were more insecurely attached (i.e. higher on avoidant and/or anxious attachment) would have higher rates of EE. A relationship between the two variables was not found in the current sample, and the correlations were particularly small.

It is possible that the relationship between attachment and EE may have been affected by fewer appraisals of loss in the sample, which have been hypothesised to trigger attachment-seeking behaviours (Patterson et al, 2000), particularly in the context of a securely attachment sample. Feelings of grief and loss have been commonly reported in carers of working age people with psychosis (e.g. Barrowclough & Parle, 1997; Davis & Schultz, 1998; Patterson et al, 2000).

4.4.2. Primary Hypotheses: Expressed emotion

4.4.2.1. EE and illness appraisals

Findings in the current study supported the relationship between higher EE and more negative illness beliefs in carers of older people with psychosis. More specifically, subsequent exploratory analyses identified that more negative beliefs regarding consequences (affect on the carer's life), the chronicity of the illness, and the amount and severity of symptoms experienced by the service user were significantly related to higher EE in carers, with consequences for carers showing the strongest relationship. Additionally, those who reported higher rates of EE appraised treatment as having less control over service users' problems and illness.

In cases where treatment is perceived to be less successful in controlling unwanted symptoms in the service users, it is possible that carers may feel that they have less personal control over the illness in terms of their role in supporting treatment adherence. Barrowclough et al (2001) found that high EE was related to carer perceptions of having less control over the illness, and similar to the present study the authors reported that more chronic views of illness timeline and negative appraisal of symptoms were also related to higher EE in carers. More negative perceptions of consequences for carers' own lives may represent another way of tapping into beliefs about the subjective burden of care, where previous studies have linked high EE with negative caregiving appraisals (Scazufca & Kuipers, 1996; Wearden et al, 2002).

These findings suggest that similar to carers of working age adults (Barrowclough et al, 2001; Barrowclough & Hooley, 2003), there is a relationship between high EE and more negative illness beliefs in carers of older people with psychosis. Thus, family interventions which target a reappraisal of illness beliefs, as part of a NICE-recommended family interventions for psychosis, may also be effective with this population of carers.

4.4.2.2. EE and coping

The current study also explored the relationship between EE and coping. The hypothesis predicted that high EE in carers would be positively associated with ‘avoidant coping’. Findings indicated that a medium positive relationship existed between the two variables in this sample. These results support existing studies that have also found a strong relationship between ‘avoidant coping’ and EE at both first-episode and later on in the illness course (Scazufca & Kuipers, 1999; Raune et al, 2004).

‘Avoidant coping’ is reported to be the outcome of the appraisal of internal and external coping resources, where if assessed as lacking may undermine self-efficacy in coping, leading to a conclusion that coping efforts will be unsuccessful (Lazarus & Folkman, 1984). Barrowclough and Parle (1997) suggested that maladaptive appraisals may contribute to high EE in carers. Thus, cognitive factors will play an important role in how coping appraisals are made, influencing the selection of less helpful coping strategies, and subsequently impacting on the quality of interactions between a carer and their relative (Raune et al, 2004). In a study by Kuipers et al (2006), carers who were higher in criticism on the CFI (Vaughn & Leff, 1976) reported more avoidant coping strategies, and higher carer criticism was associated with greater distress in service users.

Findings for this analysis suggest that the predicted influence of ‘avoidant coping’ on the quality of caregiving relationships is likely to be generalisable for carers of older people with psychosis. It is possible that targeting coping strategies and supporting carers to adopt more adaptive ways of coping may improve the caregiving relationship and carer distress (Kuipers et al, 2006). This is a key feature in family interventions for psychosis, which already holds strong evidence base with carers of working age adults with psychosis (Pharaoah et al, 2010)

4.4.2.3. EE and negative caregiving appraisals

Negative caregiving experiences were also predicted to have a relationship with EE, where the hypothesis stated that high EE in carers would be positively associated with negative caregiving experiences. The current findings supported the hypothesis, where a strong positive correlation was found between the two variables. The results of this analysis offer support to other studies that have found a link between EE and subjective burden in both the psychosis (Scazufca & Kuipers, 1996; Wearden et al, 2002; Raune et al, 2004) and dementia carer literature (e.g. Bledin et al, 1990), and offers early indications that the relationship is generalisable to carers of older adults with psychosis. Similar to interventions targeting 'avoidant coping and negative illness appraisals, negative caregiving appraisals are likely to be amenable to cognitive reappraisal within the context of family interventions (Kuipers et al, 2006).

4.4.3. Secondary Hypotheses

4.4.3.1. Distress: 'avoidant coping', negative illness appraisals and negative caregiving experiences

Subsidiary analyses looked at the relationship between distress, coping, negative illness appraisals, and negative caregiving appraisals

As expected, poor carer affect was strongly related to negative caregiving appraisals. This link offers further support to previous studies that have found the same relationship in early psychosis groups (Addington et al, 2003; Martens & Addington, 2001), longer term (e.g. Szmukler et al, 1996), and a combination of the two (Onwumere et al, 2008), and suggests findings may extend to those who care for older people with psychosis.

Overall negative illness appraisal in terms of timeline, consequences (for carers), concern (of carers), emotional representation (of carers), personal control (of service users), treatment control, illness coherence (of carers), and identity (service users' symptoms), was strongly correlated with distress. Specifically, carer reports of anxiety and depression were related to pessimistic dimensions of consequences and emotional representation, whereas beliefs about a longer timeline and greater concern were only related to carers' anxiety. Kuipers et al (2007) also found that beliefs around persistence of illness and control were related to low mood in carers. Similarly, Onwumere et al (2008) in their carer sample, found appraisal of a more chronic timeline was associated with greater distress and burden, and more negative appraisal of consequences for themselves as carers.

Though carer distress, negative illness appraisal and negative caregiving experiences have all been shown to be related, Onwumere et al (2008) found that negative illness appraisal did not account for the strong relationship between distress and negative caregiving appraisals in their study. In Mackay & Pakenham's (2012) model of adjustment and caregiving, appraisals of caregiving and threat are hypothesised to predict better or worse adjustment in carers. Their study found some evidence for these relationships, but did not look at specific caregiving demands. The findings of this study offer support to this model by considering the specific illness and caregiving appraisals relevant to those caring for older people with psychosis. As illness appraisals show a direct relationship to distress and negative caregiving experiences, they could be an important objective for clinical interventions targeting carer outcomes.

As predicted, the study also found a relationship between 'avoidant coping' and distress, where it was related to anxiety but not depression. Relationships between 'avoidant coping' and distress have consistently been reported in the literature (e.g. Scazufca & Kuipers, 1999; Raune et al, 2004; Onwumere et al, 2011). This finding is in line with recent research carried out by Mackay and Pakenham (2012) who found that 'avoidant coping' was a strong predictor in their model of adjustment in those caring for relatives with mental illness, where other ways of coping where insignificant in predicting outcome.

4.4.3.2. 'Avoidant coping' and negative caregiving experiences

The hypothesis that 'avoidant coping' would be positively associated with negative caregiving experiences was not supported by the findings. Due to the small sample size, the power of the analysis may have undermined the ability to detect a significant relationship between the variables.

4.4.5. Summary

The present study aimed to provide a detailed profile of carers of older adults with psychosis, both in terms of their demographics and their experience of caregiving. In the context of recent cognitive models of caregiving and theoretical frameworks for attachment it also sought to examine relationships between a number of salient factors relevant to the caregiving environment and carer outcomes, which have been well-established in the literature on carers of working age adults with psychosis, but until now have remained unexplored in carers of older adults with psychosis.

Descriptive and comparative analyses have shown that this sample of carers was similar to samples of carers of working age adults in that carers tended to be women, in their 50s, and residing with their relative. Dissimilarities included relationship to service user (adult child offspring carers vs. parent carers) and gender of the service user (mostly female vs. mostly male). Service users also presented with additional physical disability and many required supports with mobility (e.g. walkers and wheelchairs). Compared to carers of working age adults, carers in this sample tended to report less distress, fewer loss appraisals, fewer effects on the family, and fewer problems with services, and to appraise timeline of the illness as more chronic.

Relationships between attachment and 'avoidant coping' and EE were not found in this sample; however, the relationship between avoidant carer attachment style and distress was significant. As predicted based on the literature on carers of working age adults, the relationships between high EE, negative illness appraisals, negative caregiving experiences and 'avoidant coping' were found. Relationships between distress and 'avoidant coping', negative illness appraisals and negative caregiving experiences were also found. However, a significant relationship between 'avoidant coping' and negative caregiving appraisals was not found, but due to the small sample size the analysis may have been too underpowered to detect an association between these variables. The majority of the findings offer support to Kuipers et al's (2010) cognitive model of caregiving in psychosis and Mackay and Pakenham's (2012) model of stress and coping in adjustment to caring for an adult with mental illness.

4.5 Theoretical implications

The inter-relationships between carer distress, negative caregiving experiences, EE, illness specific beliefs and coping identified in the current sample were consistent with the literature and supported current models of caregiving in psychosis and of adjustment in carers of people with mental illness (e.g. Kuipers et al, 2010; Mackay & Pakenham, 2012). The current study extends these well-established findings to carers of older adults with psychosis, whose experiences hitherto have been largely neglected by carer research studies. Notwithstanding the sample size, it seems clear that caregiving relationships in psychosis, across different sub-groups (e.g. carers of older adults with psychosis, recent onset psychosis, parent carers, offspring carers) share many common features with respect to the relationships observed between key features such as carer distress and burden, illness beliefs, coping styles and the quality of the caregiving relationship.

4.5.1. Cognitive model of caregiving

The cross-sectional nature of this study did not allow for a causal analysis of the relationship between the variables; however, a number of findings offer some support for Kuipers et al's (2010) cognitive model for caregiving in psychosis as applied to the older adult caregiver group (Figure 2). Firstly, more negative illness appraisals were related to greater distress in carers. Distress, was in turn related to fewer supports and more reported problems with services. Higher EE (i.e. carer criticism towards the service user) was related to negative illness appraisals and other cognitive factors (i.e. negative appraisal of caregiving).

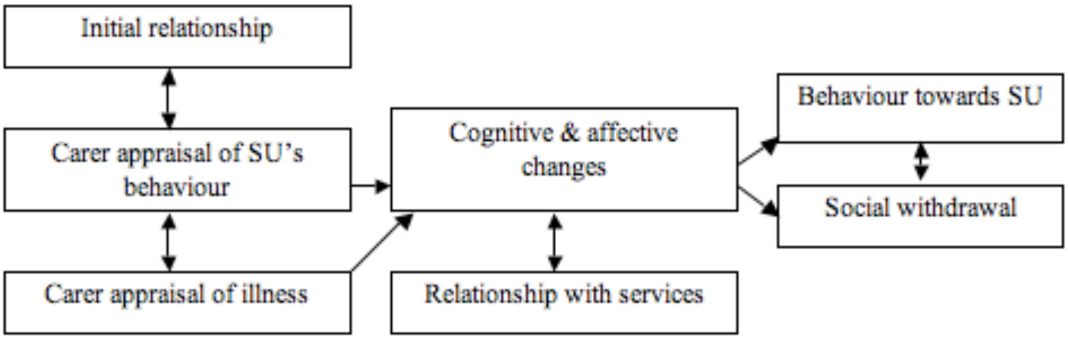


Figure 2. Cognitive model of carer responses in psychosis (Kuipers et al, 2010)

4.5.2. Attachment and carer outcomes

The relevance of attachment to 'avoidant coping' and high expressed emotion was not borne out by the findings of this study, though the limitations of the sample size and analysis strategy may have impacted on this. Exploratory analyses identified possible relationships between avoidant attachment and other ways of coping (e.g. emotional support), which could represent other fruitful avenues for future investigation. Avoidant attachment did have a positive relationship with carer distress; thus, with further research, attachment could be an important variable to consider in the caregiving environment in psychosis. This may be even more relevant when carers are offspring carers of service users' with long mental health histories extending into the carer's childhood. This study offers additional information on the variety of relationships that exist between carers and services users, as it includes more adult offspring carers than reported in any other study of carers of people with psychosis. This together, with further research on attachment, may help to enhance the typology of relationships suggested by Kuipers et al (2010).

4.5.3. Adjustment to caregiving

Building on the work of Lazarus and Folkman (1984) and the available evidence on mental health carers, Mackay and Pakenham (2012) have developed a specific framework from which to understand adjustment outcomes in terms of the caring role. Analysis of the utility of the model highlighted the role of 'avoidant coping' as a significant coping predictor in carer outcomes, where all other coping strategies were insignificant. The model gives prominence to the roles of carers' appraisals, coping strategies and coping resources as processes that determine adjustment outcomes in carers (i.e. finding benefit, health, distress, life satisfaction and positive affect). The findings of this study offer support to the model, whereby 'avoidant coping', illness appraisals and caregiving appraisals were related to carer distress. Exploratory analyses of relationships with social support offer additional support to the role of coping resources in carer adjustment, where number of supports was related to lower depression. Furthermore, poor relationship quality, as measured by higher EE, was related to poorer outcomes in carers as measured by negative caregiving experiences.

4.6 Clinical implications

This study found that carers reported high levels of burden similar to those found in carers of working age adults with psychosis, in addition to presenting with raised levels of distress relative to the general population. Over half of carers were categorised as high EE. These findings suggest that interventions aimed at improving carer outcomes and moderating critical and/intrusive responses towards the person for whom they care are indicated in carers of older people with psychosis (e.g. family interventions for psychosis; NICE schizophrenia guidelines, Update 2009). Carer avoidant attachment was related to distress, and exploratory findings suggest there may be a relationship between attachment and certain types of coping (e.g. emotional support) and access to social support.

Older adults with psychosis comprise a mix of psychosis 'graduates', both in the context of affective and non-affective disorders, as well as those presenting with late and very late-onset psychosis. People who care for these groups are most likely to be their adult offspring, with spouses representing the next largest proportion of carers. Clinical services and interventions supporting this population need to be aware of the specific psychological and physical health needs relevant to this specific demographic of carer.

4.6.1. Psychological and physical morbidity in carers

As with other psychosis carer groups, carers of older adults with psychosis were reporting high levels of distress, which underscores the importance of ensuring that mental health services are aware of and responsive to the impact of the caregiving role in this group. We know that carers of people with psychosis can also report high levels of physical health problems (Perlick et al, 2005), but may not be any more likely to visit their GP (McCrone et al, 2005). It is possible that greater attention may need to be given to how we can identify carers in need. Whilst we have a policy of carer assessments, the rate of completion across services and NHS Trusts can vary enormously. Providing greater support and incentives to primary care physicians to identify and respond to psychological distress in carers could be indicated. These types of incentives have already been used with GPs to monitor blood pressure in GP attendees with a view to improving hypertension outcomes. Mackay and Pakenham

(2012) suggest that certain background factors, such as the nature of the cared for service users' symptoms, the requirement for daily caregiving and the level objective burden, are likely to predict adjustment outcomes in carers; thus, screening for these risk factors at a primary care level may help GPs to identify carers at risk for distress and poorer outcomes.

4.6.2. Appraisals of caregiving and illness beliefs

As relationships between variables in the current sample were consistent with those found in carers of working age adults, interventions which target less adaptive coping, high EE and negative illness appraisals are also likely to be effective for carers of older adults with psychosis, such as NICE recommended family interventions for psychosis (Schizophrenia guidelines, Update 2009). Findings from this study suggest that carers of older adults with psychosis may be more likely to appraise their relatives' illness as chronic rather than short-term. These appraisals may be realistic in the context of the trajectory of their relatives' illness. Taking time to explore the impact and meaning of these beliefs with the carer may be indicated in this group of carers in order to formulate whether high endorsement on this dimension reflects feelings of hopelessness, or possibly acceptance of an immovable fact.

Need to provide service back up, difficult behaviours and stigma were the most highly endorsed sources of burden for carers in this study. The need for carers to provide service back up highlights the importance of carers in bridging the gap in care left by mental health services. As the burden of care may compromise carers' own mental and physical well-being it is essential that clinical services see carers as a population in need in their own right (Kuipers, 2010). Similar to working age adults, carers of older people continue to view service users' difficult behaviour as a particularly negative aspect of their caregiving role, and a felt sense of stigma persists despite longer caregiving histories. Families of older people with psychosis may benefit from interventions that target these areas of concern as part of individual, group and family interventions, which have some proven efficacy (Pharoah et al, 2010). Carers may also find it helpful to meet with other carers in similar circumstances to obtain support and validation, as well as to exchange ideas about adaptive ways of coping. Yalom and Leszcz (2005) highlight the importance of shared experiences and the recognition of the 'universality' of suffering among members of a group, which work to alleviate feelings of isolation and raise self-esteem, in addition to challenging perceptions of stigma.

4.6.3. Social support

Given the difficulties of social isolation amongst carers of people with psychosis (Magliano et al, 2002), improving supportive networks remains an important component of carer and family interventions (Kuipers et al, 2010; Kuipers et al 2002), and is further supported by the current findings. Carer support groups offer a forum for psycho-education and more informal supportive discussions between carers, which may facilitate more adaptive ways of coping, as mentioned above. However, finding time to attend support meetings may be a challenge for those with higher levels of burden, whose need for support may be even more outstanding. Observations made in the recruitment phase of this study, where many carers struggled to schedule in time for participation, suggest that carers' time tends to be limited and inflexible due to the combination of their caring role and additional responsibilities. Most carers were unable to travel for participation and requested to be seen at home. Thirteen percent of carers reported additional caring duties for either minors or other dependent relatives. Carers' busy schedules and lack of respite resources may consequently impede access to this type of support. Evidence from the work of Szmukler et al (2003) provides another account of the difficulties of trying to engage carers in group support and education interventions. Hence, the usefulness of other avenues of support, such as online support, forums and/or information resources, requires further exploration. Carers in the current study were provided with information on www.mentalhealthcare.org.uk, an online information and support resource run by clinicians and researchers at the Institute of Psychiatry and South London and the Maudsley NHS Foundation Trust, and supported by Rethink Mental Illness. However, the numbers of carers with online access and the confidence to navigate the information resources is unclear. Many carers may face barriers to accessing the internet, such as geographic and financial restrictions, as well as not having the required knowledge. Physical disability, language and personal preferences may also get in the way (Princess Royal Trust for Carers, 2011; *How can the web support carers?*). Consequently, 'offline' supports should also be made available to those who do not have access to the internet, and training and resources made available where these are the main barriers.

4.6.4. Attachment and clinical interventions

This study's findings also suggest that clinicians should be mindful of how carers' longstanding patterns of relating to others may impact on their relationships with support networks and services (Berry et al, 2008a; Blackburn et al, 2010). Attachment theories offer an additional pathway to understanding the interface between carers' appraisals and mental health services, extending the work of Kuipers et al (2010) who emphasised the role of carers' beliefs about the illness and the service user. Attachment is distinct in that it specifically captures interpersonal appraisals, which have implications for support-seeking and carer well-being. For example, with reference to the cognitive model of caregiving (Kuipers et al, 2010), affective changes (e.g. anxiety and depression) may influence carers' appraisals of coping resources (Lazarus & Folkman, 1984), and may particularly impact on engagement in interpersonal support (e.g. lead to social withdrawal or poorer engagement with mental health services). Carers' with avoidant attachment styles may be more difficult to engage in interventions (Lopez et al, 1998) and may be more likely to drop out of therapy (Tasca et al, 2006).

Understanding attachment could also enhance cognitive-behavioural interventions with carers. Bowlby's (1973) *internal working model* (IWM) can be viewed as analogous to Beck's (1987) cognitive schema. According to Obegi and Berant (2009), "both constructs describe mental representations or cognitive structures, the content of which includes beliefs, attitudes, and memories. Both also describe models of oneself, others, and the world and IWMs guide individual's perceptions, emotions, thoughts and expectations in later relationships" (p. 436). Attachment-informed clinical interventions provide therapists with a framework of the cognitive representations that may be negatively influencing carers' cognitions and behaviours in interpersonal relationships. Assessment and formulation of core beliefs characterised by rejection or abandonment in relation to 'others' may be most salient to those with insecure attachment. CBT may be particularly amenable to those with avoidant attachment, as one study found that people with avoidant attachment did better in CBT for depression than IPT, with authors suggesting that IPT may have been too threatening due to its focus on communication and relationships (McBride et al, 2006). Flexibility of service level interventions is essential for engaging clients and meeting their therapeutic needs by allowing for the range of difference that exists across carers' interpersonal style, where more difficult to engage clients may also be more likely to present with elevated levels of distress.

4.6.5. Caring for older people

Carers of older adults with psychosis may be contending with additional burdens due to the age-related physical disability in those for whom they care, where service users may present with an increased level of physical and emotional dependence on carers. Assessment and formulation with those who care for older people with psychosis should also take into account the increased likelihood of co-morbid physical illness and disability in this population.

4.6.6. Kinship

This study provides a cross-sectional profile of a wider variety of caregiving relationships than has been documented in the literature to date. The clinical implications of these findings suggest that a wider typology of caregiving relationships needs to be considered than those that are currently available in the evidence base. An idiosyncratic formulation of caregiving appraisals and adjustment to the role according to kinship should be taken into account.

4.6.6.1. Adult offspring carers

Adult offspring carers made up the majority of carers in this study, which is characteristically different from the profile of carers of working age adults, who are usually parents. The average age of offspring carers was 43.6 years, which was notably lower than the mean age for the entire sample (58 years). These offspring carers may be part of the growing trend described by Lee (2011), who remarked on an increasing ratio of older adult dependents on middle-aged carers, which is set to rise dramatically in the coming decades. This portion of the population may be at particular risk of burden given the likelihood that they are more likely to also have younger dependents to consider, as well as being more likely to be in employment. Thus, it is imperative that services for carers of older people with psychosis recognise the needs of this particular group, and develop services accordingly, whilst also taking into account the cumulative burden that may be felt by carers looking after an older parent with psychosis who may also have additional needs by virtue of declining ability and/or health.

Importantly, the relationship between offspring carers and their parents with psychosis is likely to be qualitatively different from other caregiving relationships (e.g. parent, sibling, spouse). Offspring carers in this study included both those caring for parents with a long history of psychosis (psychosis 'graduates'), as well as parents with late-onset psychoses. Offspring carers may express different feelings around taking on the carer role compared to parent carers, as the expectation of care is not necessarily inherent in the child to parent relationship, particularly when the carer role is assumed in childhood or early adulthood, a time when the impact on their own development and opportunities may be more keenly felt. Offspring carers may also present with different appraisals of caregiving compared to other types of carers. For example, they may be less likely to endorse feelings of self-blame and have fewer appraisals of loss relative to a parent whose child has developed psychosis. These findings were borne out in the analyses for the wider sample, but more specific analyses according to kinship using a larger sample is warranted.

Within the offspring carer population, caregiving experiences may also differ according to whether the parent has a history of psychosis that extends into the carers' childhood or if the child assumed the carer role later in life as an adult offspring carer (e.g. in the event of a late- or very late-onset psychosis). Differences in the timing of the assumption of the caregiving role are relevant to the impact of caregiving and should be explored within a thorough carer assessment. Temporal factors such as the point at which the role was assumed may provide important information to the clinician as to what aspects of life may have been interrupted for the offspring carer, including developmental transitions and missed opportunities for friendships/relationships, schooling and further education. These factors may influence current experiences of caregiving, appraisal of the caregiving role and levels of distress. The duration of the caregiving role may also be an important variable to consider in terms of burden.

The finding that offspring carers reported significantly higher levels of anxious attachment suggests additional vulnerability in this population in terms of its possible impact on carers' selection of coping strategies and emotional regulation, where anxiously attached individuals may be less likely to select adaptive ways of coping and may be at higher risk for psychological distress. In the current study, 64 percent of offspring carers were caring for a parent who had been diagnosed with psychosis either during their childhood (18.5% ≤ 11 years old) or prior to or during their infancy (45.5% ≤ 2 years old). Naslund et al's (1984) study suggests that having a mother with psychosis as an infant may adversely affect the child's attachment security, where the authors found a higher rate of anxious attachment in the one-year old offspring of mothers with non-organic schizophrenia. Attachment security that is compromised through early parent-child interaction in the context of a parent's mental illness is likely to persist to adulthood (Bretherton, 1992), and it is possible that the offspring carers in this sample are representative of this. More recent research on young carers suggests that children of parents with severe mental illness are more likely to present with psychological, emotional and behavioural disturbance than their peer group (Mowbray et al, 2006; Mowbray, et al, 2004). These children are also more likely to experience more poverty, unemployment, increased familial stress, and have poorer access to social support (Mowbray & Mowbray, 2006; Tebes et al, 2001). From a clinical perspective, identifying young carers and providing consistent and flexible support throughout their caregiving career is imperative. However, anecdotal evidence from the current study suggests that many of the current long-term offspring carers were not particularly supported in their role from a young age and the duration of their caregiving role and its impact on their own life choices was not widely recognised by mental health services. A better understanding of the nature and history of caregiving experiences of this portion of the carer population is required. Clinically, it is necessary to consider the impact of having a parent with psychosis throughout childhood and the effect of being a carer from childhood through to adulthood compared to later assumption of the role. In therapeutic work with offspring carers it may be useful to consider attachment as a factor influencing the caregiving environment, and to include attachment security in formulations in terms of its influence on coping and distress, as well as being mindful of the impact of attachment on engagement with formal and informal supports including therapy and carer support groups.

4.6.6.2. Spouse carers

The number of spouse carers in the current study was similar to those reported in other studies (Kuipers et al, 2006; Lobban et al, 2005). However, spouse carers in the current study were significantly older (70.4 years), which may be intuitive given that the mean age of service users was 71.4 years. A trend for an older carer profile across conditions has been noted in the literature (Levine et al, 2010; Kakuma et al, 2011; Lee, 2011; Shahly et al, 2012) and the development of services recognising the needs of older carers is imperative. Clinically, accounting for this demographic in the population of carers of people with psychosis is important. Irrespective of age, carers report additional financial burden (Vitaliano et al, 2003) and are more likely to have poorer physical health outcomes (e.g. Mechanic & Gallagher, 1996; Schulz & Beach, 1999), with poorer physical health being linked to greater appraisals of carer burden (Beach et al, 2000; Dyck et al, 1999). Older carers are likely to be more exposed to these vulnerabilities by virtue of their age. Furthermore, as carers age, neuropsychological and physical changes may occur that may impact on their own abiliy to manage their activities of daily living. Older carers should be offered more in depth and regular carer assessments to ensure that the burden of care does not become too great. One-off or irregular assessments may leave carers vulnerable to neglect by mental health services, as their needs change with age.

Cartensen (1999) has highlighted a tendency for the social networks of older people to narrow with age, which highlights another area of vulnerability for this group of carers. We know that social support plays a strong role in caregiving outcomes (e.g. Mackay & Pakenham, 2012; Joyce et al, 2003; Magliano et al, 2003); thus, a greater emphasis on providing acceptable and accessible support to older carers is required. Recent developments in accessible support resources have focused on ‘online’ forums and websites. Unfortunately, for older people, access to such support may be challenged due to lack of IT skills and/or access to the necessary technology. A thorough evaluation of the accessibility of supports to older carers is essential to developing services that will adequately meet their needs.

4.6.7. Streamlining carer services

In the same way that we have noted the benefits of streamlining interventions for different groups, such as early intervention services (Garety et al, 2006), it may be helpful to offer specific supportive interventions for carers of older adults with psychosis. The current study accounts for a wider variety of caregiving relationships than discussed in the literature to date, which warrants further exploration both clinically and via research studies. An expansion of Kuipers et al's (2010) typology of caregiving relationships, particularly with regard to carer appraisals, would enhance models of caregiving and inform clinical approaches with this portion of the carer population.

4.7 Limitations of the study

4.7.1. Sample

4.7.1.1. Recruitment challenges and sample size

Recruitment for this study was challenged by a number of obstacles, both in relation to the population sampled and circumstances at service level, which had a negative impact on the sample size and undermined the power for analysis of the leading hypothesis.

In accordance with ethical approval and guidance, the researcher was not able to make direct contact with carers and therefore was reliant on clinical staff to facilitate consent to being contacted. This process was supported to varying degrees across services. For example, the Oxleas MHOA pathway did not agree to consenting carers to being contacted by the researcher, but only to provide the participant information sheet and flyer to carers; thus, the method of recruitment relied on carers contacting the researcher in the first instance to communicate interest in the project. No carers were recruited via this pathway. It is possible that without the opportunity for researchers to provide carers with information about the study directly, carers may not have fully understood the purpose of the study or may not have identified with the role of carer (e.g. perhaps seeing it as a more formalised role). Furthermore, knowing that the level of burden is elevated in this population, carers may have been less likely to be proactive about making the first contact with the researcher. It is also not possible to know how many care-coordinators/clinicians followed through with the request to contact carers with this information, and motivation to do so may have been reduced by the researcher's inability to follow-up with specific individuals.

The most successful method of obtaining participants was to attend team meetings to provide care coordinators/clinicians with information on the study and request that they identify carers within their caseload who fit inclusion criteria. The researcher was then able to obtain contact details for the care-coordinator and follow-up with them individually in terms of their progress in contacting carers. Unfortunately, this process was only supported by two out of the nine CMHTs involved, despite continued attempts by the researcher to attend meetings for this purpose. The reasons for this were not made clear, though some managers suggested that they believed it was best for them to communicate to care-coordinators/clinicians about the research themselves rather than involving the researcher with the team. For one team, a request for care-coordinators' contact details (e.g. email addresses) was also denied.

When contact had been made with care-coordinators, the process of recruitment was hindered by a number of additional issues. Firstly, a large proportion of care-coordinators/clinicians did not respond to repeated follow-up attempts by the researcher to ascertain the status of carers on their caseload (i.e. had the information been provided, and whether the carer had declined or agreed to being contacted regarding the study). Some care-coordinators/clinicians cited concerns regarding the reaction of the service user being cared for, particularly when they were residing with the carer. Others deemed some carers unsuitable for the study by virtue of the fact that they believed they were either not burdened, and thus not eligible, or too burdened to participate. In cases where there were good and stable lines of communication between the care-coordinator/clinician and the researcher, it was possible to discuss the importance of giving all carers the choice of participation and to inform them that all carer experiences were important, not just those whom they believed to be under strain.

A number of care-coordinators cited significant time constraints as an obstacle to contacting carers. To overcome this challenge and to lessen the burden on the service, the option of sending a generic letter with information on the study was explored, whereby the researcher would prepare all letters and envelopes, with the only required input from the service being to transfer the address of the carer onto the envelopes (in order to protect carers' confidentiality prior to their consent to being contacted). However, this offer was declined, as according to Trust policy, administrative resources, regardless of the minimal time required, could not be used to support outside research projects.

Part way through recruitment it was decided to extend recruitment from SLaM and carer groups/organisations to include additional NHS Trusts. This firstly involved a Research and Development application to Oxleas, and this approach was later extended to NELFT when recruitment continued to prove difficult. Each application took a number of weeks to be processed, which added extra lag time onto recruitment. Once permission to recruit from the Trust was granted, the researcher had to navigate a number of service levels (e.g. service lead, team managers, care-coordinators/clinicians) in order to begin actively recruiting carers. This, again, was a protracted process whereby it became difficult to follow-up with the number of individuals involved, particularly given the high number of non-response/delayed response at every level. Though NELFT Research and Development approval had been granted, due to the time constraints of the project, there was not enough time available to continue to pursue contact with service managers and individual teams. Thus, this pathway of recruitment was terminated in favour of continuing to focus on the SLaM and Oxleas pathways.

Methods of recruitment outside the NHS pathways were self-selecting in nature, such as those advertised through Rethink Mental Illness and Princess Royal Trust for Carers. This method of recruitment yielded no participants. This, again, may be due to the fact that participation may have been appraised as burdensome by carers that are already under strain.

Uptake of the study by participants themselves was also poor. Anecdotal observations made during the recruitment process suggested that some relatives in a caring role for their relative did not identify with the definition of ‘carer’ and thus did not express interest. Kuipers et al (2006) reported encountering similar issues with carer recruitment in the same geographical catchment area of inner city London, suggesting that this population of carers may be a particularly difficult group to recruit. Szmukler et al (2003) also reported difficulties in recruiting carers into a support group for carers of service users with psychosis, despite intensive efforts to do so.

Recruiting carers of people with psychosis is a perennial problem attenuating the ability of studies to adequately answer research questions (Cleary et al., 2006; Garety et al, 2008; Jungbauer et al, 2003; Kuipers et al, 2004; Kuipers et al, 2006; Szmukler et al, 2003). The obstacles met in the current study present an opportunity for other researchers to recognise the importance of assessing the ability of services to adequately support research, and the impact of gatekeeping on recruitment when the method is reliant on input from an intermediary. This may become even more relevant in the current economic climate, given continued restrictions on staffing and resources within the NHS, which will likely influence the appropriation of time dedicated to supporting research, particularly projects originating from outside a Trust. Ideally, the researcher should have the opportunity to meet with all care-coordinators/clinicians face-to-face (e.g. at a meeting) in order to provide them with information about the study, and to answer any questions and address concerns, as well as to gather a list of names and contact details to facilitate follow-up. The ability for the researcher to directly contact the carer appears to be imperative, as none of the recruited carers were self-selecting; thus, this population are less likely to be pro-active in participating in these types of studies. The benefits of direct contact between the researcher and the prospective participant are many, and include the chance to answer questions, clarify issues over definition of a carer and their identification with the role, and to address any perceived difficulties or concerns over participation. Anecdotal evidence suggests that many carers did not recognise their own psychological needs connected to their role, and instead preferred to focus on the needs of the cared for relative.

Service user research has attempted to overcome similar obstacles to recruitment by encouraging service user involvement in the form of partnerships with research endeavours, where they are invited to fulfil an expert role in the process. This type of enterprise might also help to raise the profile of research with carers and improve participation rates. Families/Friends and Carers Together in Research (FACTOR) is a subgroup of the UK Mental Health Services Research Network (MHRN) that offers one example of this, by inviting family, friends and carers to contribute at a number of stages in the research process (e.g. planning, reviewing proposals and sitting on research steering committees). These types of initiatives may improve the validity and creditability of carer research from carers' points of view and inform better ways of attracting carer involvement in projects to ensure they do not fall off the research and service development agenda.

4.7.1.2. Sample bias

The criteria and method of recruitment may have led to sample bias. Firstly, the study was unable to include non-English speaking carers due to lack of access to translation services. Thus, these carers are not represented in the study. It is possible that non-

English speaking carers living in London could be more vulnerable to distress due to the possibility that language and culture may act as a barrier to informal and formal support. Future studies might wish to explore the experiences of this population of carers. Secondly, those who were recruited via self-selecting methods may have represented a less burdened group of carers. It is possible that refusers and those who did not make contact with the researcher were experiencing more difficulties in terms of levels of burden and relationship difficulties. Those who were recruited through NHS mental health services may have been more likely to have better relationships with services and staff, and thus more positive views of the study and its objectives. Better links with formal supports, including mental health services, may have also meant that this sample felt more supported, and hence less burdened and distressed than those who do not engage with services. Thirdly, data were collected on primary caregivers only. Although levels of distress are similar, primary caregivers are known to appraise caregiving more negatively (and positively), compared to non-primary caregivers (Harvey & Burns, 2003). Similar to many carer studies, the current study did not account for the contribution of non-primary carers.

4.7.2. Design and measures

This was a cross-sectional study, consequently the nature of the design limits the extent to which the results can be generalised, as well as the ability to infer causality or change over time. This may have particular relevance for some measures that have been shown to fluctuate over time, such as levels of EE (e.g. McCreadie et al, 1993; Scazufca & Kuipers, 1998; Treanor et al, 2011).

Indices of carer physical health and well-being were not included in the study. Previous studies have looked at these variables in terms of others aspects of morbidity in carers (e.g. Phillips et al, 2009; Wilcox & King, 1999 Beach et al, 2000; Dyck et al, 1999; Perlick et al, 2005). It would have been interesting to include a measure of physical health in the current study, particularly given that a large proportion of carers were older adults themselves who may have been at increased risk of poorer health by virtue of the aging process. Measures of physical health should be considered in future studies of carers of older people with psychosis.

Beyond screening for inclusion criteria requiring the carer to have more than 10 hours of contact with service users per week, carers were not asked to specify the exact amount of time spent with the person for whom they cared. Given that previous studies have identified higher levels of contact with service users as a predictor of burden (Canuscio et al, 2002; Roick et al, 2007), future studies looking at the experiences of carers of older adults with psychosis should consider this as a variable.

This study relied heavily on self-report measures (e.g. HADS, ECI, PAM-R, Brief COPE, BrIPQ, TBM, SSQ6). These measures are advantageous, as researchers are not required to undertake extensive training for their administration. They are also less time consuming, which cuts down both on demand from participants, as well as allowing for more data to be collected when time is limited. However, it is important to acknowledge that self-report measures are subject to response bias (e.g. socially desirable responding), which may influence findings.

4.7.2.1. Cultural considerations

Fifty-two percent of carers were from BME groups. The ethnic diversity of the sample strengthens the cultural generalisability of the results of the study; however, it may have implications for the reliable measurement of and categorisation of EE. Increasingly, studies have shown that culture and ethnicity are likely to influence emotional reactions and attitudes within families (Bhugra & McKenzie, 2003), which may impact on how psychosis is responded to by families (Jenkins & Karno, 1992). Additionally, according to Lopez et al (2009) “observing cross-ethnic and cross-national differences may not necessarily reflect ‘cultural’ differences in EE, but instead may reflect, at least in part, an artifact of applying an instrument that inadequately measures the given construct in a new cultural context,” (p.181). The authors further elaborate by suggesting a label of EOI may be wrongly applied in cultures where that level of involvement is considered normative. In their study comparing Mexican Americans to White Anglo Americans, they found that Mexican Americans expressed significantly fewer critical comments, less hostility, more EOI, and more warmth. Further research and development on measures of EE is required to explore ways in which its measurement can reliably account for ethnic and cultural differences.

4.7.3. Data analyses

Due to recruitment difficulties, as discussed above, the study was underpowered for the leading primary hypothesis predicting that 'avoidant coping' would have a medium positive correlation with avoidant attachment. A retrospective sample size calculation based on the correlation between 'avoidant coping' and avoidant attachment in the current study (rho = .193) indicated that a sample of 208 carers would be required in order to find a significant relationship of that size with 80% power (alpha level of 0.05). The small size of the correlation might suggest that the relationship between the variables in this sample is unlikely to be clinically or theoretically meaningful. More research would be required to draw further conclusions about the role of attachment and 'avoidant coping' in this population.

Due to the number of correlations used in the analysis, it is important to recognise the increased probability of making a Type I error. In order to control for multiple comparisons, ideally an alpha level of 0.01 would have been adopted in the power analyses, but due to the study's limitation for recruitment potential, power analysis was carried out at the 0.05 level. Thus, these findings should be interpreted with a degree of caution with regard to the possibility of Type I errors. All significant findings of the study were reported in order to highlight trends in relationships between the variables, which can be further examined in future studies with larger sample sizes and more power.

4.8 Future directions

This study identified a number of key associations that support the existing evidence-base for relationships between illness specific appraisals, expressed emotion, appraisals of caregiving experiences, coping and distress, and extends cognitive models of caregiving (Kuipers et al, 2010) and adjustment to caregiving (Mackay & Pakenham, 2012) to include the experiences of carers of older adults with psychosis. Studies with larger sample sizes and that are longitudinal in design, however, are required in order to further support the presence of these relationships and ascertain their direction. It also suggests a role for attachment styles in the coping efforts reported by carers.

The sample included carers of people with both non-affective psychosis and affective presentations of psychosis. Other studies interested in disorder specific effects might wish to draw from a more homogenous diagnostic population in which psychotic symptoms are present, such as non-affective psychosis.

In the older adult population, psychosis can also present in the context of organic conditions such as dementia (e.g. Alzheimer’s disease) and as a side effect of treatments for neurodegenerative disorders (e.g. Parkinson’s disease). Additionally, older people with non-organic psychosis may go on to develop organic conditions, which could hypothetically exacerbate objective levels of burden for carers. Findings in the current study only reflect the experiences of carers of older adults with psychosis without dementia. In order to provide a more comprehensive account of the experiences of carers of older people with psychosis, future research should also explore the experiences of those who care for older adults with an original diagnosis of psychosis who then go on to develop dementia, and for older adults who present with psychosis in the context of an organic condition (e.g. Alzheimer’s disease). Specifically, it would be interesting to explore possible differences in caregiving appraisals, illness beliefs and attributions of control between these two groups, and with carers of older adults with non-organic psychosis. A better understanding of these types of caregiving experiences is essential to developing clinical services that are tailored to carers’ specific needs, and would contribute to the evidence base for effective psychological interventions for such carers.

This study suggests that the composition of carers of older people with psychosis is characteristically different than the carers of younger people, where most of the sample was made up of adult offspring carers. In order to extend our knowledge of how different relationship types might impact on carer attitudes and appraisal of their role, further research is required. It may be particularly interesting to consider the appraisal of loss given the differences that were noted between this sample and those reported in carers of working age adults (Szmukler et al, 1996). The current study employed a quantitative method in order to provide a profile of carers of older adults with psychosis and to identify relationships between key factors in the caregiving environment; however, a better qualitative exploration would augment our understanding of carer-service user relationships and their concerns. A qualitative analysis could also improve on existing relationship typologies (Kuipers et al, 2010), and inform ways in which psychosis services may be streamlined for the older adult population and their families.

In order to better understand adjustment to caregiving in this population, future studies may wish to clarify and refine what types of social support may be most salient to carers of older people with psychosis and what formats are most accessible, keeping in mind key demographic differences (e.g. older adult carers) and the limitations of flexibility and time reported by carers during the recruitment phase. Additional research explicating the role of attachment in carers' engagement with formal supports may also be important in thinking about how services can best meet the needs of less securely attached individuals who may be at higher risk of distress in the context of caregiving.

As stated previously, this study is unique in that it is the first to include a majority of offspring carers, highlighting a gap in our understanding of this portion of the carer population to date. Within the offspring carer subgroup, the majority were caring for a parent whose illness history extended into their own childhood. Previous, research has identified significant psychosocial vulnerabilities in young carers (Mowbray et al, 2006; Mowbray, et al, 2004; Mowbray & Mowbray, 2006; Tebes et al, 2001), which could impact on their well-being later in life. Furthermore, the current study found that offspring carers were more likely to be anxiously attached than other kinship types; interestingly, this echoes the findings an early study by Naslund et al (1984) that found greater anxious attachment in infants of mothers with non-organic psychosis. Further research with this group of carers is essential as they may be at particular risk for poorer outcomes given the constellation of psychosocial stressors and early developmental disturbances to which they may have been exposed. Longitudinal studies of young carers of parents with psychosis with follow-ups at childhood, adolescence, early adulthood and mid-life could provide important information on the adjustment of young carers over time, and examine the impact of the role on their own lives in terms of physical and mental well-being and their psychological and social development. In the meantime, cross-sectional qualitative studies may provide a more detailed consideration of the experiences of adult carers who grew up with a parent with mental illness and for whom they have to come care.

References

Addington, J. & Addingon, D. (2008). Social and cognitive functioning in psychosis. *Schizophrenia Research, 99,* 176 – 181.

Addington, J., Coldham, E. L., Jones, B., Ko, T., & Addington, D. (2003). The first episode of psychosis: The experience of relatives. *Acta PsychiatricaScandinavica,108*, 285–289.

Addington, J., Saeedi, H., & Addington, D. (2005). The course of cognitive functioning in first episode psychosis: changes over time and impact on outcome. *Schizophrenia Research, 78,* 35–43.

Altamura, C., & Elliott, T. (2003). Schizophrenia in the elderly: A special case requiring special management? *European Psychiatry, 18,* 46−53.

American Psychiatric Association (APA). (1994). *Diagnostic and Statistical Manual of Mental Disorders—IV edition (DSM-IV).* Washington, USA: American Psychiatric Association.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.). Washington, DC: American Psychiatric Association

Andreasen, N. C., Arndt, S., Alliger, R., Miller, D., & Flaum, M. (1995). Symptoms of schizophrenia: methods, meanings, and mechanisms. *Archives of General Psychiatry, 52*(5), 341.

Angermeyer, M.C, Holzinger, A., & Matschinger, H. (2009). Mental health literacy and attitude towards people with mental illness: a trend analysis based on population surveys in the eastern part of Germany. *European Psychiatry, 24*(4), 225-32.

Angermeyer, M.C., Schulze, B., & Dietrich, S. (2003). Courtesy stigma--a focus group study of relatives of schizophrenia patients. *Social Psychiatry and Psychiatric Epidemiology, 38*(10), 593-602.

Antonucci, T.C. & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. *Journal of Gerontology, 42*(5), 519 – 527.

Arno, P.S., Levine, C., & Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs, 18*(2), 182-188.

Awad, A.G., & Voruganti, L.N.P. (2008). The burden of schizophrenia on caregivers: A review. *Pharmacoeconomics,26,* 149–162.

Awad, A.G., & Wallace, M. (1999). *Patient and carer perspectives in schizophrenia: a workshop.*The First Worldwide Pfizer Neuroscience Consultants Forum. April 14: Barcelona.

Barberger-Gateau, P., Commenges, D., Gagnon, M., & Letenneur, L. (1992). Instrumental Activities of Daily Living as a screening tool for cognitive impairment and dementia in elderly community dwellers. *Journal of the American Geriatrics Society, 40*(11), 1129-1134.

Barford, A., Dorling, D., Smith, G. D., & Shaw, M. (2006). Life expectancy: women now on top everywhere: During 2006, even in the poorest countries, women canexpect to outlive men. *BMJ: British Medical Journal*, *332*(7545), 808.

Barker, S., Lavender, T., & Morant, N. (2001).Client and family narratives on schizophrenia. *Journal of Mental Health, 10,* 199–212.

Barrowclough, C., & Hooley, J. M. (2003). Attributions and expressed emotion: A review. *Clinical Psychology Review, 23,* 849–80.

Barrowclough, C., & Tarrier, N. (1990). Social functioning in schizophrenic patients. I. The effects of expressed emotion and family intervention. *Social Psychiatry and Psychiatric Epidemiology, 25*(3), 125-9.

Barrowclough, C., Johnston, M., & Tarrier, N. (1994). Attributions, expressed emotion and patient relapse: An attributional model of relatives' response to schizophrenic illness. *Behavior Therapy, 25,* 67–88.

Barrowclough, C., King, P., Colville, J., et al. (2001). A randomized trial of the effectiveness of cognitive–behavioural therapy and supportive counselling for anxiety symptoms in older adults. *Journal of Consulting and Clinical Psychology, 69*, 756–762.

Barrowclough, C., Lobban, F., Hatton, C., & Quinn J. (2001).An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology, 40*(4), 371-85.

Barrowclough,C., &Parle, M. (1997). Appraisal, psychological adjustment and expressed emotion in relatives of patients suffering from schizophrenia.*British Journal of Psychiatry, 171,* 26–30.

Bartels, S.J., Dums, A.R., Schneider, L.S., Arean, P.A., Alexopoulos, G.S., & Jeste, D.V. (2002). Evidence-based practices in geriatric mental health care. *Psychiatric Services, 53,* 1419−1431.

Bartels, S.J., Mueser, K.T. & Miles, K.M. (1997). A comparative study of elderly patients with schizophrenia and bipolar disorder in nursing homes and the community. *Schizophrenia Research, 27,* 181 -190.

Bartholomew, K. & Horowitz, L.M. (1991). Attachment styles among young adults: a test of a four-category model. *Journal of Personality and Social Psychology, 61*(2), 226 – 244.

Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging.* 2000;*15*:259–271.

Bebbington, P., &Kuipers, L. (1994). The predictive utility of expressed emotion in schizophrenia: An aggregate analysis. *Psychological Medicine, 24,* 707–718.

Beck, A. T. (1987). Cognitive models of depression. *Journal of Cognitive Psychotherapy; Journal of Cognitive Psychotherapy*.

Bentsen, H., Notland, T.H., Munkvold, O.G., Boye, B., Ulstein I, Bjorge H., et al. (1998). Guilt proneness and expressed emotion in relatives of patients with schizophrenia or related psychoses. *British Journal of Medical Psychology, 71,* 125–138.

Berry, K., & Drake, R. (2010). Attachment theory in psychiatric rehabilitation: informing clinical practice. *Advances in Psychiatric Treatment*, *16*(4), 308-315.

Berry, K., Band, R., Corcoran, R., Barrowclough, C., &Wearden, A. (2007a). Attachment styles, earlier interpersonal relationships and schizotypy in a non-clinical sample. *Psychology and Psychotherapy, 80,* 563 – 576.

Berry, K., Barrowclough, C., & Wearden, A. (2008a). Attachment theory: A framework for understanding symptoms and interpersonal relationships in psychosis. *Behaviour Research and Therapy, 46,* 1275 – 1282.

Berry, K., Barrowclough, C., & Wearden, A. (2009) Adult attachment, perceived earlier experiences of care giving and trauma in people with psychosis. *Journal of Mental Health*, *18*(4), 280-287.

Berry, K., Barrowclough, C., & Wearden, A. (2009). A pilot study investigating the use of psychological formulations to modify psychiatric staff perceptions of service users with psychosis. *Behavioural and Cognitive Psychotherapy*, *37*(1), 39-48.

Berry, K., Rakhi, S., Cook, A., Geater, E., Barrowclough, C. & Wearden, A. (2008b). Staff attachment styles: a pilot study investigating the influence of adult attachment styles on staff psychological mindedness and therapeutic relationships. *Journal of Clinical Psychology, 64,* 355 – 363.

Berry, K., Wearden, A., & Barrowclough, C. (2010). Psychiatric staff perceptions of patient attachments: A pilot study to investigate differences in and predictors of psychiatric staff perceptions of patient attachments. *Social Psychiatry and Psychiatric Epidemiology*, *45*(11), 1081-1086.

Berry, K., Wearden, A., Barrowclough, C., & Liversidge, T. (2006). Attachment styles, interpersonal relationships and psychotic phenomena in a non-clinical student sample. *Personality and Individual Differences, 41,* 707 – 718.

Bhugra, D. (2005). The Global Prevalence of Schizophrenia. *PLoS Med, 2*(5), 151.

Bhugra, D., & McKenzie, K. (2003). Expressed emotion across cultures.*Advances in Psychiatric Treatment*, *9*(5), 342-348.

Birchwood, M., & Cochrane, R. (1990) Families coping with schizophrenia – coping styles, their origins and correlates. *Psychological Medicine, 20,* 857–65.

Birchwood, M., & Spencer, E. (1999).*Psychotherapies for schizophrenia: a review.* In M. Maj& N. Sartorious (Eds.) *Schizophrenia* (pp. 139 – 241).Chichester: Wiley.

Birchwood, M., &Iqbal, Z. (1998). Depression and suicidal thinking in psychosis: A cognitive approach. In T. Wykes, N. Tarrier, N. & S. Lewis, (Eds.), *Outcome and innovation in psychological treatment of schizophrenia* (pp. 81-100). John Wiley: Hoboken, NJ.

Birchwood, M., Smith, J., Cochrane, R., Wetton, S. & Copestake, S. (1990). The Social Functioning Scale. The development and validation of a new scale of social adjustment for use in family intervention programmes with schizophrenic patients. *British Journal of Psychiatry, 157,* 853 – 859.

Birnbaum, G., Orr, I., Mikuincer, M., & Florian, V. (1997). When marriage breaks up— Does attachment style contribute to coping and mental health? *Journal of Social and Personal Relation- ships, 14,* 643-654.

Bjelland, I., Dahl, A.A., Haug, T.T. & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale: An updated literature review. *Journal of Psychosomatic Research, 52,* 69 -77.

Blackburn, C., Berry, K., Cohen, K. (2010). Factors correlated with client attachment to mental health services. *Journal of Nervous and Mental Disease*, *198*(8), 572-575.

Bledin, K.D., MacCarthy, B., Kuipers, L. & Woods, R.T. (1990). Daughters of people with dementia: Expressed emotion, strain and coping. *British Journal of Psychiatry, 157,* 221 – 227.

Blumhagen, D. (1980). On the nature of explanatory models.*Culture, Medicine and Psychiatry, 5,* 337 – 340.

Bowlby, J. (1973). *Attachment and loss: Vol. 2. Separation: Anxiety and anger.* New York: Basic Books.

Bowlby, J. (1980). *Attachment and loss.*In *Loss, Vol. 3.* New York: Basic Books.

Braithwaite, V. (1996). Between stressors and outcomes: Can we simplify caregiving process variables? *Gerontologist 36*: 42–53.

Bretherton, I. (1992). "The Origins of Attachment Theory: John Bowlby and Mary Ainsworth".*Developmental Psychology, 28* (5), 759.

Brewin, C. R., MacCarthy, B., Duda, K., Vaughn, C. E. (1991). Attribution and expressed emotion in the relatives of patients with schizophrenia. *J Abnorm Psychol* 100(4), 546-554.

Broadbent, E., Petrie, K.J., Main, J., &Weinman, J. (2006). The Brief Illness Perception Questionnaire.*Journal of Psychomatic Research, 60,* 631 – 637.

Brown, G. W., &Rutter, M. (1966). The measurement of family activities and relationships: A methodological study. *Human Relations, 19,* 241–263.

Brown, M.A., (1997). Knowledge generation for the HIV affected family. *Journal of Nursing Scholarship, 29* (3), 269-274.

Brown, S., & Birtwistle, J. (1998). People with schizophrenia and their families. Fifteen-year outcome. *British Journal of Psychiatry, 173,* 139–144.

Brugha, T. S., Wing, J. K., Brewin, C. R., MacCarthy, B., & Lesage, A. (1993). The relationship of social network deficits with deficits in social functioning in long-term psychiatric disorders. *Social Psychiatry and Psychiatric Epidemiology*, *28*(5), 218-224.

Butzlaff, R. L., & Hooley, J. M. (1998). Expressed emotion and psychiatric relapse. *Archives of General Psychiatry, 55,* 547–552.

Canuscio, C.C., Jones, C., Kawachi, I., Colditz, G.A., Berkman, L., & Rimm, E. (2002). Reverberations of family illness: a longitudinal assessment of informal caregiving and mental health status in the Nurses' Health Study. *American Journal of Public Health, 92,* 1305 – 1311.

Canuscio, C.C., Jones, C., Kawachi, I., *et al.* (2002). Reverberations of family illness: a longitudinal assessment of informal caregiving and mental health status in the Nurses' Health Study. *American Journal of Public Health, 92,* 1305 – 1311.

Canuso, C.M. & Pandina, G. (2007). Gender and schizophrenia. *Psychopharmcology Bulletin, 40*(4), 178 – 190.

Carlisle, A., John, M., Fife-Schaw, C.R. & Lloyd, M. (2005). The self-regulatory model in women with rheumatoid arthritis: relationships between illness representations, coping procedures, self-efficacy beliefs and outcome. *British Journal of Health Psychology*, 10, 571-587.

Carnelley, K. B., Pietromonaco, P. R., & Jaffe, K. (1994). Depression, working models of others, and relationship functioning. *Journal of Personality and Social Psychology, 66*, 127-140.

Carpenter, B. D. (2001). Attachment bonds between adult daughters and their older mothers: Associations with contemporary caregiving. *The Journals of Gerontology: Psychological Sciences and Social Sciences, 56B,* p. 257-P267.

Carstensen, L.L., Isaacowitz, D.M. & Charles, S.T. (1999). Taking time seriously: A theory of socioemotional selectivity. *American Psychologist, 54,* 165-181.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4, 92-100.

Cassidy, J., &Kobak, R. R. (1988). Avoidance and its relation to other defensive processes. In J. Belsky& T. Nezworski (Eds.), *Clinical implications of attachment* (pp. 300–323). London: Erlbaum.

Chakrabarti, S. & Gill, S. (2002). Coping and its correlates among caregivers of patients with bipolar disorder: a preliminary study. *Bipolar Disorders, 4,* 50-60.

Chambers, M., Ryan, A. A., & Connor, S. L. (2001). Exploring the emotional support needs and coping strategies of family carers. *Journal of Psychiatric and Mental Health Nursing*, *8*(2), 99-106.

Chen, C.K., Lin, S.K., Sham, P.C., Ball, D., Loh, E.W., & Murray, R.M. (2005). Morbid risk for psychiatric disorder among the relatives of methamphetamine users with and without psychosis. *American Journal of Medical Genetics, 136B,* 87 – 91.

Chen, F. P., & Greenberg, J. S. (2004). A positive aspect of care-giving: The influence of social support on care-giving gains for family members of relatives with schizophrenia. *Community Mental Health Journal, 40,* 423–435.

Ciompi, L. (1980). Three lectures on schizophrenia: The natural history of schizophrenia in the long term. *British Journal of Psychiatry, 136,* 413–420.

Cleary, M., Freeman, A. & Walter, G. (2006). Carer participation in mental health service delivery. *International Journal of Mental Health Nursing, 15*(3), 189 – 94.

Cohen, C. I. (1990). Outcome of schizophrenia into later life: An overview. *The Gerontologist, 30,* 790−797.

Cohen, C. I. (1995). Studies of the course and outcome of schizophrenia in later life. *Psychiatric Services, 46,* 877−879.

Cohen, C. I. (2003). Social vicissitudes of schizophrenia in later life. In C. I. Cohen (Ed.), *Schizophrenia into later life* (pp. 155−176). Arlington: American Psychiatric Publishing.

Cohen, C. I., & Kochanowicz, N. (1989). Schizophrenia and social network patterns: A survey of black inner-city outpatients. *Community Mental Health Journal, 25,* 197−207.

Cohen, C. I., Cohen, G. D., Blank, K., Gaitz, C., Katz, I. R., Leuchter, A., et al. (2000). Schizophrenia and older adults. An overview: Directions for research and policy. *American Journal of Geriatric Psychiatry, 8,* 19−28.

Cohen, C. I., Talavera, N., & Hartung, R. (1997). Predictors of subjective well-being among older, community dwelling persons with schizophrenia. *American Journal of Geriatric Psychiatry, 5,* 145−155.

Cohen, S. (2004). Social relationships and health*. American Psychologist*, *59*(8), 676–684.

Collins, N. L., & Feeney, B. C. (2000). A safe haven: An attachment theory perspective on support seeking and caregiving in intimate relationships. *Journal of Personality and Social Psychology*, *78*, 1053–1073.

Collins, P., Patel, V. & Joestl, S.S. (2011). Grand challenges in global mental health. *Nature, 475,* 27 – 30.

Connor, M., & Norman, P. (1995).The role of social cognition in health behaviours. In M. Connor & P. Norman (Eds.), *Predicting health behaviour: Research and practice with social cognition models*. Oxford: Oxford University Press.

Cooper, C., Owens, C., Katona, C. & Livingston, G. (2008). Attachment style and anxiety in carers of people with Alzheimer's disease: results from the LASER-AD study. *International Psychogeriatrics, 20,* 494 – 507.

Couture, J.A., Roberts, D.L., Penn, D.L., Cather, C., Otto, M.W., & Goff, D. (2006). Do baseline client characteristics predict the therapeutic alliance in the treatment of schizophrenia? *Journal of Nervous and Mental Disease, 194,* 10 – 14.

Crawford, J.R., Henry, J.D., Crombie, C. & Taylor, E. (2001). Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology, 40*(4), 429 – 434.

Crispi, E. L., Schiaffino, K., Berman, W. H. (1997) The contribution of attachment to burden in adult children of institutionalized parents with Alzheimers. *Gerontologist, 37*, 52–60.

Czuchta, D. &McCay, E. (2001). Help-seeking for parents of individuals experiencing a first episode of schizophrenia. *Archives of Psychiatric Nursing, 15,* 159 – 170.

Davis, D. J. & Schultz, C. L., (1998). Grief, Parenting and Schizophrenia, *Social Science Medicine,* 46, 3: 369–79.

Davis, M. W., Morris, M. M., & Kraus, L. A. (1998). Relationship-specific and global perceptions of social support, associations with well-being, and attachment. Journal of Personality and Social Psychology, 74, 468 – 481.

Dearden, C. & Becker, S. (2004). *Young carers in the UK: the 2004 report.* London: Carers UK.

DeLisi, L. E., Stritzke, P., Riordan, H., et al. (1992) The timing of brain morphological changes in schizophrenia and their relationship to clinical outcome. *Biological Psychiatry, 31*, 241– 254.

Department of Health. (1999). Caring About Carers: A National Strategy for Carers. London: Department of Health.

DiMatteo, M. R., Lepper, H. S., & Croghan, T. W. (2000). Depression is a risk factor for noncompliance with medical treatment - Meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine, 160* (14), 2101-2107.

Dixon, L., Lyles, A., Scott, J., Lehman, A., Postrado, L., Goldman, H. &McGlynn, E. (1999). Services to families of adults with schizophrenia: from treatment recommendations to dissemination. *Psychiatric Services, 50*, 233–238.

Duncan, D. & Taylor, D. (1996). Treatment of psychosis in Parkinson's disease.*The Psychiatrist, 20,* 157 – 159.

Dutta, R., Murray, R. M., Allardyce, J., Jones, P. B. &Boydell, J. E. (2012). Mortality in first-contact psychosis patients in the UK: a cohort study. *Psychological Medicine, 42,* 1649-1661.

Dyck, D. G., Short, R., &Vitaliano, P. P. (1999). Predictors of burden and infectious illness in schizophrenia caregivers.*Psychosomatic Medicine, 61,* 411–419.

Eack, S.M. &Newhill, C. (2007). Psychiatric symptoms and quality of life in schizophrenia: a meta-analysis. *Schizophrenia Bulletin, 33,* 1225 – 1237.

Esterling, B.,Antoni, M., Fletcher, M., Margulies, S. & Schneiderman, N. (1994). Emotional disclosure through writing or speaking modulates latent Epstein–Barr virus antibody titers. *Journal of Consulting and Clinical Psychology 62(1),* 130– 140.

Faul, F., Erdfelder, E., Lang, A.G. & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral and biomedical sciences. *Research Methods, 39,* 175 – 191.

Favrod, J., Guiliani, F., Ernst, F. & Bonsack, C. (2010). Anticipatory pleasure skills training: A new intervention to reduce anhedonia in schizophrenia. *Perspectives in Psychiatric Care, 3,* 171 – 181.

Fiori, K.L., Antonucci, T.C. & Cortina, K.S. (2006) Social network typologies and mental health among older adults. *The Journals of Gerontology: Series B, 61,* 25-32.

Fortune, D. G., Smith, J. V. & Garvey, K. (2005). Perceptions of psychosis, coping, appraisals, and psychological distress in the relatives of patients with schizophrenia: An exploration using self-regulation theory. *British Journal of Clinical Psychology, 44,*319–331.

Fortune, G., Barrowclough, C., Lobban, F. (2004). Illness representations in depression. *British Journal of Clinical Psychology, 43,* 347–364.

Fraley, R.C., & Brumbaugh, C.C. (2005). A dynamical systems approach to conceptualising and studying stability and change in attachment security.In W. S. Rholes & J. A. Simpson (Eds.).*Adult attachment: Theory, research and clinical applications* (pp. 86 – 133). New York: Guilford Press.

Freeman, D., Garety, P.A., Bebbington, P.E., Smith, B., Rollinson, R., Fowler, D., et al. (2005). Psychological investigation of the structure of paranoia in a non-clinical population. *British Journal Psychiatry, 186,*427 – 435.

Freeman, D., Garety, P.A., Bebbington, P.E., Smith, B., Rollinson, R., Fowler, D., Kuipers, E., Ray, K. & Dunn, G. (2005). Psychological investigation of the structure of paranoia in a non-clinical population. *British Journal Psychiatry, 186,* 427 – 435.

Gallagher, S.K. & Mechanic, D. (1996). Living with the mentally ill: Effects on the health and functioning of other household members. *Social Science & Medicine*, *42,* 1691-1701.

Garcia, J. I. R., Chang, C. L., Young, J. S., Lopez, S. R., & Jenkins, J. H. (2006). Family support predicts psychiatric medication usage among Mexican American individuals with schizophrenia. *Social Psychiatry & Psychiatric Epidemiology*, *41*, 624–631.

Garety, P.A., Fowler, D.G., Freeman, D., Bebbington, P., Dunn, G. Kuipers, E. (2008). Cognitive–behavioural therapy and family intervention for relapse prevention and symptom reduction in psychosis: randomised controlled trial. *British Journal of Psychiatry, 192,* 412 – 423.

Garety, P.A., Kuipers, E., Fowler, D., Freeman, D. & Bebbington, P.E. (2001). A cognitive model of positive symptoms of psychosis. *Psychological Medicine, 31,* 189 – 195.

Glaser, R., & Kiecolt-Glaser, J. K. (1997). Chronic stress modulates the virus-specific immune response to latent herpes simplex virus type 1. *Annals of Behavioral Medicine, 19*(2), 78-82.

Goldberg, D. P., & Hillier, V. A. (1979). A scaled version of the General Health Questionnaire.*Psychological Medicine, 9,* 139–145.

Goldstein, J. M., Buka, S., Seidman, L., Kremer, W., & Tsuang, M. (1995). Sex differences in the effects of obstetric complications in schizophrenia. *Schizophrenia Research,* 15:118.

Goodwin, I. (2003). The relevance of attachment theory to the philosophy, organization and practice of adult mental health services. *Clinical Psychology Review, 23,* 35 – 56.

Gore, S., & Colten, M. E. (1991). Gender, stress, and distress: social-relational influences. In J. Eckenrode (Ed.), The Social Context of Coping (pp. 139–163). New York: Plenum Press.

Groff, A., Burns, B., Swanson, J., Swartz, M., Wagner, H. R. & Tompson, M. (2004). Caregiving for persons with mental illness: the impact of outpatient commitment on caregiving strain. *Journal of Nervous and Mental Disease, 192*, 554-562.

Gutierrez-Maldonado, J., Caqueo-Urizar, A., & Kavanagh, D. J. (2005). Burden of care and general health in families of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 40,* 899–904.

Hahlweg, K., Goldstein, M. J., Nuechterlein, K. H., Magafia, A. B., Mintz, J., Doane, J. A., Miklowitz, D. J. & Snyder, K. S. (1989) Expressed emotion and patient-relative interactionn in families of recent onset schizophrenics. *Journal of Consulting and Clinical Psychology, 57,* 11-18.

Hahlweg, K., Nuechterlein, K. H., Goldstein, M. J., Magana, A., Doane, J. A., Snyder, K. S. (1987). Parental expressed emotion, attitudes, and intrafamilial communication behavior. In Understanding Major Mental Disorder: The Contribution of Family Interaction Research. ed. K. Hahlweg, M. J. Goldstein. NY: Family Process Press. In Press

Harris, M.J., &Jeste, D.V. (1988). Late-onset schizophrenia: an overview. *Schizophrenia Bulletin, 14*, 39-55.

Harvey, K. & Burns, T. (2003). Relatives of Patients With Severe Mental Disorders: Unique Traits and Experiences of Primary, Nonprimary, and Lone Caregivers. *American Journal of Orthopsychiatry, 73(3),* p. 324 – 333.

Harvey, K., Burns, T., Fahy, T., Manley, C. &Tattan, T. (2001). Relatives of patients with severe psychotic illness: Factors that influence appraisal of caregiving and psychological distress. *Social Psychiatry and Psychiatric Epidemiology, 36,* 456–461.

Harvey, P. D. (1999). Cognitive functioning in late life schizophrenia: Its importance and implications for overall outcome. *Journal of Clinical Psychiatry, 60*(S13), 10−16.

Hazan, C., & Shaver, P. (1990). Love and work: An attachment-theoretical perspective. *Journal of Personality and Social Psychology*, *59*, 270–280.

Hazan,C., & Shaver, P. (1987). Romantic love conceptualized as an attachment process. *Journal of Personality and Social Psychology*, *52*(3), 511–524.

Heikkila, J., Karlsson, H., Taiminen, T., Lauerma, H., Ilonen, T., Leinonen, K. M., et al. (2002). Expressed emotion is not associated with disorder severity in first-episode mental disorder. *Psychiatry Research, 111,* 155–165.

HM Government (February 2011). *No health without mental health: a cross-government mental health outcomes strategy for people of all ages.*

Hoenig, J., & Hamilton, M. W. (1965). Extramural care of psychiatric patients. *The Lancet, 285*(7399), 1322-1325.

Hoenig, J., & Hamilton, M.W. (1966). The schizophrenia patient in the community and his effect on the household.*International Journal of Social Psychiatry, 12,* 165–176.

Hooley, J. M., & Parker, H. A. (2006). Measuring expressed emotion: An evaluation of the shortcuts. *Journal of Family Psychology, 20,* 386–396.

Hooley, J.M. (1985). Expressed emotion: A review of the critical literature. *Clinical Psychology Review, 5,* 119 – 139.

Hooley, J.M. (1987). The nature and origins of expressed emotion. In M.J. Goldstein & K. Hahlweg (Eds.) *Understanding major mental disorder: The contribution of family interaction research* (pp.176-194). New York: Family Process Press.

Howard, R., Rabins, P. V., Seeman, M. V., &Jeste, D. V. (2000). Late-onset schizophrenia and very-late-onset schizophrenia-like psychosis: An international consensus. *American Journal of Psychiatry, 157*(2), 172-178.

Jenkins, J.H. & Karno, M. (1992). The meaning of expressed emotion: theoretical issues raised by cross-cultural research. *American Journal of Psychiatry, 149*(1), 9 – 21.

Jeppesen, P., Petersen, L., Thorup, A., et al. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden: OPUS trial. *Br J Psychiatry Suppl*; 48:s85–s90.

Jeste, D. V. & Twamley, E. W. (2003). Understanding and managing psychosis in late life. Psychiatric Times, (3).

Jeste, D.V., &Lebowitz, B.D. (1997) Coming of age. *The Leifer Report, Special Edition* (pp. 39–40).

Jeste, D.V., Caligiuri, M..P., Paulsen, J.S., Heaton, R.K., Lacro, J.P., Harris, M.J., et al. (1995). Risk of tardive dyskinesia in older patients: A prospective longitudinal study of 266 patients. *Archives of General Psychiatry, 52,* 756−765.

Jeste, D.V., Palmer, B.W. & Harris, M.J. (1998). Early- vs. late-onset schizophrenia: is it time to define the difference? *American Journal of Geriatric Psychiatry, 6,* 346-347.

Jeste, D.V., Twamley, E.W., EylerZorrilla, L.T., Golshan, S., & Patterson, T.L. (2003). Aging and outcome in schizophrenia. *ActaPsychiatrica Scandinavia, 107*, 336−343.

Jiska, E.D. Wolthaus, M.A., Peter, M.A.L. *et al.* (2002). Caregiver burden in recent onset schizophrenia and spectrum disorders: the influence of symptoms and personality traits. *Journal of Nervous Mental Disorders, 190,* 241 – 247.

Johns, L. & van Os, J. (2001). The continuity of psychotic experiences in the general population. *Clinical Psychology Review, 21,* 1125 – 1141.

Jolley, S., Garety, P., Dunn, G., White, J., Aitken, M., Challacombe, F., Griggs, M., Wallace, M., & Craig, T. (2005). A pilot validation study of a new measure of activity in psychosis.*Social Psychiatry and Psychiatric Epidemiology, 40*(11), 905-911.

Jolley, S., Garety, P.A., Ellett, L., Kuipers, E., Freeman, D., Bebbington, P.E., Fowler, D.G., & Dunn, G. (2006). A validation of a new measure of activity in psychosis.*Schizophrenia Research, 85*(1-3), 288-295.

Jones, S. (1996). The association between objective and subjective caregiver burden. Archives of Psychiatric Nursing, 10, 77-84.

Joyce, J., Leese, M., Kuipers, E., Szmukler, G., Harris, T., & Staples, E. (2003). Evaluating a model of caregiving for people with psychosis. *Social Psychiatry and Psychiatric Epidemiology, 38,* 189–195.

Jungbauer, J., Wittmund, B., Dietrich, S. and Angermeyer, M.C. (2003). Subjective burden over 12 months in parents of patients with schizophrenia. *Archives of Psychiatric Nursing, 17*(3), 126 – 134.

Kafetsios, K. & Sideridis, G. (2006). Attachment, Social Support and Well-being in Young and Older Adults. *Journal of Health Psychology, 11,* 863 – 875.

Kakuma, R., Minas, H., van Ginneken, N., Dal Poz, M.R., Desiraju, K., Morris, J.E., Saxena, S. & Scheffler, R.M. (2011). Human resources for mental health care: current situation and strategies for action. *Lancet, 378,* 1654 – 63.

Kartalova-O'Doherty, Y.K. & Doherty, D.T. (2008). Coping strategies and styles of family carers of persons with enduring mental illness: a mixed methods analysis. *Scandinavian*

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. *JAMA: the journal of the American Medical Association, 185*(12), 914-919.

Kessler, R., Stang, P., Wittchen, H., Stein, M., & Walters, E. (1999). Lifetime co-morbidities between social phobia and mood disorders in the US National Comorbidity Survey. *Psychological Medicine, 29*(3), 555-567.

King, S., Collins, C. & Liken, M. (1995). Values and the use of community services. *Qualitative Health Research, 5,* 332–347.

Klapow, J. C., Evans, J., Patterson, T. L., Heaton, R. K., Koch, W. L., & Jeste, D. V. (1997). Direct assessment of functional status in older patients with schizophrenia. *American Journal of Psychiatry, 154*:1022-1024.

Klonoff, E.A. &Landrine, H. (1994). Culture and gender diversity in commonsense beliefs about the causes of six illnesses. Journal of behavioral medicine, 17, 407 – 418.

Knapp, M., Mangalore, R. & Simon, J. (2004). The global costs of schizophrenia. *Schizophrenia Bulletin, 30,* 279 - 293.

Knifton, L., Gervais, M., Newbiggin, K., Mirza, N., Quinn, N., Wilson, N. & Hunkins-Hutchinson, E. (2010). Community conversation: addressing mental health stigma with ethnic minority communities. *Soc Psychiatry Psychiatr Epidemiol, 45*(4), 497 – 504.

Kobak, R.R., Sudler, N., & Gamble, W. (1991). Attachment and depressive symptoms during adolescence: A developmental pathways analysis. *Development and Psychopathology, 3,* 461–474.

Kotler, T., Buzwell, S., Romeo, Y. & Bowland, J. (1994). Avoidant attachment as a risk factor for health. *British Journal of Medical Psychology, 67*, 237-245.

Kuipers, E. (2010).Time for a separate psychosis caregiver service? *Journal of Mental Health, 19*, 401–404.

Kuipers, E., &Bebbington, P. (2005). Research on burden and coping strategies in families of people with mental disorders: problems and perspectives. In N. Sartorius, J. Leff, & J. J. Lopez (Eds.), *Families and Mental Disorder: From Burden to Empowerment* (pp. 217–234). Chichester: John Wiley & Sons.

Kuipers, E., &Raune, D. (2000). The early development of expressed emotion and burden in the families of first onset psychosis. In M. Birchwood, D. Fowler, & C. Jackson (Eds.), *Early Intervention in Psychosis* (pp. 128–140). Chichester: John Wiley & Sons.

Kuipers, E., Bebbington, P., Dunn, G., Fowler, D., Freeman, D., Watson, P., et al. (2006). Influence of carer expressed emotion and affect on relapse in non-affective psychoses. *British Journal of Psychiatry, 188,* 173–9.

Kuipers, E., Onwumere, J., &Bebbington, P. (2010). Cognitive model of caregiving in psychosis. *The British Journal of Psychiatry, 196,* 259–265.

Kuipers, E., Watson, P., Onwumere, J., Bebbington, P., Dunn, G., Weinman, J., et al. (2007). Discrepant illness perceptions, affect and expressed emotion in people with psychosis and their carers. *Social Psychiatry and Psychiatric Epidemiology, 42,* 277–283.

Kurtz, M.M. (2005). Neurocognitive impairment across the lifespan in schizophrenia: An update. *Schizophrenia Research, 74*, 15−26.

Lawson, V.L., Bundy, C., Lyne, P.A. & Harvey, J.N. (2004). Using the IPQ and PMDI to predict regular diabetes care-seeking among patients with Type 1 diabetes. *British Journal of Health Psychology, 9,* 241 – 252.

Lawton, M., Brody, E., & Médecin, U. (1988). Instrumental Activities of daily living (IADL). *Psychopharmacol Bull, 24*, 785-787.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Verlag.

Lee, R. (2011). The outlook for population growth. *Science*, *333*(6042), 569-573.

Leff, J., & Vaughn, C. (1985). *Expressed Emotion in Families*. London: Guilford Press.

Leventhal, H., Diefenbach, M.,& Leventhal, E.A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research, 16,* 143 – 163.

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachxnan (Ed.), *Contributions to medical psychology* (Vol. 11, pp. 7-30). New York Pergamon Press.

Leventhal, H., Nerenz, D. R., & Steele, D. F. (1984). Illness representations and coping with health threats. In A. Baum & J. Singer (Eds.) *A handbook of psychology and health* (pp. 219–252). Hillsdale, NJ: Erlbaum.

Lewis, G. & Wessely, S. (1990). Comparison of the General Health Questionnaire and the Hospital Anxiety and Depression Scale. *British Journal Psychiatry, 157,* 860 – 864.

Lobban, F., Barrowclough, C. & Jones, S. (2004). The impact of beliefs about mental health problems and coping on outcome in schizophrenia. *Psychological Medicine*, *34*, 1165–1176.

Lobban, F., Barrowclough, C., & Jones, S. (2005). Assessing cognitive representations of mental health problems. II. The illness perception questionnaire for schizophrenia: relatives' version. *British Journal of Clinical Psychology, 44*, 163–79.

Lobban, F., Barrowclough, C., & Jones, S. (2005b). Assessing cognitive representations of mental health problems. The illness perception questionnaire for schizophrenia: Relatives' version. *Br J Clin Psychol 44 (Pt. 2),* 163-179.

Lobban, F., Barrowclough, C., & Jones, S. (2006). Does expressed emotion need to be understood within a more systemic framework? An examination of discrepancies in appraisals between patients diagnosed with schizophrenia and their relatives. *Social Psychiatry and Psychiatric Epidemiology, 41,* 50–55.

Lopez, F. G., Melendez, M. C., Sauer, E. M., Berger, E., & Wyssmann, J. (1998). Internal working models, self-reported problems, and help-seeking attitudes among college students. *Journal of Counseling Psychology*, *45*(1), 79.

Lopez, S.R., Ramirez Garcia, J.I., Ullman, J.B., Kopelowicz, A., Jenkins, J., Breitborde, N.J.K. & Placencia, P. (2009). Cultural Variability in the Manifestation of Expressed Emotion. Fam Process, 48(2), 179 – 194.

Lowenstein, J. A., Butler, D. W., & Ashcroft, K. (2010). The efficacy of a cognitively orientated carers group in an early intervention in psychosis service–a pilot study. *Journal of psychiatric and mental health nursing*,*17*(7), 628-635.

Lowyck, B., De Hert, M., Peeters, E., Wampers, M., Gilis, P. & Peuskens, J. (2004). A study of the family burden of 150 family members of schizophrenia patients. *European Psychiatry, 19*: 395–401.

Luanaigh, C. Ó., & Lawlor, B. A. (2008). Loneliness and the health of older people. *International journal of geriatric psychiatry, 23*(12), 1213-1221.

Mackay, C. & Pakenham, K.L. (2012). A stress and coping model of adjustment to caring for an adult with mental illness. *Community Mental Health, 48,* 450 – 462.

Magai, C., & Passman, V. (1997). The interpersonal basis of emotional behaviour and emotion regulation in adulthood. In M. P. Lawton & K. W. Schaie (Eds.), *Annual review of gerontology and geriatrics* (Vol. 17, pp. 104–137). New York: Springer.

Magaña, A. B., Goldstein, M. J., Karno, M., Miklowitz, D. J., Jenkins, J., & Falloon, I. R. H. (1986). A brief method for assessing expressed emotion in relatives of psychiatric patients. *Psychiatry research, 17*(3), 203-212.

Magaña, A.B., Goldstein, M.J., Karno, M., Miklowitz, D.J., Jenkins, J., & Falloon, I.R.H. (1986). A brief method for assessing expressed emotion in relatives of psychiatric patients. *Psychiatry Research, 17,* 203–212.

Magliano, L., Fadden, G., Economou, M., Held, T., Xavier, M., Guarneri, M., et al. (2000). Family burden and coping strategies in schizophrenia: 1-year follow-up data from the BIOMED 1 study. *Social Psychiatry and Psychiatric Epidemiology, 35,* 109–115.

Magliano, L., Fadden, G., Economou, M., Xavier, M., Held, T., Guarneri, M., et al. (1998). Burden on the families of patients with schizophrenia: results from the BIO-MED I study. *Social Psychiatry and Psychiatric Epidemiology, 33,* 412 – 419.

Magliano, L., Fiorillo, A., De Rosa, C., Malangone, C., & Maj, M. (2005). Family burden in long-term diseases: a comparative study in schizophrenia vs. physical disorders. *Social Sciences& Medicine, 61,* 313–322.

Magliano, L., Fiorillo, A., Malangone, C., Marasco, C., Guarneri, M., Maj, M., et al. (2003). The effect of social network on burden and pessimism in relatives of patients with schizophrenia. *American Journal of Orthopsychiatry, 73*, 302–9.

Magliano, L., Marasco, C., Fiorillo, A., Guarneri, M., & Maj, M. (2002). The impact of professional and social network support on the burden of families of patients with schizophrenia in Italy. *Acta Psychiatrica Scandinavica, 106,* 291–298.

Magliano,L., Fiorillo, A., Malangone, C., De Rosa, C., &Maj, M. (2006). Social network in long-term diseases: A comparative study in relatives of persons with schizophrenia and physical illnesses versus a sample from the general population. *Social Science and Medicine, 62,* 1392–1402.

Mangalore, R., & Knapp, M. (2007). Cost of Schizophrenia in England. *The Journal of Mental Health Policy and Economics, 10,* 23 – 41.

Marder, S., Essock, S., Miller, A. (2004). Physical health monitoring of patients with schizophrenia. *American Journal of Psychiatry.* 161, 8, 1334-1349.

Marriott, A., Donaldson, C., Tarrier, N., & Burns, A. (2000). Effectiveness of cognitive— behavioural family intervention in reducing the burden of care in carers of patients with Alzheimer's disease. *The British Journal of Psychiatry*, *176*(6), 557-562.

Martens, L., & Addington, J. (2001). The psychological well-being of the family members of individuals with schizophrenia. *Social Psychiatry, 36,* 128–133.

McBride, C., Atkinson, L., Quilty, L. C., & Bagby, R. M. (2006). Attachment as moderator of treatment outcome in major depression: A randomized control trial of interpersonal psychotherapy versus cognitive behavior therapy. *Journal of Consulting and Clinical Psychology; Journal of Consulting and Clinical Psychology*, *74*(6), 1041.

McCreadie, R. G., Connolly, M. A., Williamson, D. J., Athawes, R. W., Tilak, D. (1994). The Nithsdale Schizophrenia Surveys. XII. ´Neurodevelopmental´ Schizophrenia: a Search for Clinical Correlates and Putative Aetiological Factors. *Br J Psychiatr* 1994; 165(3): 340-346.

McCreadie, R.G., Robertson, L.J., Hall, D.L. & Berry, I. (1993). The Nithsdale schizophrenia surveys. XI: Relatives' expressed emotion. Stability over five years and its relation to relapse. *The British Journal of Psychiatry, 162,* 393–397.

McCrone P., Szmukler G., & Kuipers E. (2005) Service use and cost associated with caring for people with serious mental illness. *Journal of Mental Health, 14,* 37-47.

Meeks, S., & Hammond, C.T. (2001). Social network characteristics among older outpatients with long-term mental illness. *Journal of Mental Health and Aging, 7*, 445−464.

Meeks, T. W., Jeste, D. V. (2008). Beyond the black box: what is the role for antipsychotics in dementia? *Current Psychiatry,* 7(6): 50-65.

Meltzer, H.Y. (1998). Suicide in schizophrenia: risk factors and clozapine treatment. *Journal of Clinical Psychiatry, 59* (S3), 15-20.

Meyer, J. M. (2001) Novel antipsychotics and severe hyperlipidemia. *Journal of Clinical Psychopharmacology, 21*, 369– 374.

Mikulincer, M., & Florian,V. (1995). Appraisal of and coping with a real-life stressful situation: The contribution of attachment styles. *Personality and Social Psychology Bulletin*, *21*, 406–414.

Mikulincer, M., &Florian,V. (2001). Attachment style and affect regulation: Implications for coping with stress and mental health. In G. J. O. Fletcher & M. S. Clark (Eds.), *Blackwell handbook of social psychology: Interpersonal processes* (pp. 537–557). Oxford: Blackwell.

Mikulincer, M., Shaver, P.R., & Pereg, D. (2003). Attachment Theory and Affect Regulation: The Dynamics, Development, and Cognitive Consequences of Attachment-Related Strategies. *Motivation and Emotion, 27*, 77-102.

Miller, F., Dworkin, J., Ward, M. &Barone, D. (1990). A preliminary study of unresolved grief in families of seriously mentally ill patients. *Hospital and Community Psychiatry, 12,* 1321 – 1325.

Miller, F.E. (1996). Grief therapy for relatives of persons with serious mental illness. *Psychiatric Services, 47,* 633 – 637.

Miyamotto, Y., Ito., H., Otsuka, T. & Kurita, H. (2002). Caregiver burden in mobile and non-mobile demented patients: a comparative study. *International Journal of Geriatric Psychiatry, 17,* 765 – 773.

Miyamotto, Y., Ito., H., Otsuka, T. & Kurita, H. (2002). Caregiver burden in mobile and non-mobile demented patients: a comparative study. *International Journal of Geriatric Psychiatry, 17,* 765 – 773.

Mowbray, C., & Mowbray, O. (2006). Psychosocial outcomes of adult children of mothers with depression and bipolar disorder. *Journal of Emotional and Behavioural Disorders 14* (3), 130–142.

Mowbray, C.T., Bybee, D., Oyserman, D., MacFarlane, P., & Bowersox, N. (2006). Psychosocial outcomes for adult children of parents with severe mental illnesses: demographic and clinical history predictors. *Health in Social Work 31*(2), 99–108.

Mowbray, C.T., Lewandowski, L., Bybee, D., & Oyserman, D. (2004). Children of mothers diagnosed with serious mental illness: patterns and predictors of service use. *Mental Health Services Research 6*(3), 167–183.

Moore, E. & Kuipers, E. (1999). The measurement of expressed emotion in relationships between staff and service users: The use of short speech samples. *Clinical Psychology, 38,* 345 – 356.

Moore, E., Ball, R.A. &Kuipers, L. (1992).Expressed emotion in staff working with the long-term mentally ill.*British Journal of Psychiatry, 12,* 802 – 808.

Morris, R.G., Morris, L.W., & Britton, P.G. (1988). Factors affecting emotional well-being of the caregivers of dementia sufferers. *British Journal of Psychiatry, 153,* 147–156.

Moss-Morris, R., Weinman, J., Petri, K., Horne, R., Camerons, L.D. & Buick, D. (2002).The revised illness perception questionnaire.*Psychology and Health, 17,* 1 -16.

Mueser, K. T., Doonan, R., Perm, D. L., Blanchard, J. J., Bellack, A. S., Nishith, P., & de Leon, J. (1996). Emotion recognition and social competence in chronic schizophrenia. *Journal ofAbnormal Psychology,* 105:271-275.

Naslund, B., Persson-Blennow, I., McNeil, T., Kaij, L. & Malmquist-Larsson, A. (1984). Offspring of women with nonorganic psychosis: infant attachment to the mother at one year of age. *Acta Psychiatr Scand, 69*(3), p. 231 – 241.

National Institute for Clinical Excellence (2009). Schizophrenia (Update).*Retrieved May 26, 2012, from (*http://www.guidance.nice.org.uk/CG82*).*

Navaie-Waliser, M., Spriggs, A., & Feldman, P. H. (2002). Informal caregiving. Differential experiences by gender. *Medical Care, 40(12),* 1249–1259.

Norman, R. M. G., Lewis, S. W. & Marshall, M. (2005) Duration of untreated psychosis and its relationship to clinical outcome. *British Journal of Psychiatry, 187* (suppl. 48), s19 - s23.

Obegi, J. & Berant, E. (2009). *Attachment Theory and Research in Clinical Work with Adults.* London: Guildford Press.

Ohaeri, J.U. (2003). The burden of caregiving in families with a mental illness; a review of 2002. *Current Opinion in Psychiatry, 16,* 457–465

Olstad, R., Sexton, H. & Sogaard, A. J. (1999). The Finnmark study. Social support, social network and mental distress in a prospective population study. *Social Psychiatry and Psychiatric Epidemiology, 34*, 519.

Onwumere, J., Kuipers, E., Bebbington, P. (2011). Family interventions in Psychosis: Specificity and effectiveness. *Epidemiologia e Psichiatria Sociale*, 20, 113-119.

Onwumere, J., Kuipers, E., Bebbington, P., Dunn, G., Fowler, D., Freeman, D., et al. (2008). Caregiving and illness beliefs in the course of psychotic illness. *Canadian Journal of Psychiatry, 53,* 460–468.

Onwumere, J., Kuipers, E., Bebbington, P., Dunn, G., Freeman, D., Fowler, D., et al. (2009). Patient perceptions of caregiver criticism in psychosis. *The Journal of Nervous and Mental Disease, 197,* 85–91.

Östling, S. & Skoog, I. (2002). Psychotic symptoms and paranoid ideation in a nondemented population-based sample of the very old. *Ach Gen Psychiatry, 59* (1):53-59.

Ostman, M., & Kjellan, L. (2002). Stigma by association: Psychological factors in relatives of people with a mental illness. *The British Journal of Psychiatry, 181* (6), 494-498.

Palmer, B.W., Heaton, S.C., & Jeste, D.V. (1999). Older patients with schizophrenia: challenges in the coming decades. *Psychiatr Serv, 50,* 1178 – 1183.

Palmer, B.W., Heaton, S.C., & Jeste, D.V. (1999). Older patients with schizophrenia: challenges in the coming decades. *PsychiatrServ, 50,* 1178 – 1183.

Parabiaghi, A., Lasalvia, A., Bonetto, C., Cristafalo, D., Marrella, G., Tansella, M. & Ruggeri, M. (2007). Predictors of changes in caregiving burden in people with schizophrenia: a 3-year follow-up study in a community mental health service. *Acta Psychiatrica Scandinavica, 116,* 66 – 76.

Patterson, P., Birchwood, M. & Cochrane, R. (2000). Preventing the entrenchment of high expressed emotion in first episode psychosis: early developmental attachment pathways. *Australian and New Zealand Journal of Psychiatry, 34,* S191 – S197.

Patterson, P., Birchwood, M., & Cochrane, R. (2005). Expressed emotion as an adaptation to loss – prospective study in first episode psychosis. *British Journal of Psychiatry*, *187*, 59–64.

Patterson, T. L., Kaplan, R. M., Grant, I., Semple, S. J., Moscona, S., Koch, W. L., et al. (1996). Quality of well being in late life psychosis.*Psychiatry Research, 63,* 199−210.

Patterson, T. L., Klapow, J. C., Eastham, J. H., Heaton, R. K., Evans, J. D., Koch, W. L., et al. (1998). Correlates of functional status in older outpatients.*Psychiatry Research, 80,* 41−52.

Patterson, T. L., Semple, S. J., Shaw,W. S., Halpain, M., Moscona, S., Grant, I., et al. (1997). Self reported social functioning among older patients with schizophrenia. *Schizophrenia Research, 27,* 199−210.

Perlick, D. A., Rosenheck, R. A., Clarkin, J. F., Maciejewski, P. K., Sirey, J. A., Struening, E., et al. (2004). Impact of family burden and affective response on clinical outcome among patients with bipolar disorder. *Psychiatric Services, 55*(9), 1029-1035.

Perlick, D., Mattis, S., Stastny, P., & Teresi, J. (1992). Gender differences in cognition in schizophrenia. *Schizophrenia research, 8*(1), 69-73.

Perlick, D.A., Hohenstein, J.M., Clarkin, J.F., Kaczynski, R., &Rosenheck, R.A. (2005). Use of mental health and primary care services by caregivers of patients with bipolar disorder: a preliminary study. *Bipolar Disorders, 7,* 126–135.

Peterson, E. C., & Docherty, N. M. (2004). Expressed emotion, attribution, and control in parents of schizophrenic patients.*Psychiatry, 67,* 197–207.

Pharoah, F., Mari, J., Rathbone, J., & Wong, W. (2006). Family intervention for schizophrenia. *Cochrane Database of Systematic Reviews*, *4*(4).

Phelan, M., Slade, M., Thornicroft, G., Dunn, G., Holloway, F., Wykes, T., et al. (1995). The Camberwell Assessment of Need: The validity and reliability of an instrument to assess the needs of people with severe mental illness. *British Journal of Psychiatry, 167,* 589−595.

Phillips, A. C., Gallagher, S., Hunt, K., Der, G., & Carroll, D. (2009). Symptoms of depression in non-routine caregivers: The role of caregiver strain and burden. *British Journal of Clinical Psychology, 48,* 335–346.

Phillips, M. R., Pearson, V., Feifei, L. I., Minjie, X. U. & Yang, L. (2002). Stigma and expressed emotion: A study of people with schizophrenia and their family members in China. *British Journal of Psychiatry, 181,* 488–493.

Pitschel-Walz, G. Leucht, S., Baumi, J. *et al.* (2001). The effect of family interventions on relapse and rehospitalisation in schizophrenia– a meta-analysis. *Schizophrenia Bulletin, 27,* 73 – 92.

Platt, S. (1985). Measuring burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychological Medicine, 15,* 383 – 393.

Platt, S., Weyman, A., Hirsch, S., & Hewett, S. (1980). The Social Behaviour Assessment Schedule (SBAS): rationale, contents, scoring and reliability of a new interview schedule. *Social Psychiatry and Psychiatric Epidemiology,15*(1), 43-55.

Quinn, M. E., Johnson, M. A., Andress, E. L. & Mcginnis, P. (2003). Health characteristics of elderly residents in personal care homes: Dementia, Possible early dementia, and no dementia. *Journal of Gerontological Nursing. 29* (8):16-23,.

Raune, D., Kuipers, E., &Bebbington, P. E. (2004). Expressed emotion at first-episode psychosis: investigating a carer appraisal model. *British Journal of Psychiatry, 184,* 321–326.

Roberts, J. S, Connell, C. M. (2000). Illness representations among first-degree relatives of people with Alzheimer disease. *Alzheimer Dis Assoc Disord.* 14(3), 129–136.

Roick, C., Heider, D., Bebbington, P.E., Angermeyer, M.C., Azorin, J.M., Brugha, T.S., et al. (2007). Burden on caregivers of people with schizophrenia: Comparison between Germany and Britain. *British Journal of Psychiatry, 190,* 333–338.

Rose, L. E. (1996). Families of psychiatric patients: a critical review and future research directions. *Archives of Psychiatric Nursing*, *10*(2), 67-76.

Rutter, M., & Brown, G. W. (1966). The reliability and validity of measures of family life and relationships in families containing a psychiatric patient. *Social Psychiatry and Psychiatric Epidemiology, 1,* 38-53.

Sanbrook, M., & Harris, A. (2003). Origins of early intervention in first-episode psychosis. *Australian Psychiatry, 11(2),* 215-219.

Sarason, I. G., Levine, H. M., Basham, R. B., & Sarason, B. R. (1983). Assessing social support: The social support questionnaire. *Journal of personality and social psychology, 44*(1), 127.

Sarason, I. G., Sarason, B. R., & Pierce, G. R. (1992). Three contexts of social support. *The meaning and measurement of social support*, 143-154.

Sarason, I.G., Sarason, B.R., Shearin, E.N. & Pierce, G.R. (1987). A brief measure of social support: Practical and theoretical implications. *Journal of Social and Personal Relationships, 4,* 497 – 510.

Scazufca, M. & Kuipers, E. (1996). Links between expressed emotion and burden of care in relatives of patients with schizophrenia. *British Journal of Psychiatry, 168,* 580–587.

Scazufca, M. & Kuipers, E. (1998). Stability of expressed emotion in relatives of those with schizophrenia and its relationship with burden of care and perception of patients' social functioning. *Psychological Medicine, 28,* 453 – 461.

Scazufca, M., &Kuipers, E. (1999). Coping strategies in relatives of people with schizophrenia before and after psychiatric admission. *British Journal of Psychiatry, 174,* 154–158.

Schene, A., van Wijngaarden, B., &Koeter, M. W. (1998). Family caregiving in schizophrenia: domains and distress. *Schizophrenia Bulletin, 24,* 609–618.

Schoos, R.,&Cohen, C. I. (2003). Medical co-morbidity in older persons with schizophrenia. In C. I. Cohen (Ed.), *Schizophrenia into later life* (pp. 113−140). Arlington: American Psychiatric Publishing.

Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 15, 2215–2219.

Seeman, M. (2007). An Outcome Measure in Schizophrenia: Mortality. *The Canadian Journal of Psychiatry,* 52(1) 55-59.

Segal, D.L., Coolidge, F.L., Mincic, M.S. & O'Riley, A. (2005). Beliefs about mental illness and willingness to seek help: A cross-sectional study. *Aging Ment Health, 9*(4), p. 363 – 367.

Shahly, V., Chatterji, S., Gruber, M. J., Al-Hamzawi, A., Alonso, J., Andrade, L. H., & Kessler, R. C. (2012). Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys.*Psychological Medicine*, *1*(1), 1-15.

Shaver, P. R., & Hazan, C. (1993). Adult romantic attachment: Theory and evidence. *Advances in personal relationships, 4*, 29-70.

Shaver, P.R. &Mikulincer, M. (2002). Attachment-related psychodynamics. *Attachment and Human Development, 4,* 133 – 161.

Shefer, G., Rose, D., Nellums, L., Thornicroft, G., Henderson, C. & Evans-Lacko, S. (2012). ‘Our community is the worst’: The influence of cultural beliefs on stigma, relationships with family and help-seeking in three ethnic communities in London. *Int J Soc Psychiatry* [epub ahead of print]

Smith, J., Birchwood, M., Cochrane, R., & George, S. (1993). The needs of high and low expressed emotion families: a normative approach. Social Psychiatry and Psychiatric Epidemiology, 28(1), 11-16.

Smith, J., Birchwood, M., Cochrane, R., et al. (1993). The needs of high and low expressed emotion families: a normative approach. *Social Psychiatry and Psychiatric Epidemiology,* 28, 11.

Stockford, K., Turner, H. & Cooper, M. (2007). Illness perception and its relationship to readiness to change in the eating disorders: A preliminary investigation. *British Journal of Clinical Psychology, 46,* 139 – 154.

Stone, R.I. & Short, P.F. (1990). The competing demands of employment and informal caregiving to disabled elders. *Medical Care, 28,* 513 – 526.

Struening, E., Perlick, D., Link, B., Hellman, F., Herman, D., & Sirey, J. (2001). Stigma as a barrier to recovery: The extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services, 52,* 1633–1638.

Struening, E.L., Stueve, a., Vine, p., et al. (1995). Factors associated with grief and depressive symptoms in caregivers of people with serious mental illness. *Research in Community and Mental Health, 8,* 91-94.

Stueve, A., Vine, P. & Struening, E. L. (1997). Perceived burden among caregivers of adults with serious mental illness: comparison of Black, Hispanic and White families. *American Journal of Orthopsychiatry, 67*, 199 -209.

Szmukler, G. I., Burgess, P., Herrman, H., Benson, A., Colusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: the development of the Experiences of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemiology, 31,* 137–148.

Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W., et al. (2003). An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis. *Social Psychiatry and Psychiatric Epidemiology, 38,* 411–418.

Tait, L., Birchwood, M., &Trower, P. (2004). Adapting to the challenge of psychosis: Personal resilience and the use of sealing-over (avoidant) coping strategies. *British Journal of Psychiatry, 185,* 410 – 415.

Targum, S. D. (2001) Treating psychotic symptoms in elderly patients. *Primary Care Companion to the Journal of Clinical Psychiatry, 3*, 156–163.

Targum, S. D. & Abbott, J. L. (1999). Pyschosis in the elderly: a spectrum of disorders. *Journal of Clinical Psychiatry, 60* (suppl. 8), 4.

Tasca, G. A., Kowal, J., Balfour, L., Ritchie, K., Virley, B., & Bissada, H. (2006). An attachment insecurity model of negative affect among women seeking treatment for an eating disorder. *Eating behaviors*, *7*(3), 252-257.

Tebes, J.K., Kaufman, J.S., Adnopoz, J., & Racusin, G. (2001). Resilience and family psychosocial processes among children of parents with serious mental disorders. *Journal of Child & Family Studies 10*(1), 115–136.

Ten, H. M., Vollerbergh, W., Bij, L. R. & Ormel, J. (2002). Combined effect of mental disorder and low social support on care service use for mental health problems in the Dutch general population. *Psychological Medicine, 32,* 311- 323.

Ten, H.M., Vollerbergh, W., Bij, L.R. and Ormel, J. (2002).Combined effect of mental disorder and low social support on care service use for mental health problems in the Dutch general population. *Psychological Medicine, 32,* 311- 323.

Tomlinson, E.K. (2009). Are social cognition difficulties related to distress, understanding of problems and negative relationships in patients with earl psychosis and their carers? (DClinPsy thesis).

Tomlinson, E.K. (2009). Are social cognition difficulties related to distress, understanding of problems and negative relationships in patients with earl psychosis and their carers? (DClinPsy thesis).

Tompson, M. C., Goldstein, M. J., Lebell, M. B., Mintz, L. I., Marder, S. R., & Mintz, J. (1995). Schizophrenic patients' perceptions of their relatives' attitudes. *Psychiatry Research,* 57:155-167.

Treanor, L., Lobban, F. & Barrowclough, C. (2011). Relatives' responses to psychosis: An exploratory investigation of low expressed emotion relatives. Psychology and Psychotherapy: Theory Research and Practice *Psychiatry* [epub ahead of print]

Tryssenaar, J., & Tremblay, M. (2002). Aging with a serious mental disability in rural Northern Ontario: Family members's experiences. *Psychiatric Rehabilitation Journal, 25,* 255–264.

Van Os, J. (2003). Is there a continuum of psychotic experiences in the general population? *Epidemiologia e psichiatria sociale, 12*, 242-252.

Vaughan, C.E. & Leff, J.P. (1976). The influence of family and social factors on the course of psychiatric illness: a comparison of schizophrenic and depressed neurotic patients. *British Journal of Psychiatry, 129,* 125 – 137.

Veltman, A., Cameron, J. I., & Stewart, D. E. (2002). The experience of providing care to relatives with chronic mental illness. *Journal of Nervous and Mental Disorders, 190,* 108–114.

Vitaliano, P. P., Young, H. M., Russo, J., Romano, J., & Magana-Amato, A. (1993). Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer's disease? *Journal of Gerontology: Psychological Sciences, 48B,* P202-P209.

Vitaliano, P.P., Zhang, J. & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull, 129*(6), p. 946 – 972.

Waller, H., Garety, P., Jolley, S., Fornells-Ambrojo, M., Kuipers, E., Onwumere, J., et al. (2012). Low intensity cognitive behavioural therapy for psychosis: A pilot study. *Journal of Behavior Therapy and Experimental Psychiatry*.

Wearden, A.J., Tarrier, N., Barrowclough, C., Zastowny, T., & Armstrong, A. (2002).A review of expressed emotion research in health care. *Clinical Psychology Review,20*, 633–666.

Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health, 11,* 431–445.

Weinstein, N.D. (1988). The precaution adoption process. *Health Psychology, 4*, 355-86.

White, R., Bebbington, P., Pearson, J., Johnson, S. & Ellis, D. (2000). The social context of insight in schizophrenia.*Social psychiatry and psychiatric epidemiology, 35,* 500 – 507.

Wilcox, S. & King, A.C. (1999). Sleep complaints in older women who are family caregivers. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 54B*, 189-198.

Williams, S. W., Dilworth-Anderson, P., & Goodwin, P. (2003). Caregiver role strain: The contribution of multiple roles and available resources in African-American women. *Aging & Mental Health, 7*(2), 103-112.

Wittmund, B., Wilms, H.U., Mory, C. &Angermeyer, M.C. (2002).Depressive disorders in spouses of mentally ill patients. *Social Psychiatry and Psychiatric Epidemiology, 37,* 177 – 182.

Woo, S., Goldstein, M., & Nuechterlein, K. (2004). Relatives' affective style and the expression of subclinical psychopathology in patients with schizophrenia. *Family Process, 43*, 233-247.

World Health Organization (1992).*The ICD-10 Classification of Mental and Behavioural Disorders.* Geneva: WHO.

Yalom, I. D. & Leszcz, M. (2005). *The Theory and Practice of Group Psychotherapy.* Basic Books.

Zigmond, A., & Snaith, R. (1983). The Hospital Anxiety and Depression scale. *Acta Psychiatrica Scandinavica, 67,* 361–370.

Zubin, J., & Spring, B. (1977). Vulnerability: a new view of schizophrenia.*Journal of Abnormal Psychology; Journal of Abnormal Psychology*, *86*(2), 103.

APPENDIX A

GENERAL INFORMATION QUESTIONNAIRE

For each question, either write the answer on the line or tick the box which most applies to you. Some questions may have more than one answer.

1. Date of birth ------/------/---------
(dd/mm/yyyy)

……………………………………………………………………………………………

2. Your gender
☐ Male
☐ Female

……………………………………………………………………………………………

3. Gender of person you care for
☐ Male
☐ Female

……………………………………………………………………………………………

4. Ethnic background
☐ White ☐ Black Caribbean
☐ Black African ☐ Black Other
☐ Indian ☐ Pakistani
☐ Other → please specify______________

……………………………………………………………………………………………

5. Is English your first language?

☐ Yes
☐ No → What is your first language? ___________

……………………………………………………………………………………………

6. What is your relationship status?

☐ Single ☐ Married
☐ Divorced ☐ Separated
☐ Widowed ☐ Cohabiting/living with another
☐ Other → please specify__________________

……………………………………………………………………………………………

7. Are you
☐ employed full-time ☐ a full-time student
☐ employed part-time ☐ a part-time student
☐ self-employed ☐ unemployed
☐ a homemaker ☐ retired
☐ Other → please specify__________________

……………………………………………………………………………………………

Please Turn Over →

8. How old is the person you care for? ________________________

……………………………………………………………………………………………

9. How would you specify your relationship to the person you care for?

I am their:

☐ Daughter ☐ Son
☐ Brother ☐ Sister
☐ Partner ☐ Spouse
☐ Mother ☐ Father
☐ Friend
☐ Other → please specify__________________

……………………………………………………………………………………………

10. Do you know the diagnosis of the person you care for?

☐ Yes → please specify_________________________
☐ No

……………………………………………………………………………………………

11. Does the person live with you?

☐ Yes
☐ No → ☐ They reside in privately owned/rented accommodation
☐ They reside in sheltered accommodation
☐ They reside in council accommodation
☐ Other → please specify_________________________

……………………………………………………………………………………………

12. Approximately, how long have you known the person you care for?__________________

……………………………………………………………………………………………

13. Approximately, for how long has the person you care for had their current difficulties with their mental health? ____________________

……………………………………………………………………………………………

14. Are you a parent/legal guardian to any children under the age of 18 years?

☐ Yes → How many children? _______________
☐ No

……………………………………………………………………………………………

15. Do you provide care to any one else (other than the above)?

☐ Yes → How many people? _______________
☐ No

APPENDIX B

FIVE MINUTE SPEECH SAMPLE – INSTRUCTIONS

I'd like to hear your thoughts and feelings about (relative's name) in your own words and without interrupting with any questions or comments. When I ask you to begin, I'd like you to speak for five minutes, telling me what kind of a person s/he is and how the two of you get along together. It may feel a little strange at first, but there are no right or wrong answers. I'll tell you when 5 minutes has passed so try to keep talking until then. After you begin to speak, I prefer not to answer any questions until after the five minutes are over. Do you have any questions before we begin?

Give minimal eye contact. If necessary, give eye contact and prompt using the following neutral statements:

-Take your time/ you've got a bit more time left.
-Anything else?

Keep the stopwatch going for five minutes and stop only if they are struggling or refuse to continue.

Rated by: Date rated: Participant Number: Parent:			Mother	Father
Initial Statement:		positive	neutral	negative
Quality of Relationship: code each statement	Overall rating:	positive	neutral	negative
Criticism:	Total number:			
Dissatisfaction:			Y	N
Total CRIT EE:		high	borderline	low
Emotional Over-involvement:				
Self-sacrificing/ overprotective			Y	N
Emotional display			Y	N
Excessive detail:			Y	N
Positive remarks	Total number: Excessive praise (5+)?		Y	N
Statements of attitude	Total number:			
Total EOI EE:		high	borderline	low
Other Notes				

APPENDIX C

Time Budget Measure

ID:………………………………….   Date:………………….

We are interested in finding out a bit more about how you / the service user spends your / their time. This would include activities outside the home, such as work, study, any groups or centres that you / the service user attend, how you / the service user spends your / their leisure time, as well as home-based things for example, watching TV, reading, cooking and housework.

I would also like to know about social activities- seeing or going out with friends, talking on the phone, chatting to neighbours or other people and so on.

1. What activities do you do on a weekly basis? (Populate table below)
2. Have you done any additional activities other than the ones that you just told me about? (Populate table below)

M Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	
T Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	
W Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	
T Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	

F Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	

S Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	

S Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	

3. Thinking about the past week, perhaps we could divide up each day and think about what you have done. Could you describe an average day? (Populate table below)

A Morning	N	R	Middle of Day	N	R	Afternoon	N	R	Evening	N	

4. Are there any things that you are not doing at the moment, but have plans to do, or would like to do in the future?

5. How satisfied are you with what you have been doing in the past week on a scale of 1-5, with 1 = not satisfied, and 5 = very satisfied?

1 2 3 4 5

6. If you are not satisfied, what would need to happen to make you more satisfied?

APPENDIX D

Hospital Anxiety and Depression Score (HADS)

This questionnaire asks questions about how you are feeling. Read every sentence. Circle the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more importan

A	**I feel tense or 'wound up':**	
	▪ Most of the time	3
	▪ A lot of the time	2
	▪ From time to time (occ.)	1
	▪ Not at all	0
D	**I still enjoy the things I used to enjoy:**	
	▪ Definitely as much	0
	▪ Not quite as much	1
	▪ Only a little	2
	▪ Hardly at all	3
A	**I get a sort of frightened feeling as if something awful is about to happen:**	
	▪ Very definitely and quite badly	3
	▪ Yes, but not too badly	2
	▪ A little, but it doesn't worry me	1
	▪ Not at all	0
D	**I can laugh and see the funny side of things:**	
	▪ As much as I always could	0
	▪ Not quite so much now	1
	▪ Definitely not so much now	2
	▪ Not at all	3
A	**Worrying thoughts go through my mind:**	
	▪ A great deal of the time	3
	▪ A lot of the time	2
	▪ From time to time, but not often	1
	▪ Only occasionally	0
D	**I feel cheerful:**	
	▪ Not at all	3
	▪ Not often	2
	▪ Sometimes	1
	▪ Most of the time	0
A	**I can sit at ease and feel relaxed:**	
	▪ Definitely	0
	▪ Usually	1
	▪ Not often	2
	▪ Not at all	3

D	**I feel as if I am slowed down:**	3
	▪ Nearly all the time	2
	▪ Very often	1
	▪ Sometimes	0
	▪ Not at all	
A	**I get a sort of frightened feeling like "butterflies" in the stomach:**	
	▪ Not at all	0
	▪ Occasionally	1
	▪ Quite often	2
	▪ Very often	3
D	**I have lost interest in my appearance:**	
	▪ Definitely	3
	▪ I don't take as much care as I should	2
	▪ I may not take quite as much care	1
	▪ I take just as much care	0
A	**I feel restless as I have to be on the move:**	
	▪ Very much indeed	3
	▪ Quite a lot	2
	▪ Not very much	1
	▪ Not at all	0
D	**I look forward with enjoyment to things:**	
	▪ As much as I ever did	0
	▪ Rather less than I used to	1
	▪ Definitely less than I used to	2 3
	▪ Hardly at all	
A	**I get sudden feelings of panic:**	3
	▪ Very often indeed	2
	▪ Quite often	1
	▪ Not very often	0
	▪ Not at all	
D	**I can enjoy a good book or radio/TV program:**	
	▪ Often	0
	▪ Sometimes	1
	▪ Not often	2
	▪ Very seldom	3

APPENDIX E

INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADL)

A. Ability to use telephone	☐ Operates telephone on own initiative; looks up and dials numbers, etc. ☐ Dials a few well-known numbers, etc. ☐ Answers telephone but does not dial ☐ Does not use telephone at all
B. Shopping	☐ Takes care of all shopping needs independently ☐ Shops independently for small purchases ☐ Needs to be accompanied on any shopping trip ☐ Completely unable to shop
C. Food preparation	☐ Plan, prepares and serves adequate meals independently ☐ Prepares adequate meals if supplied with ingredients ☐ Heats, serves and prepares meals or prepares meals but does not maintain adequate diet ☐ Needs to have meals prepared and served
D. Housekeeping	☐ Maintains house alone or with occasional assistance (e.g. 'heavy work domestic help') ☐ Performs light daily tasks such as dishwashing, bed making ☐ Performs light daily tasks but cannot maintain acceptable level of cleanliness ☐ Needs help with all home maintainence tasks ☐ Does not participate in any housekeeping tasks
E. Laundry	☐ Does personal laundry completely ☐ Launders small items; rinses stockings, etc. ☐ All laundry must be done by others

F. Mode of transportation	☐ Travels independently on public transportation or drives own car ☐ Arranges own travel via taxi, but does not otherwise use public transportation ☐ Travels of public transportation when accompanied by another ☐ Travel limited to taxi or automobile with assistance of another ☐ Does not travel at all
G. Responsibility for own medications	☐ Is responsible for taking medication in correct dosages at correct time ☐ Takes responsibility if medication is prepared in advance in separate dosage ☐ Is not capable of dispensing own medication
H. Ability to handle finances	☐ Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income. ☐ Mangages day-to-day purchases, but needs help with banking, major purchases, etc. ☐ Incapable if handling money.

PHYSICAL SELF MAINTENANCE SCALE (PSMS)

Circle one statement in each category that applies to the person you care for:

A. Toilet

1. Cares for self at toilet completely, no incontinence
2. Needs to be reminded or needs help cleaning self, or has rare (weekly at most) accidents
3. Soiling or wetting while asleep more than once a week
4. Soiling or wetting while awake more than once a week
5. No control of bowels or bladder

B. Feeding

1. Eats without assistance
2. Eats with minor assistance at meal times and/or with special preparation of food, or help in cleaning up after meals
3. Feeds self with moderate assistance and is untidy
4. Requires extensive assistance for all meals
5. Does not feed self at all and resists efforts of others to feed him/her

C. Dressing

1. Dresses, undresses, and selects clothing from own wardrobe
2. Dresses and undresses self, with minor assistance
3. Needs moderate assistance in dressing or selection of clothes
4. Needs major assistance in dressing, but cooperates with efforts of others to help
5. Completely unable to dress self and resists efforts of others to help

D. Grooming (neatness, hair, nails, hands, face, clothing)

1. Always neatly dressed, well-groomed, without assistance

2. Grooms self adequately with occasional minor assistance, e.g.. shaving

3. Needs moderate and regular assistance or supervision in grooming

4. Needs total grooming care, butt can remain well-groomed after help from others

5. Actively negates all efforts of others to maintain grooming

E. Physical Ambulation

1. Goes about grounds or city

2. Ambulates within residence or about one block distant

3. Ambulates with assistance of (circle one):

    i. Another person
    ii. Railing
    iii. Cane
    iv. Walker
    v. Wheelchair
        1. Gets in and out without help
        2. Needs help getting in, out

F. Bathing

1. Bathes self (tub, shower, sponge bath) without help

2. Bathes self with help in getting in and out of tub

3. Washes face and hands only, but cannot bathe rest of body

4. Does not wash self, but is cooperative with those who bathe him/her

5. Does not try to wash self, and resists efforts to keep him/her clean

APPENDIX F

EXPERIENCE OF CAREGIVING INVENTORY

The following statements commonly apply to persons who care for relative or friends with a serious mental illness. We would like you to read each statement and decide how often it has applied to you over the **PAST ONE MONTH.** If it has **never** happened or **rarely** happened you would CIRCLE the number 0 or 1. If it has happened **sometimes**, then you would CIRCLE the number 2. If it has happened **often** or seems to have happened **nearly always**, then you would CIRCLE the number 3 or 4. It is important to note that there are no right or wrong answers. Also it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While there seem to be a lot of statements, you will find that it won't take more than a moment or so to answer each one.

During the past month *how often have you thought about:*

		NEVER	***RARELY***	***SOME-TIMES***	***OFTEN***	***NEAR ALWA***
1.	Your covering up his/her illness	0	1	2	3	4
2.	Feeling unable to tell anyone of the illness	0	1	2	3	4
3.	His/her difficulty looking after money	0	1	2	3	4
4.	Having to support him/her	0	1	2	3	4
5.	What life he/she might have had	0	1	2	3	4
6.	His/Her risk of committing suicide	0	1	2	3	4
7.	I have learnt more about myself	0	1	2	3	4
8.	I have contributed to others understanding of the illness	0	1	2	3	4
9.	Being unable to do the things you want to do	0	1	2	3	4
10.	How health professionals do not take you seriously	0	1	2	3	4
11.	His/Her dependence on you	0	1	2	3	4
12.	Helping him/her to fill in the day	0	1	2	3	4
13.	I have contributed to his/her wellbeing	0	1	2	3	4
14.	That he/she makes a valuable contribution to the household	0	1	2	3	4
15.	The effect on your finances if he/she becomes more seriously ill	0	1	2	3	4
16.	Dealing with psychiatrists	0	1	2	3	4
17.	Him/Her always being at the back of your mind	0	1	2	3	4
18.	Whether you have done something to make him/her ill	0	1	2	3	4
19.	That he/she has shown strengths in coping with her illness	0	1	2	3	4
20.	I have become more confident in dealing with others	0	1	2	3	4
21.	How family members do not understand your situation	0	1	2	3	4
22.	That he/she is good company	0	1	2	3	4
23.	I have become more understanding of others with problems..	0	1	2	3	4
24.	How he/she thinks a lot about death	0	1	2	3	4
25.	His/Her lost opportunities	0	1	2	3	4
26.	How to deal with mental health professionals	0	1	2	3	4
27.	Feeling unable to have visitors at home	0	1	2	3	4
28.	How he/she gets on with other family members	0	1	2	3	4
29.	Backing him/her up when she runs out of money	0	1	2	3	4

30. How family members do not understand the illness	0	1	2	3	4
31. How he/she deliberately attempts to harm herself	0	1	2	3	4
32. I have become closer to some of my family	0	1	2	3	4
33. I have become closer to friends	0	1	2	3	4
34. I share some of his/her interests	0	1	2	3	4
35. I feel useful in my relationship with him/her	0	1	2	3	4
36. How health professionals do not understand your situation	0	1	2	3	4
37. Whether he/she will ever get well	0	1	2	3	4
38. Feeling the stigma of having a mentally ill relative	0	1	2	3	4
39. How to explain his/her illness to others	0	1	2	3	4
40. Others leaving home because of the effect of his/her illness	0	1	2	3	4
41. Setting him/her up in accommodation	0	1	2	3	4
42. How to make complaints about his/her care	0	1	2	3	4
43. I have met helpful people	0	1	2	3	4
44. I have discovered strengths in myself	0	1	2	3	4
45. Feeling unable to leave him/her home alone	0	1	2	3	4
46. The effect of the illness on children in the family	0	1	2	3	4
47. The illness causing a family breakup	0	1	2	3	4
48. Him/Her keeping bad company	0	1	2	3	4
49. How his/her illness effects special family events	0	1	2	3	4
50. Finding out how hospitals or mental health services work	0	1	2	3	4
51. Doctors' knowledge of the services available to families	0	1	2	3	4
52. The difficulty getting information about her illness	0	1	2	3	4

<u>During the past month</u> *how often have you thought about him/her being:*

53. Moody	0	1	2	3	4
54. Unpredictable	0	1	2	3	4
55. Withdrawn	0	1	2	3	4
56. Uncommunicative	0	1	2	3	4
57. Not interested	0	1	2	3	4
58. Slow at doing things	0	1	2	3	4
59. Unreliable about doing things	0	1	2	3	4
60. Indecisive	0	1	2	3	4
61. Irritable	0	1	2	3	4
62. Inconsiderate	0	1	2	3	4
63. Behaving in a reckless way	0	1	2	3	4
64. Suspicious	0	1	2	3	4
65. Embarrassing in appearance	0	1	2	3	4
66. Behaving in a strange way	0	1	2	3	4

APPENDIX G

Social Support Questionnaire (Short Form)

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people know, excluding yourself, whom you can count on for help or support in the manner described. Give the persons initials, their relationship to you (see example).

If you have had no support for a question, check the words "No one".

EXAMPLE:

Who do you know whom you can trust with information that could get you in trouble?

☐ No one	1) A.B. (Mother)	4) G.H. (friend)	7)
	2) C.D. (Father)	5)	8)
	3) E.F. (Partner)	6)	9)

For the second part, circle how satisfied you are with the overall support you have, even if you have selected "No one".

1a) Whom can you really count on to be dependable when you need to help?

☐ No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

1b) How satisfied?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

---

2a) Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

☐ No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

2b) How satisfied?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

---

3a) Who accepts you totally, including both your worst and your best points?

☐ No one 1) 4) 7)
2) 5) 8)
3) 6) 9)

3b) How satisfied?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

---

4a) Whom can you really count on to care about you, regardless of what is happening to you?

☐ No one 1) 4) 7)
2) 5) 8)
3) 6) 9)

4b) How satisfied?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

---

5a) Whom can you really count on to help you feel better when you are feeling generally down-in-the dumps?

☐ No one 1) 4) 7)
2) 5) 8)
3) 6) 9)

5b) How satisfied?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

---

6a) Whom can you count on to console you when you are very upset?

☐ No one

1)

2)

3)

4)

5)

6)

7)

8)

9)

6b) How satisfied?

6	5	4	3	2	1
Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied

APPENDIX H

PAMS-R

SELF-REPORT MEASURE

We all differ in how we relate to other people. This questionnaire lists different thoughts, feelings and ways of behaving in relationships with others.

PART A

Thinking generally about how you relate to other key people in your life, please use a tick the relevant box to show how much each statement is like you. Key people could include family members, friends, or partners, etc. There are no right or wrong answers.

	Not at all	**A little**	**Quite a bit**	**Very much**
1. I prefer not to let other people know my 'true' thoughts and feelings.				
2. I find it easy to depend on other people for support with problems or difficult situations.				
3. I tend to get upset, anxious or angry if other people are not there when I need them.				
4. I usually discuss my problems and concerns with other people.				
5. I worry that key people in my life won't be around in the future.				
6. I ask other people to reassure me that they care about me.				
7. If other people disapprove of something I do, I get very upset.				
8. I find it difficult to accept help from other people when I have problems or difficulties.				
9. It helps to turn to other people when I'm stressed.				
10. I worry that if other people get to know me better, they won't like me.				

	Not at all	**A little**	**Quite a bit**	**Very much**
11. When I'm feeling stressed, I prefer being on my own to being in the company of other people.				
12. I worry a lot about my relationships with other people.				
13. I try to cope with stressful situations on my own.				
14. I worry that if I displease other people, they won't want to know me anymore.				
15. I worry about having to cope with problems and difficult situations on my own.				
16. I feel uncomfortable when other people want to get to know me better.				

PART B

In answering the previous questions, what relationships were you thinking about?

____
(E.g. relationship with mother, father, sister, brother, husband, wife, friend, romantic partner, etc)

APPENDIX I

BRIEF ILLNESS PERCEPTION QUESTIONNAIRE

For the following questions, please circle the number that best corresponds to your views:

1. How much do his/her problems/illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
No affect at all										*Severely affects my life*

2. How long do you think his/her problems/illness will continue?

0	1	2	3	4	5	6	7	8	9	10
A very short time										*Forever*

3. How much control do you feel he/she has over his/her problems/illness?

0	1	2	3	4	5	6	7	8	9	10
Absolutely no control										*Extreme control*

4. How much do you think his/her treatment can help him/her problems/illness?

0	1	2	3	4	5	6	7	8	9	10
Not at all helpful										*Extremely helpful*

5. How much does he/she experience symptoms from his/her problems/illness?

0	1	2	3	4	5	6	7	8	9	10
No symptoms at all										*Many severe symptoms*

6. How concerned are you about his/her problems/illness?

0	1	2	3	4	5	6	7	8	9	10
Not at all concerned										*Extremely concerned*

7. How well do you feel you understand his/her problems/illness?

0	1	2	3	4	5	6	7	8	9	10
Don't understand at all										*Understand very clearly*

8. How much do his/her problems/illness affect you emotionally? (e.g. does it make you angry, scared, upset, or depressed?)

0	1	2	3	4	5	6	7	8	9	10
Not at all affected emotionally										*Extremely affected emotionally*

Please list in rank-order the ***three*** *most important factors that you believe caused his/****her problems/illness***

1. ____

2. ____

3. ____

APPENDIX J

BRIEF COPE

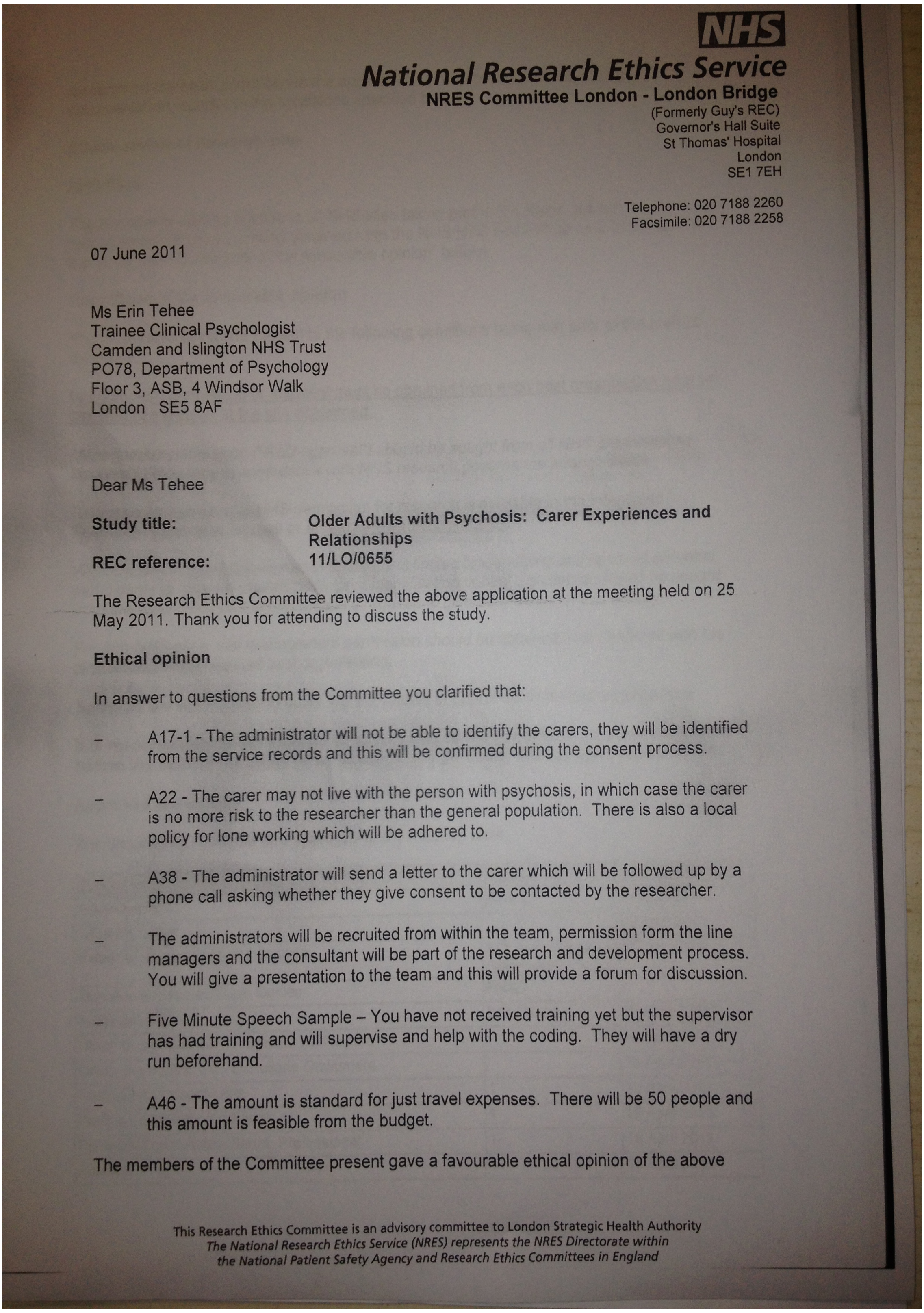
These items deal with ways you've been coping with the stress in your life as a result of caring for someone with a severe mental illness. There are many ways to try to deal with stress and difficulties. These items ask what you've been doing to cope with stress and difficulties specific to looking after the person for whom you care.

Obviously, different people deal with things in different ways, but I'm interested in how you have tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says, in addition to how much or how frequently. Don't answer on the basis of whether it seems to be working or not, just whether or not you're doing it. Use the response choices given. Try to rate each item separately in your mind from the others. Make you answer as true FOR YOU as you can. To answer, for each item place an 'X' under the response that indicates most accurately how much you have been using this way of coping.

	1 = I haven't been doing this at all	***2 = I've been doing this a little bit***	***3 = I've been doing this a medium amount***	***4 = I've been doing this a lot***
1. I've been turning to work or other activities to take my mind off things.				
2. I've been concentrating my efforts on doing something about the situation I'm in.				
3. I've been saying to myself "this isn't real."				
4. I've been using alcohol or other drugs to make myself feel better.				
5. I've been getting emotional support from others.				
6. I've been giving up trying to deal with it.				
7. I've been taking action to try to make the situation better.				
8. I've been refusing to believe that it has happened.				
9. I've been saying things to let my unpleasant feelings escape.				

	1 = I haven't been doing this at all	***2 = I've been doing this a little bit***	***3 = I've been doing this a medium amount***	***4 = I've been doing this a lot***
10. I've been getting help and advice from other people.				
11. I've been using alcohol or other drugs to help me get through it.				
12. I've been trying to see it in a different light, to make it seem more positive.				
13. I've been criticizing myself.				
14. I've been trying to come up with a strategy about what to do.				
15. I've been getting comfort and understanding from someone.				
16. I've been giving up the attempt to cope.				
17. I've been looking for something good in what is happening.				
18. I've been making jokes about it.				
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.				
20. I've been accepting the reality of the fact that it has happened.				
21. I've been expressing my negative feelings.				
22. I've been trying to find comfort in my religion or spiritual beliefs.				
23. I've been trying to get advice or help from other people about what to do.				
24. I've been learning to live with it.				
25. I've been thinking hard about what steps to take.				
26. I've been blaming myself for things that happened.				
27. I've been praying or meditating.				
28. I've been making fun of the situation.				

APPENDIX K



NHS
National Research Ethics Service
NRES Committee London - London Bridge
(Formerly Guy's REC)
Governor's Hall Suite
St Thomas' Hospital
London
SE1 7EH

Telephone: 020 7188 2260
Facsimile: 020 7188 2258

07 June 2011

Ms Erin Tehee
Trainee Clinical Psychologist
Camden and Islington NHS Trust
PO78, Department of Psychology
Floor 3, ASB, 4 Windsor Walk
London SE5 8AF

Dear Ms Tehee

Study title: **Older Adults with Psychosis: Carer Experiences and Relationships**
REC reference: **11/LO/0655**

The Research Ethics Committee reviewed the above application at the meeting held on 25 May 2011. Thank you for attending to discuss the study.

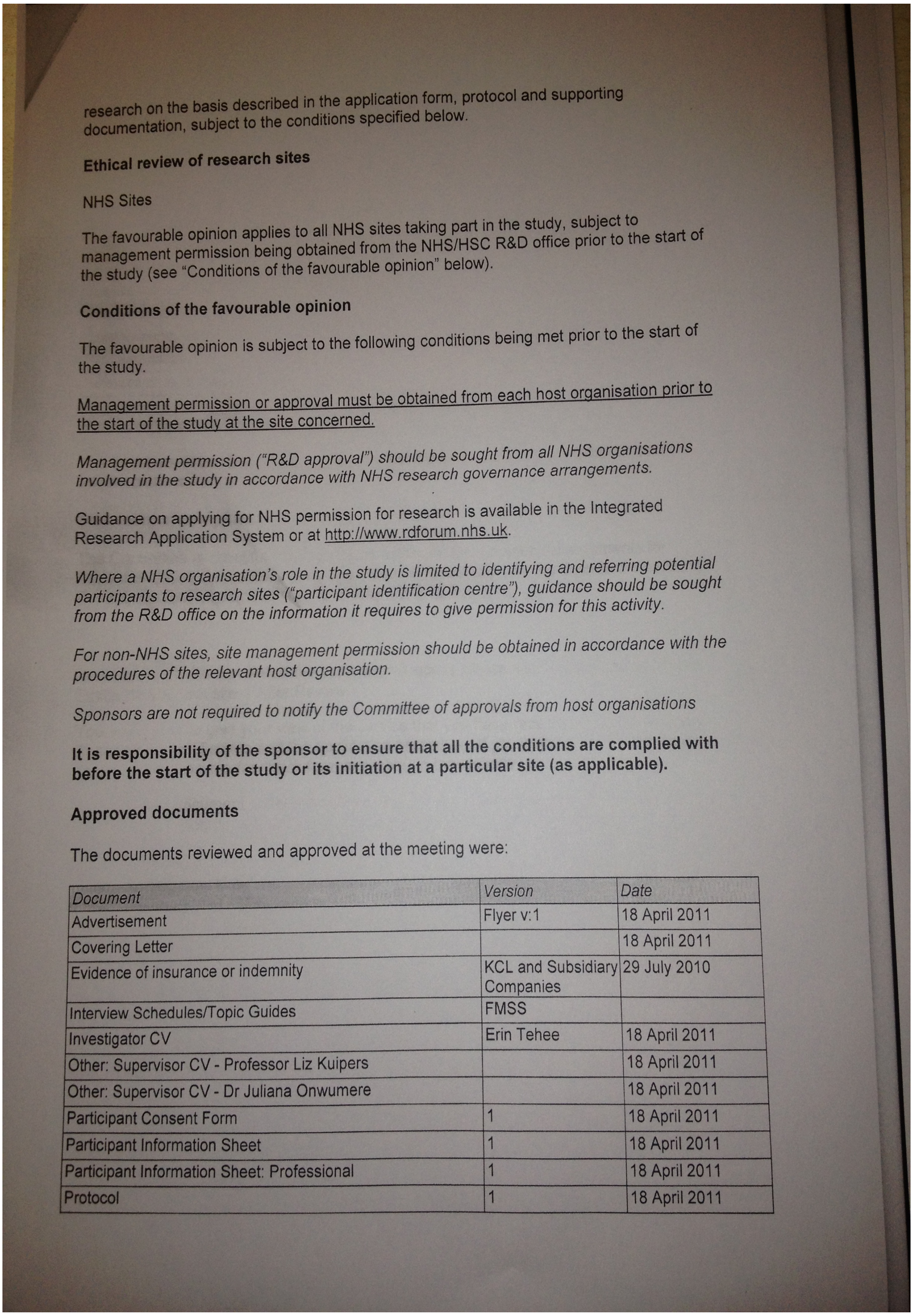
Ethical opinion

In answer to questions from the Committee you clarified that:

- A17-1 - The administrator will not be able to identify the carers, they will be identified from the service records and this will be confirmed during the consent process.
- A22 - The carer may not live with the person with psychosis, in which case the carer is no more risk to the researcher than the general population. There is also a local policy for lone working which will be adhered to.
- A38 - The administrator will send a letter to the carer which will be followed up by a phone call asking whether they give consent to be contacted by the researcher.
- The administrators will be recruited from within the team, permission form the line managers and the consultant will be part of the research and development process. You will give a presentation to the team and this will provide a forum for discussion.
- Five Minute Speech Sample – You have not received training yet but the supervisor has had training and will supervise and help with the coding. They will have a dry run beforehand.
- A46 - The amount is standard for just travel expenses. There will be 50 people and this amount is feasible from the budget.

The members of the Committee present gave a favourable ethical opinion of the above

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England



research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

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

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

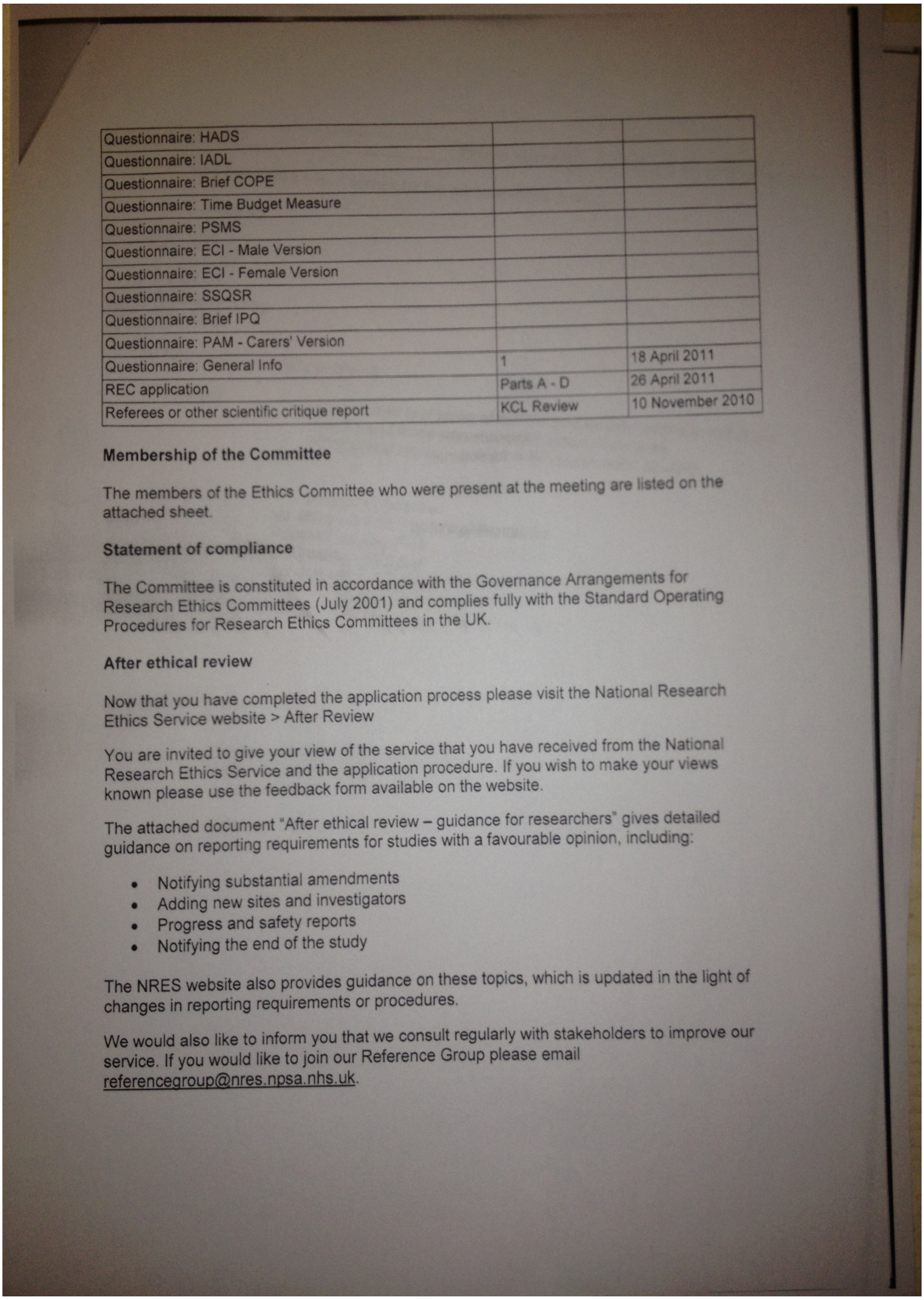
Sponsors are not required to notify the Committee of approvals from host organisations

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Advertisement	Flyer v:1	18 April 2011
Covering Letter		18 April 2011
Evidence of insurance or indemnity	KCL and Subsidiary Companies	29 July 2010
Interview Schedules/Topic Guides	FMSS	
Investigator CV	Erin Tehee	18 April 2011
Other: Supervisor CV - Professor Liz Kuipers		18 April 2011
Other: Supervisor CV - Dr Juliana Onwumere		18 April 2011
Participant Consent Form	1	18 April 2011
Participant Information Sheet	1	18 April 2011
Participant Information Sheet: Professional	1	18 April 2011
Protocol	1	18 April 2011



Questionnaire: HADS		
Questionnaire: IADL		
Questionnaire: Brief COPE		
Questionnaire: Time Budget Measure		
Questionnaire: PSMS		
Questionnaire: ECI - Male Version		
Questionnaire: ECI - Female Version		
Questionnaire: SSQSR		
Questionnaire: Brief IPQ		
Questionnaire: PAM - Carers' Version		
Questionnaire: General Info	1	18 April 2011
REC application	Parts A - D	26 April 2011
Referees or other scientific critique report	KCL Review	10 November 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

After ethical review

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

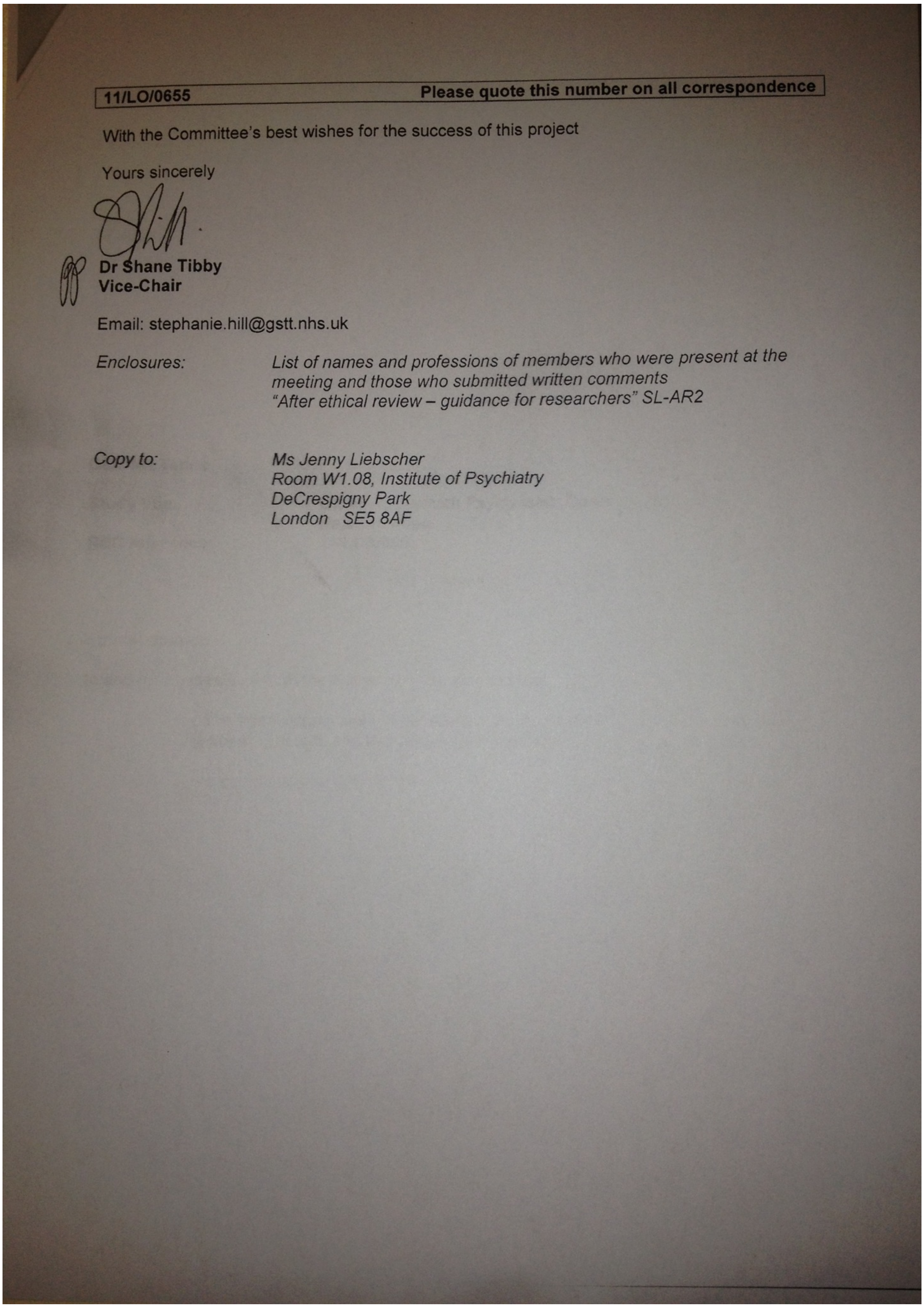
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

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

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

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



11/LO/0655 **Please quote this number on all correspondence**

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

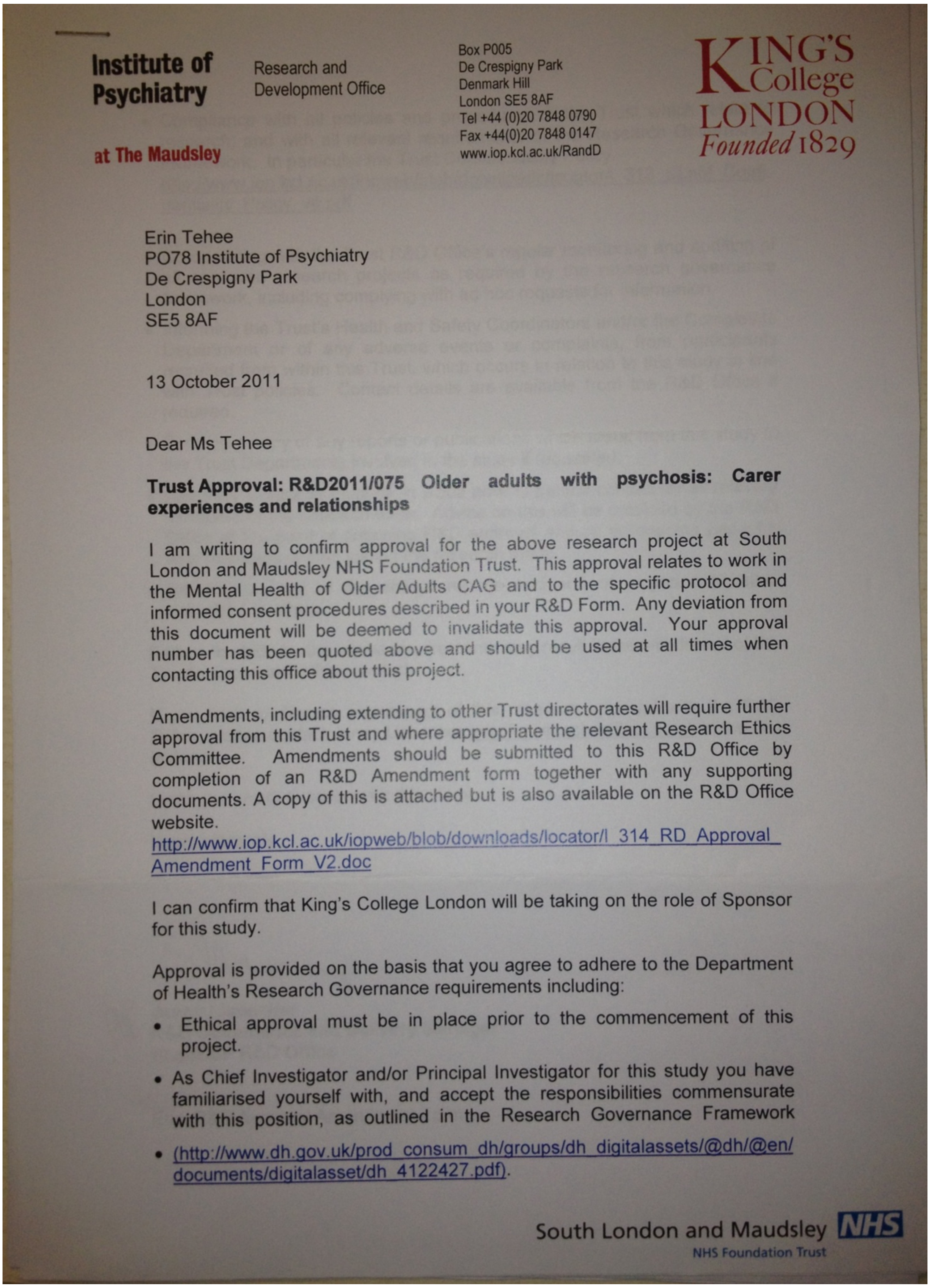
Yours sincerely

Dr Shane Tibby
Vice-Chair

Email: stephanie.hill@gstt.nhs.uk

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* *"After ethical review – guidance for researchers" SL-AR2*
Copy to:	*Ms Jenny Liebscher* *Room W1.08, Institute of Psychiatry* *DeCrespigny Park* *London SE5 8AF*

APPENDIX L



Institute of Psychiatry
at The Maudsley

Research and Development Office

Box P005
De Crespigny Park
Denmark Hill
London SE5 8AF
Tel +44 (0)20 7848 0790
Fax +44(0)20 7848 0147
www.iop.kcl.ac.uk/RandD

KING'S College LONDON Founded 1829

Erin Tehee
PO78 Institute of Psychiatry
De Crespigny Park
London
SE5 8AF

13 October 2011

Dear Ms Tehee

Trust Approval: R&D2011/075 Older adults with psychosis: Carer experiences and relationships

I am writing to confirm approval for the above research project at South London and Maudsley NHS Foundation Trust. This approval relates to work in the Mental Health of Older Adults CAG and to the specific protocol and informed consent procedures described in your R&D Form. Any deviation from this document will be deemed to invalidate this approval. Your approval number has been quoted above and should be used at all times when contacting this office about this project.

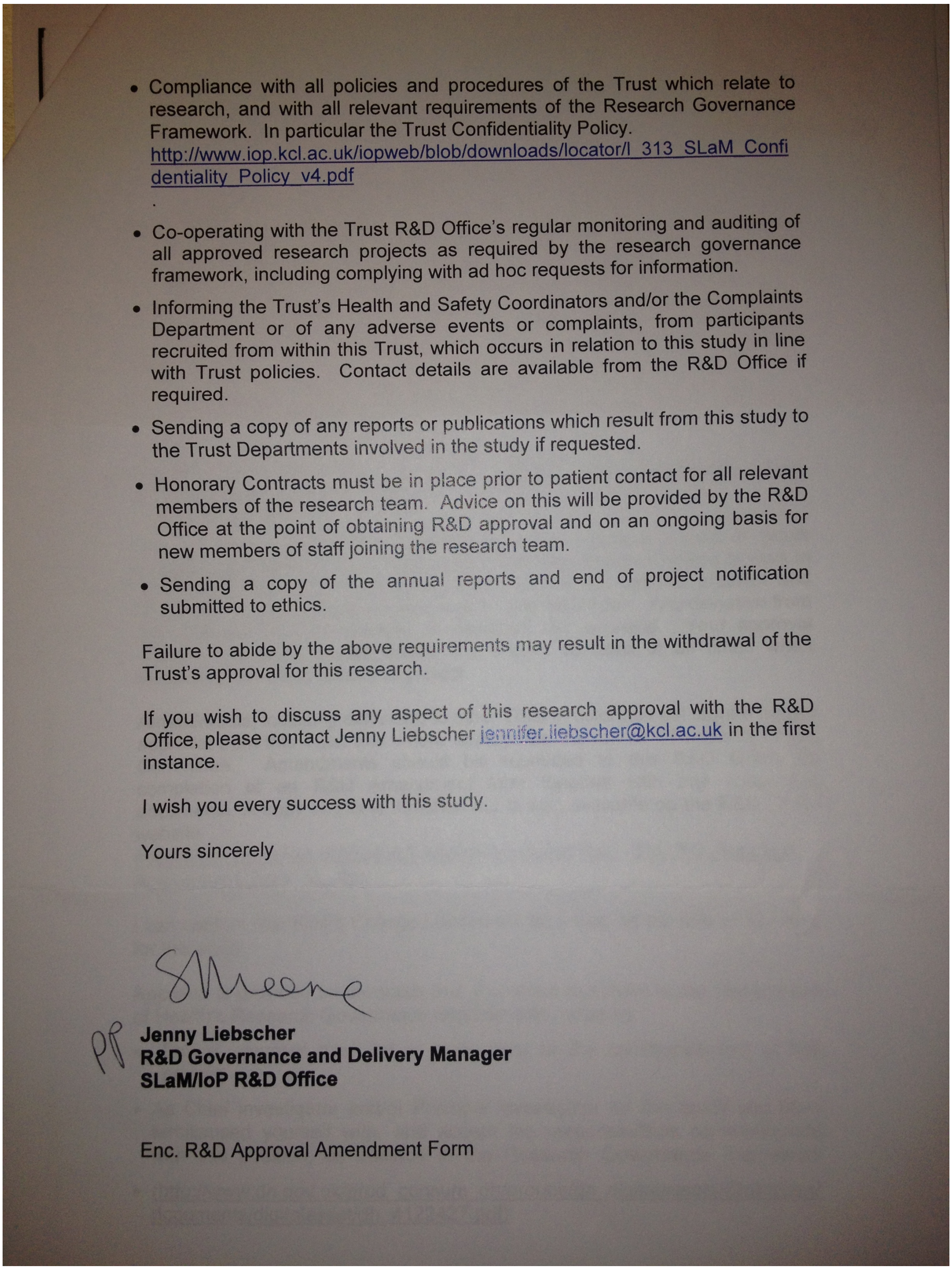
Amendments, including extending to other Trust directorates will require further approval from this Trust and where appropriate the relevant Research Ethics Committee. Amendments should be submitted to this R&D Office by completion of an R&D Amendment form together with any supporting documents. A copy of this is attached but is also available on the R&D Office website.
http://www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/l_314_RD_Approval_Amendment_Form_V2.doc

I can confirm that King's College London will be taking on the role of Sponsor for this study.

Approval is provided on the basis that you agree to adhere to the Department of Health's Research Governance requirements including:

- Ethical approval must be in place prior to the commencement of this project.
- As Chief Investigator and/or Principal Investigator for this study you have familiarised yourself with, and accept the responsibilities commensurate with this position, as outlined in the Research Governance Framework
- (http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122427.pdf).

South London and Maudsley NHS
NHS Foundation Trust



- Compliance with all policies and procedures of the Trust which relate to research, and with all relevant requirements of the Research Governance Framework. In particular the Trust Confidentiality Policy. http://www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/l_313_SLaM_Confidentiality_Policy_v4.pdf
.
- Co-operating with the Trust R&D Office's regular monitoring and auditing of all approved research projects as required by the research governance framework, including complying with ad hoc requests for information.
- Informing the Trust's Health and Safety Coordinators and/or the Complaints Department or of any adverse events or complaints, from participants recruited from within this Trust, which occurs in relation to this study in line with Trust policies. Contact details are available from the R&D Office if required.
- Sending a copy of any reports or publications which result from this study to the Trust Departments involved in the study if requested.
- Honorary Contracts must be in place prior to patient contact for all relevant members of the research team. Advice on this will be provided by the R&D Office at the point of obtaining R&D approval and on an ongoing basis for new members of staff joining the research team.
- Sending a copy of the annual reports and end of project notification submitted to ethics.

Failure to abide by the above requirements may result in the withdrawal of the Trust's approval for this research.

If you wish to discuss any aspect of this research approval with the R&D Office, please contact Jenny Liebscher jennifer.liebscher@kcl.ac.uk in the first instance.

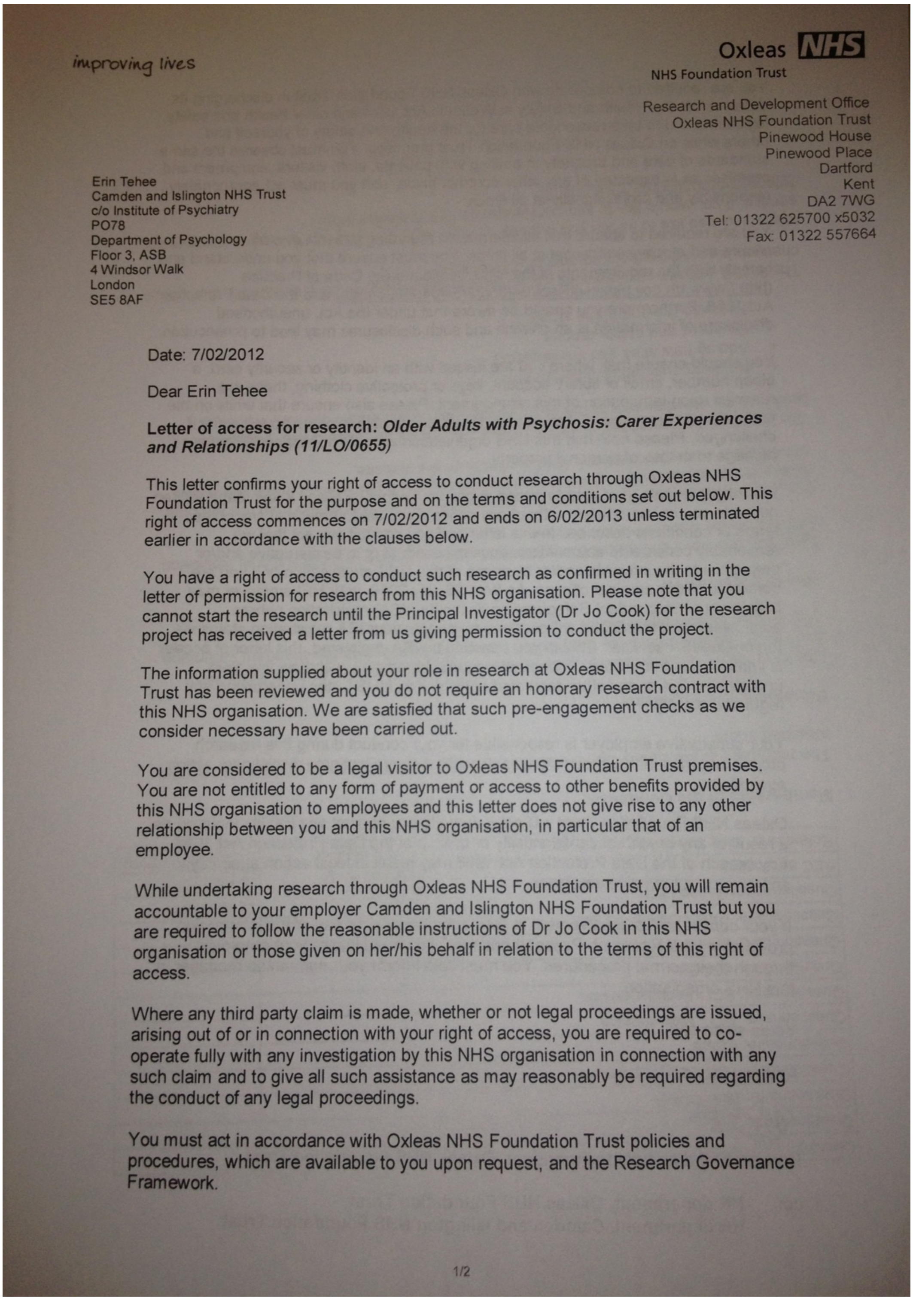
I wish you every success with this study.

Yours sincerely

pp **Jenny Liebscher**
R&D Governance and Delivery Manager
SLaM/IoP R&D Office

Enc. R&D Approval Amendment Form

APPENDIX M



improving lives

Oxleas NHS
NHS Foundation Trust

Research and Development Office
Oxleas NHS Foundation Trust
Pinewood House
Pinewood Place
Dartford
Kent
DA2 7WG
Tel: 01322 625700 x5032
Fax: 01322 557664

Erin Tehee
Camden and Islington NHS Trust
c/o Institute of Psychiatry
PO78
Department of Psychology
Floor 3, ASB
4 Windsor Walk
London
SE5 8AF

Date: 7/02/2012

Dear Erin Tehee

Letter of access for research: *Older Adults with Psychosis: Carer Experiences and Relationships (11/LO/0655)*

This letter confirms your right of access to conduct research through Oxleas NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 7/02/2012 and ends on 6/02/2013 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator (Dr Jo Cook) for the research project has received a letter from us giving permission to conduct the project.

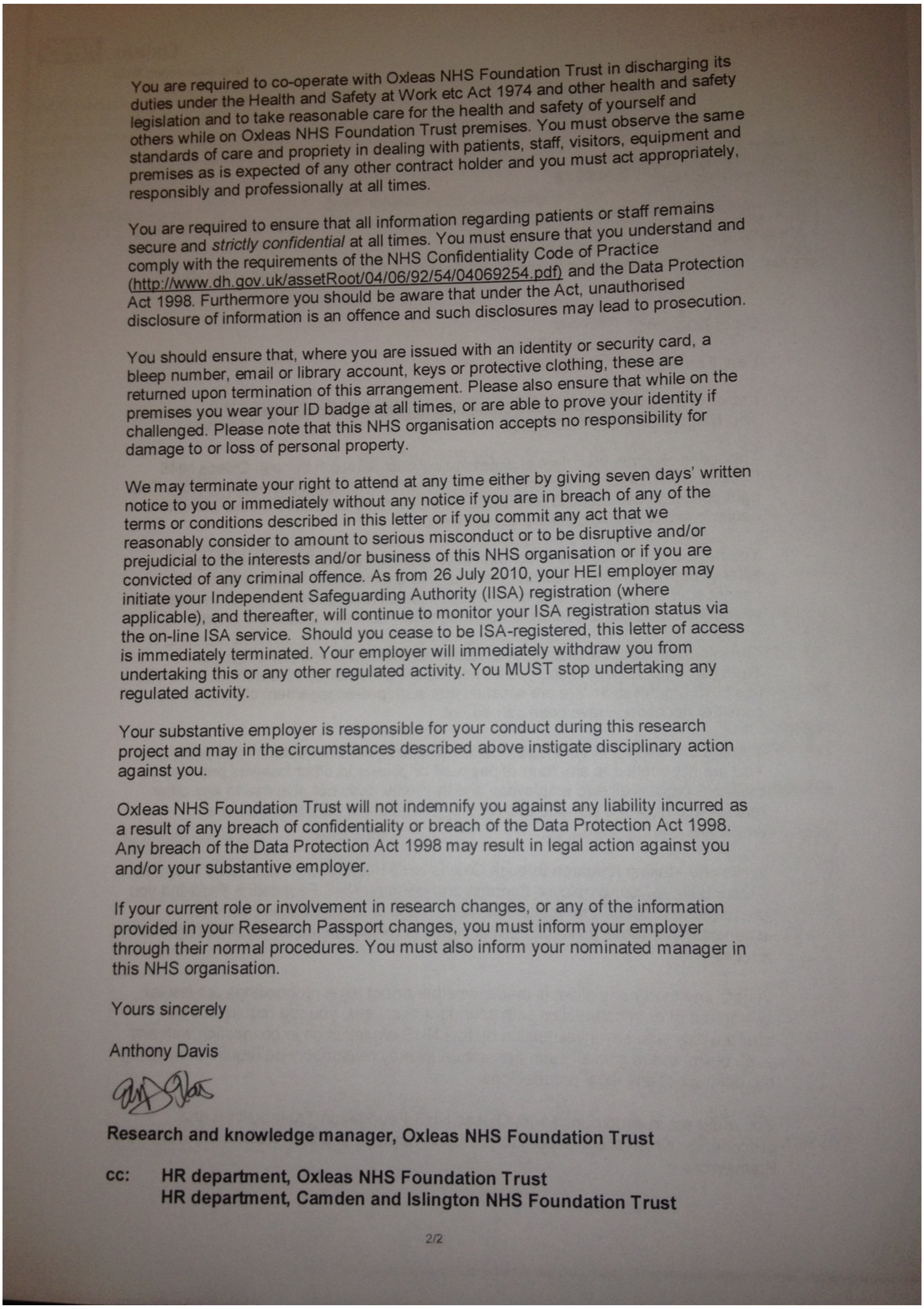
The information supplied about your role in research at Oxleas NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Oxleas NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Oxleas NHS Foundation Trust, you will remain accountable to your employer Camden and Islington NHS Foundation Trust but you are required to follow the reasonable instructions of Dr Jo Cook in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Oxleas NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.



You are required to co-operate with Oxleas NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Oxleas NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. As from 26 July 2010, your HEI employer may initiate your Independent Safeguarding Authority (IISA) registration (where applicable), and thereafter, will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity. You MUST stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Oxleas NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

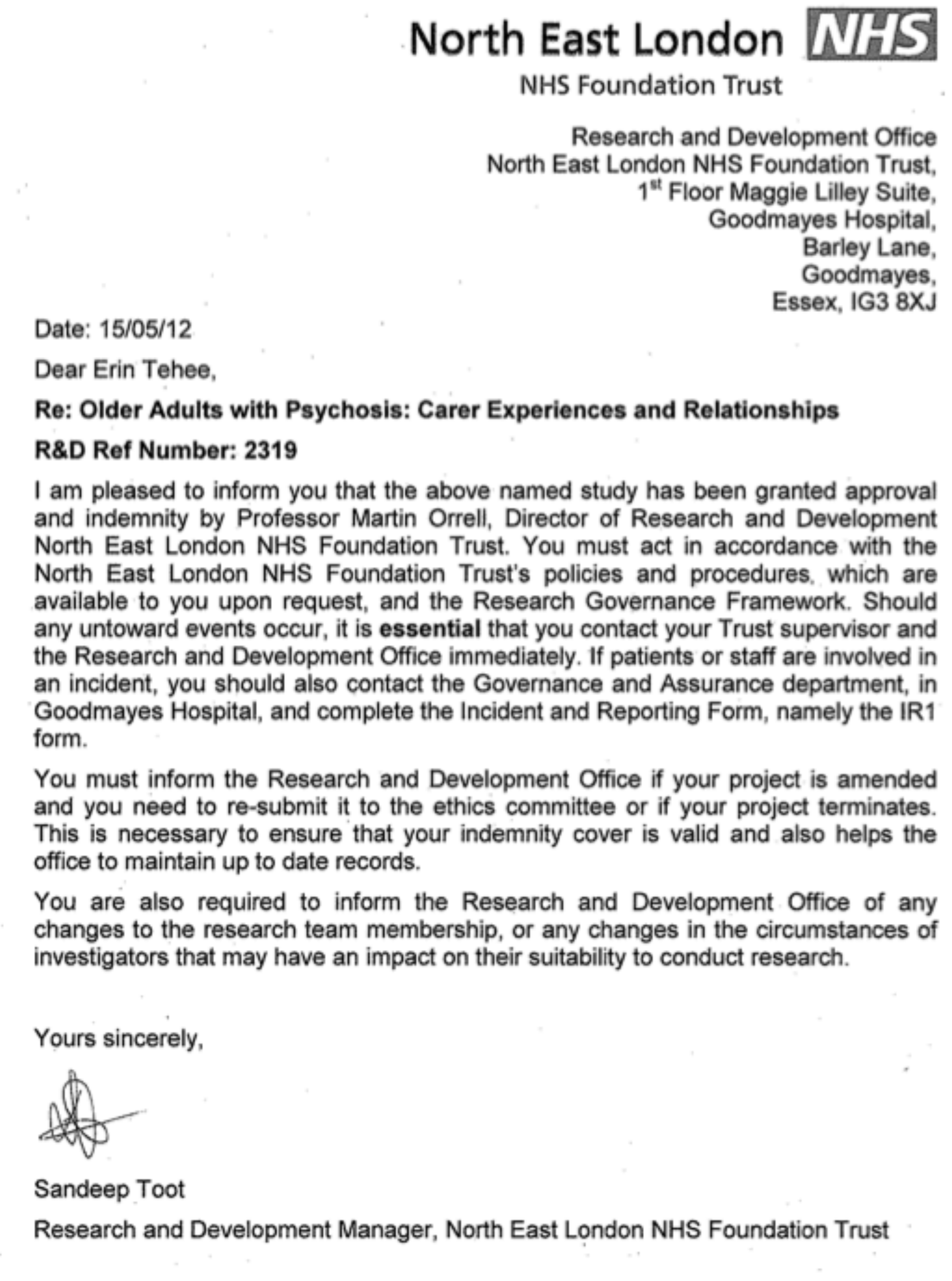
Anthony Davis

Research and knowledge manager, Oxleas NHS Foundation Trust

cc: **HR department, Oxleas NHS Foundation Trust**
HR department, Camden and Islington NHS Foundation Trust

2/2

APPENDIX N



North East London NHS
NHS Foundation Trust

Research and Development Office
North East London NHS Foundation Trust,
1st Floor Maggie Lilley Suite,
Goodmayes Hospital,
Barley Lane,
Goodmayes,
Essex, IG3 8XJ

Date: 15/05/12

Dear Erin Tehee,

Re: Older Adults with Psychosis: Carer Experiences and Relationships

R&D Ref Number: 2319

I am pleased to inform you that the above named study has been granted approval and indemnity by Professor Martin Orrell, Director of Research and Development North East London NHS Foundation Trust. You must act in accordance with the North East London NHS Foundation Trust's policies and procedures, which are available to you upon request, and the Research Governance Framework. Should any untoward events occur, it is **essential** that you contact your Trust supervisor and the Research and Development Office immediately. If patients or staff are involved in an incident, you should also contact the Governance and Assurance department, in Goodmayes Hospital, and complete the Incident and Reporting Form, namely the IR1 form.

You must inform the Research and Development Office if your project is amended and you need to re-submit it to the ethics committee or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records.

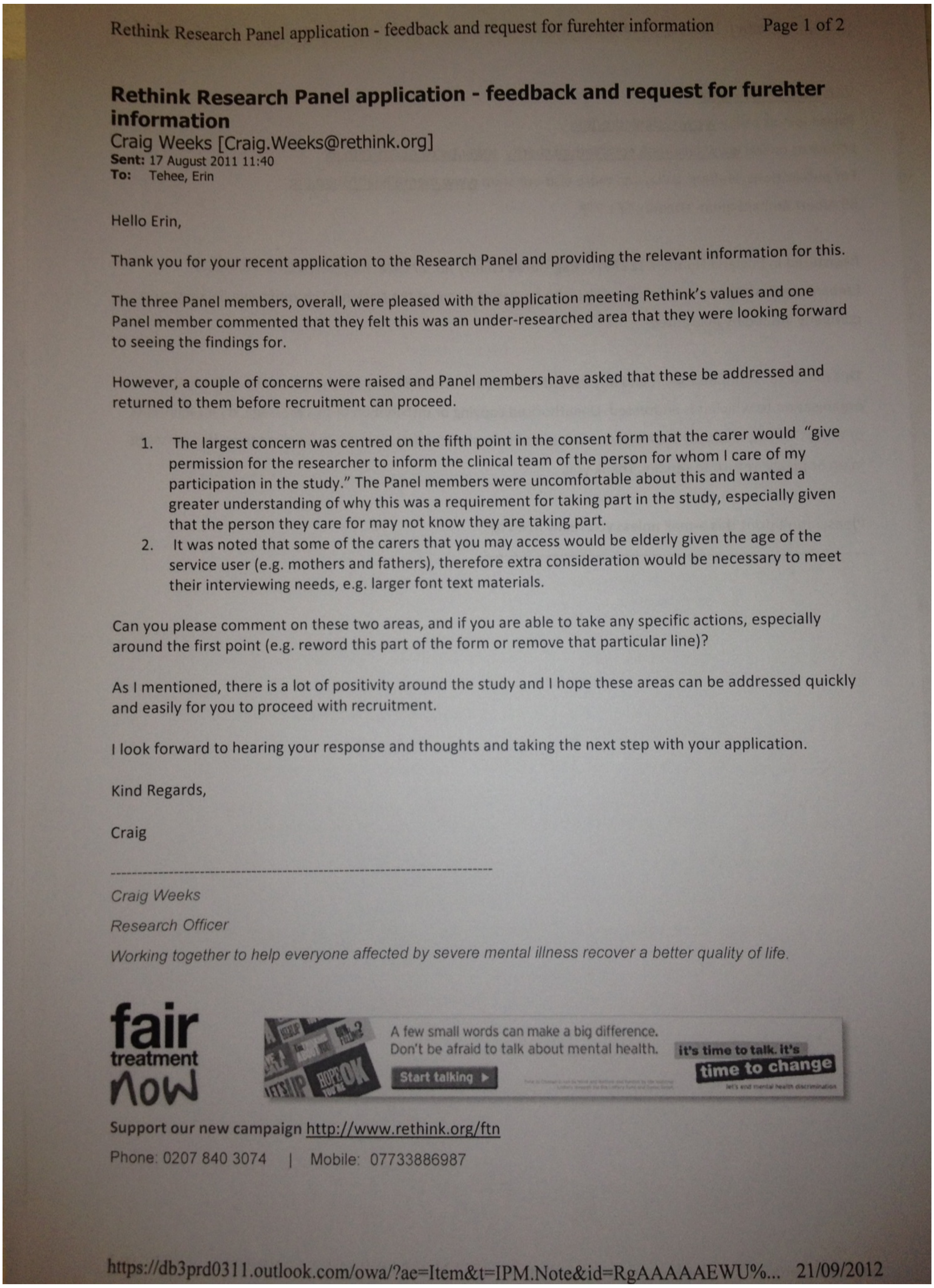
You are also required to inform the Research and Development Office of any changes to the research team membership, or any changes in the circumstances of investigators that may have an impact on their suitability to conduct research.

Yours sincerely,

Sandeep Toot

Research and Development Manager, North East London NHS Foundation Trust

APPENDIX O



Rethink Research Panel application - feedback and request for furehter information Page 1 of 2

Rethink Research Panel application - feedback and request for furehter information

Craig Weeks [Craig.Weeks@rethink.org]
Sent: 17 August 2011 11:40
To: Tehee, Erin

Hello Erin,

Thank you for your recent application to the Research Panel and providing the relevant information for this.

The three Panel members, overall, were pleased with the application meeting Rethink's values and one Panel member commented that they felt this was an under-researched area that they were looking forward to seeing the findings for.

However, a couple of concerns were raised and Panel members have asked that these be addressed and returned to them before recruitment can proceed.

1. The largest concern was centred on the fifth point in the consent form that the carer would "give permission for the researcher to inform the clinical team of the person for whom I care of my participation in the study." The Panel members were uncomfortable about this and wanted a greater understanding of why this was a requirement for taking part in the study, especially given that the person they care for may not know they are taking part.
2. It was noted that some of the carers that you may access would be elderly given the age of the service user (e.g. mothers and fathers), therefore extra consideration would be necessary to meet their interviewing needs, e.g. larger font text materials.

Can you please comment on these two areas, and if you are able to take any specific actions, especially around the first point (e.g. reword this part of the form or remove that particular line)?

As I mentioned, there is a lot of positivity around the study and I hope these areas can be addressed quickly and easily for you to proceed with recruitment.

I look forward to hearing your response and thoughts and taking the next step with your application.

Kind Regards,

Craig

Craig Weeks

Research Officer

Working together to help everyone affected by severe mental illness recover a better quality of life.

Support our new campaign http://www.rethink.org/ftn

Phone: 0207 840 3074 | Mobile: 07733886987

https://db3prd0311.outlook.com/owa/?ae=Item&t=IPM.Note&id=RgAAAAAEWU%... 21/09/2012

APPENDIX P

PROFESSIONAL INFORMATION SHEET

THE STUDY Carers of individuals with symptoms of psychosis are vulnerable to psychological distress and negative caregiving experiences. To date, there is a lack of literature on the experiences of *carers of older adults* with psychosis. This research is essential in both acknowledging the needs of such individuals and providing evidence based individually tailored interventions where necessary. The quality of the carer-patient relationship may influence the experience of the caregiving role and appraisal of the caregiving relationship and thus impact on carer outcomes. This study will explore the relationship between caregiving experiences and a number of other key variables in carers of older adults with psychosis in addition to providing descriptive analyses of this population's characteristics.

INCLUSION CRITERIA:

A participant must be:

- **A relative, friend or significant other of a service user (aged ≥ 60 years) with a diagnosis of a schizophrenia spectrum disorder, or psychosis in the context of dementia**
- **Be identified by themselves and the service records as being a carer and have frequent contact with the service user (including phone contact).**
- **Be over the age of 18 years.**
- **Be able to provide informed consent.**

INVOLVEMENT FOR PARTICIPANTS Once participants have agreed to take part in the study, the researcher will obtain informed consent. The researcher will then arrange a meeting with participants at a time that is convenient for them.

Participation involves the completion of a series of self-report questionnaires in addition to a brief interview (5 minutes). Participation will take approximately 1 hour 20 minutes. Participants will be reimbursed £25.

YOUR INVOLVEMENT If you know of any carers who meet criteria for this project, please ask them if they would be interested in participating. If they express interest we would be grateful if you could pass their contact details on to Erin Tehee, either by phone (07578269087) or email (erin.tehee@slam.nhs.uk or erin.tehee@kcl.ac.uk). Erin will then call or write to them.

We would appreciate if you could post the flyers, enclosed, on noticeboards or places where they are likely to be seen by carers. Additionally, please feel free to disseminate the flyers to individuals who may be interested in participation. We would be happy for them to contact Erin directly with the contact information provided.

ETHICAL APPROVAL This study has been approved by NHS National Research Ethics Service (NRES) London – London Bridge.

RESEARCH TEAM

This research is being completed as part of the Doctorate in Clinical Psychology by:

- Ms Erin Tehee – Main Researcher and Trainee Clinical Psychologist

And is supervised by:

- Dr Juliana Onwumere –Research Clinical Psychologist, Consultant Clinical Psychologist and Research Supervisor
- Professor Elizabeth Kuipers – Professor of Clinical Psychology, Consultant Clinical Psychologist and Research Supervisor

Thank you very much for taking time to read this information sheet

If you have any questions about the study please contact Erin Tehee by email at Erin.Tehee@slam.nhs.uk or Erin.Tehee@kcl.ac.uk or phone her on **07578269087**

APPENDIX Q

PROFESSIONAL INFORMATION SHEET

THE STUDY Carers of individuals with symptoms of psychosis are vulnerable to psychological distress and negative caregiving experiences. To date, there is a lack of literature on the experiences of *carers of older adults* with psychosis. This research is essential in both acknowledging the needs of such individuals and providing evidence based individually tailored interventions where necessary. The quality of the carer-patient relationship may influence the experience of the caregiving role and appraisal of the caregiving relationship and thus impact on carer outcomes. This study will explore the relationship between caregiving experiences and a number of other key variables in carers of older adults with psychosis in addition to providing descriptive analyses of this population's characteristics.

INCLUSION CRITERIA:

A participant must be:

- **A relative, friend or significant other of a service user (aged ≥ 60 years) with a diagnosis of a schizophrenia spectrum disorder.**
- **Be identified by themselves and the service records as being a carer and have at least 10 hours per week of contact with the service user (including phone contact).**
- **Be over the age of 18 years.**
- **Be able to provide informed consent.**

INVOLVEMENT FOR PARTICIPANTS Once participants have agreed to take part in the study, the researcher will obtain informed consent. The researcher will then arrange a meeting with participants at a time that is convenient for them.

Participation involves the completion of a series of self-report questionnaires in addition to a brief interview (5 minutes). Participation will take approximately 1 hour 20 minutes. Participants seen at home will be reimbursed £15. Participants seen at the Institute of Psychiatry will be reimbursed £20.

YOUR INVOLVEMENT If you know of any carers who meet criteria for this project, please ask them if they would be interested in participating. If they express interest we would be grateful if you could pass their contact details on to Erin Tehee, either by phone (07578269087) or email (erin.tehee@slam.nhs.uk or erin.tehee@kcl.ac.uk). Erin will then call or write to them.

We would be grateful if you could post the flyers, enclosed, on noticeboards or places where they are likely to be seen by carers. Additionally, please feel free to disseminate the flyers to individuals who may be interested in participation. We would be happy for them to contact Erin directly with the contact information provided.

ETHICAL APPROVAL This study has been approved by NHS National Research Ethics Service (NRES) London – London Bridge.

RESEARCH TEAM

This research is being completed as part of the Doctorate in Clinical Psychology by:

- Ms Erin Tehee – Main Researcher and Trainee Clinical Psychologist

And is supervised by:

- Dr Juliana Onwumere –Research Clinical Psychologist, Consultant Clinical Psychologist and Research Supervisor
- Professor Elizabeth Kuipers – Professor of Clinical Psychology, Consultant Clinical Psychologist and Research Supervisor

Thank you very much for taking time to read this information sheet

Oxleas NHS
NHS Foundation Trust

APPENDIX R

PARTICIPANT INFORMATION SHEET
Older Adults with Psychosis: Carer Experiences and Relationships
(REC Reference No.: 11/L0/0655)

Please take time to read the following information carefully. Talk to others about the study if you wish.

You are being invited to take part in a research study. Before you decide whether to take part it is important that you understand why the research is being done and what it would involve for you.

Ask us if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Part 1

What is the purpose of the study?

Carers play a significant role in facilitating care and well being of service users with mental health problems. This study aims to improve our understanding of the experiences of those who provide care and support for older adults with psychosis. We hope the results of this study may be useful in helping us to identify the service needs of carers of older adults.

Why have I been chosen?

We are recruiting individuals who are primary carers of older adults (60 years old and above) with a diagnosis of psychosis.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part.

What will the study involve?

The study involves completing some questionnaires and a short interview with a researcher. You will be given the option to complete the questionnaires and the interview either in your own home or in a private space at the Institute of Psychiatry.

What will happen to me if I decide to take part?

If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not impact on you or the provision of support to you or to the person for whom you care.

The study involves answering some questionnaires with the researcher about the following: your experiences as a carer, your wellbeing, how you cope and your beliefs about the difficulties experienced by person for whom you care. We will also conduct a brief audiotaped interview (5 minutes) asking you about your thoughts and feelings about this person. You will meet with the researcher once, unless you would prefer to complete the questionnaires and interview over two separate occasions. In total, this will take approximately 1 hour 20 minutes, and you can take breaks any time you wish.

Will I be reimbursed for my participation?

Yes, if you choose to complete the questionnaires and interview at home, we will pay you £15. If you would rather be seen in private space at the Institute of Psychiatry, we will pay you £20 to reimburse you for travel costs.

What happen to the information I provide?

All your answers are confidential and will not be shared with the service, organisation or support group you are linked to.

What are the possible disadvantages and risks of taking part?

We do not think that participating will be harmful in any way. However, if you find anything upsetting, please let the researcher know (details below). To check how you found taking part in this study, the researcher will call you, if you agree, one week after the study.

What are the possible benefits of taking part?

There is no direct benefit from participation. However, some participants may find talking about their experiences of caregiving helpful.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes, all the information about your participation in this study will be kept confidential. The details and exceptions to this are included in Part 2.

Contact Details:

Ms Erin Tehee, Trainee Clinical Psychologist

Department of Psychology, Level 3, Addictions Sciences Building, 4 Windsor
Walk, London, SE5 8AF

Tel: 02078480224

Email: erin.tehee@kcl.ac.uk

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

Complaints: If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions

(Contact details are below and in Part 1). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from your local hospital or team base.

Harm: In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against your local NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. All your answers to the questionnaires and the tasks will be kept anonymously and will be identifiable only by a number, not by your name. Paper copies of questionnaires will be kept securely by the researchers in a locked filing cabinet in a locked office.

The information you give will be available only to the research team. Should you give any information, such as criminal disclosures, or information relating to your own or others safety, which requires action, including passing on information to others, the research team will take this action as appropriate.

What will happen to the results of the research study?

We intend to publish the results of the research. You will not be personally identified in any report/publication. If you would like to receive a copy of the results of the research please let the researcher know so that she can arrange this for you. Once the study has finished we also plan to publish a summary of our findings on the website www.mentalhealthcare.org.uk

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed by the NHS National Research Ethics Service (NRES) London – London Bridge.

How can I take part?

If you would like to take part in this project, please complete the enclosed consent form. You will be given a copy of the information sheet and a signed copy of the consent form to keep. If you have any questions or concerns about taking part please contact the researcher below.

Contact Details:

Ms Erin Tehee, Trainee Clinical Psychologist

Department of Psychology, Level 3, Addictions Sciences Building, 4 Windsor Walk, London, SE5 8AF

Tel: 02078480224

Mob: 07578269087

Email: erin.tehee@kcl.ac.uk

This completes Part 2 of the Information Sheet.

APPENDIX S

Do you care for an older person with psychosis?

Carer experiences matter.

Research project: Carers of older adults with psychosis

What is the project about? As part of our overall aim of improving our understanding of carer experiences and their specific needs, we are keen to meet with people who provide care for older adults with psychosis. We are interested in finding out how different relationship styles and ways of coping relate to carer well-being. We hope that this research may be useful in identifying the needs of carers of older adults with symptoms of psychosis so that appropriate support and services can be developed and provided where necessary.

To participate in this project you must:

- **Be a relative, friend or significant other caring for an *older adult* (aged 60 years or older) with a diagnosis of psychosis**
- **Have regular contact with this person (this can include phone contact)**
- **Be aged 18 years or older**

What will the project involve? Participation involves completing some questionnaires and a short interview with a researcher. You will be given the option to complete the questionnaires at a time and place that is convenient for you. It should take no more than 1 hour 20 minutes.

If you choose to complete the questionnaires and interview, ***you will be given £25*** to reimburse you for travel costs and time.

If you are **interested in participation or finding out more**, please call or text Erin Tehee at 0757 826 9087 or email erin.tehee@kcl.ac.uk. The closing date for participation is 25th May 2012, but we would like to hear from you as soon as possible.

This research has ethical approval (NHS National Research Ethics Service Committee London – London Bridge. Ref No. 11/LO/0655). It forms part of a Doctorate in Clinical Psychology qualification as awarded by the Institute of Psychiatry, King's College London. The study is being conducted by Ms Erin Tehee, Dr Juliana Onwumere, and Professor Elizabeth Kuipers

Institute of
Psychiatry

at The Maudsley

KING'S
College
LONDON
Founded 1829

APPENDIX T

PARTICIPANT INFORMATION SHEET
Older Adults with Psychosis: Carer Experiences and Relationships
(REC Reference No.: 11/L0/0655)

Please take time to read the following information carefully. Talk to others about the study if you wish.

You are being invited to take part in a research study. Before you decide whether to take part it is important that you understand why the research is being done and what it would involve for you.

Ask us if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Part 1

What is the purpose of the study?

Carers play a significant role in facilitating care and well being of service users with mental health problems. This study aims to improve our understanding of the experiences of those who provide care and support for older adults with psychosis. We hope the results of this study may be useful in helping us to identify the service needs of carers of older adults.

Why have I been chosen?

We are recruiting individuals who are primary carers of older adults (60 years old and above) with a diagnosis of psychosis.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part.

What will the study involve?

The study involves completing some questionnaires and a short interview with a researcher. You will be given the option to complete the questionnaires and the interview either in your own home or in a private space at the Institute of Psychiatry, Denmark Hill.

What will happen to me if I decide to take part?

If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not impact on you or the provision of support to you or to the person for whom you care.

The study involves answering some questionnaires with the researcher about the following: your experiences as a carer, your wellbeing, how you cope and your beliefs about the difficulties experienced by person for whom you care. We will also conduct a brief audiotaped interview (5 minutes) asking you about your thoughts and feelings about this person. You will meet with the researcher once, unless you would prefer to complete the questionnaires and interview over two separate occasions. In total, this will take approximately 1 hour 20 minutes, and you can take breaks any time you wish.

Will I be reimbursed for my participation?

Yes, if you choose to participate you will be reimbursed £25 for your time.

What happen to the information I provide?

All your answers are confidential and will not be shared with the service, organisation or support group you are linked to.

What are the possible disadvantages and risks of taking part?

We do not think that participating will be harmful in any way. However, if you find anything upsetting, please let the researcher know (details below). To check how you found taking part in this study, the researcher will call you, if you agree, one week after the study.

What are the possible benefits of taking part?

There is no direct benefit from participation. However, some participants may find talking about their experiences of caregiving helpful.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes, all the information about your participation in this study will be kept confidential. The details and exceptions to this are included in Part 2.

Contact Details:

Ms Erin Tehee, Trainee Clinical Psychologist

Department of Psychology, Level 3, Addictions Sciences Building, 4 Windsor
Walk, London, SE5 8AF

Mobile: 07578269087

Text: 07578269087

Email: erin.tehee@kcl.ac.uk

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

Complaints: If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions (Contact details are below and in Part 1). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from your local hospital or team base.

Harm: In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against your local NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. All your answers to the questionnaires and the tasks will be kept anonymously and will be identifiable only by a number, not by your name. Paper copies of questionnaires will be kept securely by the researchers in a locked filing cabinet in a locked office.

The information you give will be available only to the research team. Should you give any information, such as criminal disclosures, or information relating to your own or others safety, which requires action, including passing on information to others, the research team will take this action as appropriate.

What will happen to the results of the research study?

We intend to publish the results of the research. You will not be personally identified in any report/publication. If you would like to receive a copy of the results of the research please let the researcher know so that she can arrange this for you. Once the study has finished we also plan to publish a summary of our findings on the website www.mentalhealthcare.org.uk

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed by the NHS National Research Ethics Service (NRES) London – London Bridge.

How can I take part?

If you would like to take part in this project, please complete the enclosed consent form. You will be given a copy of the information sheet and a signed copy of the consent form to keep. If you have any questions or concerns about taking part please contact the researcher below.

Contact Details:

Ms Erin Tehee, Trainee Clinical Psychologist

Department of Psychology, Level 3, Addictions Sciences Building, 4 Windsor
Walk, London, SE5 8AF

Mobile: 07578269087

Text: 07578269087

Email: erin.tehee@kcl.ac.uk

This completes Part 2 of the Information Sheet.

Institute of Psychiatry

at The Maudsley

KING'S College LONDON Founded 1829

APPENDIX U

CONSENT FORM

Title of Project: **Older Adults with Psychosis: Carer Experiences and Relationships**

Name of Researcher: **Erin Tehee**

1. I confirm that I have read and understand the Information Sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights, my own care, or the care of the person I care for being affected. ☐
3. I understand that should I withdraw from the study, data already collected with consent will be retained and used in the study, unless I request otherwise. ☐
4. I understand that the interview will be recorded. ☐
5. I give permission for the researcher to inform the clinical team of the person for whom I care of my participation in the study. ☐
6. I understand that all information I provide for the study will remain anonymous and will not include any personal details or information that could identify me in any way. ☐
7. I am interested in receiving a written summary of the main results of the study once the research is completed. ☐
8. I agree to participate in the above study.

Name of Participant	Date	Signature

I have explained the purpose of the study to the participant and have answered their questions honestly and fully.

Name of Person taking consent	Date	Signature

APPENDIX V

1.	ALCOHOL/VIOLENCE	ALCOHOL ABUSE
2.	DEPRESSION	ANXIETY/MOOD
3.	HEALTH ANXIETY	ANXIETY/MOOD
4.	ANXIETY RE BEING ALONE	BEING ALONE – FEAR AND LONELINESS
5.	BEING ALONE	BEING ALONE – FEAR AND LONELINESS
6.	LONELINESS	BEING ALONE – FEAR AND LONELINESS
7.	LONELINESS	BEING ALONE – FEAR AND LONELINESS
8.	LONELINESS	BEING ALONE – FEAR AND LONELINESS
9.	HAVING NOTHING TO DO/BOREDOM	BOREDOM/POOR SOCIAL FUNCTIONING
10.	NO ROLE/JOB LOSS	BOREDOM/POOR SOCIAL FUNCTIONING
11.	ABUSE (ISOLATION, NEGLECT, BUL	CHILDHOOD - ABUSE/VIOLENCE EXPERIENCED
12.	ABUSED BY PARENTS AS CHILD	CHILDHOOD - ABUSE/VIOLENCE EXPERIENCED
13.	WHEN SHE WAS A CHILD SHE SAW HER FATHER ATTACKED WITH AN AXE	CHILDHOOD - ABUSE/VIOLENCE EXPERIENCED
14.	BAD NURTURING/PARENTING	CHILDHOOD - DIFFICULTIES EXPERIENCED
15.	DIFFICULT CHILDHOOD	CHILDHOOD - DIFFICULTIES EXPERIENCED
16.	DIFFICULT CHILDHOOD	CHILDHOOD - DIFFICULTIES EXPERIENCED
17.	DIFFICULT CHILDHOOD	CHILDHOOD - DIFFICULTIES EXPERIENCED

18.	UPBRINGING	CHILDHOOD - DIFFICULTIES EXPERIENCED
19.	FAMILIAL CONFLICTS	CONFLICT IN FAMILY
20.	PRESSURE FROM MOTHER	CONFLICT IN FAMILY
21.	DON’T KNOW	DON’T KNOW
22.	DON’T KNOW	DON’T KNOW
23.	DON’T KNOW	DON’T KNOW
24.	DON’T KNOW	DON’T KNOW
25.	DON’T KNOW	DON’T KNOW
26.	DON’T KNOW	DON’T KNOW
27.	PRESENT FROM BIRTH	GENETICS
28.	GENETIC	GENETICS
29.	GENETIC	GENETICS
30.	GENETIC	GENETICS
31.	GENETIC	GENETICS
32.	GENETIC	GENETICS
33.	GENETICS	GENETICS
34.	GENETICS	GENETICS
35.	HEREDITY/GENETICS	GENETICS
36.	BEREAVEMENT	LOSS/BEREAVEMENT
37.	BEREAVEMENT	LOSS/BEREAVEMENT
38.	HUSBAND DYING	LOSS/BEREAVEMENT
39.	LOSS OF FATHER AS CHILD	LOSS/BEREAVEMENT
40.	LOSS OF WIFE	LOSS/BEREAVEMENT
41.	CHANGE IN MEDICINE	MEDICINE

42.	DISTRUST OF CHILDREN	MISTRUST OF OTHERS
43.	MISTRUST OF PEOPLE	MISTRUST OF OTHERS
44.	BRAIN	ORGANIC CAUSE
45.	ORGANIC	ORGANIC CAUSE
46.	FAITH (REINFORCEMENT)	OTHER
47.	MONEY CONCERNS	STRESS RELATED TO MONEY
48.	SUPERSTITION	OTHER
49.	LOSING EYESIGHT IN 1 EYE	PHYSICAL/SENSORY DISABILITY
50.	PHYSICAL HEALTH	PHYSICAL/SENSORY DISABILITY
51.	FEELING ENTITLED	RELATIVE'S PERSONALITY/ATTITUDES
52.	INTROVERSION	RELATIVE'S PERSONALITY/ATTITUDES
53.	NEGATIVE ATTITUDES	RELATIVE'S PERSONALITY/ATTITUDES
54.	HAVING CHILDREN	STRESS RELATED TO CARING/CHILDCARE
55.	PARENTS TAKING MONEY	STRESS RELATED TO MONEY
56.	DANGEROUS ENVIRONMENT	STRESSFUL ENVIRONMENT
57.	LIFE EVENTS AND RETIREMENT	STRESSFUL LIFE EVENTS
58.	MOVING TO LONDON	STRESSFUL LIFE EVENTS
59.	PAST STRESSFUL HAPPENINGS	STRESSFUL LIFE EVENTS
60.	STRESS	STRESSFUL LIFE EVENTS
61.	STRESS	STRESSFUL LIFE EVENTS
62.	STRESS	STRESSFUL LIFE EVENTS
63.	STRESS LIFE EVENTS - LOSS OF JOB	STRESSFUL LIFE EVENTS
64.	STRESSFUL LIFE EVENTS-	STRESSFUL LIFE EVENTS

	ABORTION	
65.	STRESSFUL LIFE EVENTS/PRESSURE	STRESSFUL LIFE EVENTS
66.	WHEN SHE WAS 25 SHE LOST HER FIRST CHILD AND BECAME VERY ILL	STRESSFUL LIFE EVENTS
67.	PHYSICAL ABUSE	VIOLENCE EXPERIENCED AS AN ADULT
68.	THERE WAS VIOLENCE IN HER MARRIAGE WITH MY FATHER	VIOLENCE EXPERIENCED AS AN ADULT
69.	VIOLENCE	VIOLENCE EXPERIENCED AS AN ADULT

SERVICE EVALUATION PROJECT

AN EVALUATION OF THE EFFECTIVENESS, RELEVANCE AND USEFULNESS OF SERVICE USER INVOLVEMENT WORKSHOPS FOR CLINICAL PSYCHOLOGISTS

Erin Tehee
Supervised by Dr Joe Oliver

Table of Contents

Tables

Figure

1. Introduction

In the last number of decades, users of mental health services have become increasingly better informed about their treatment and are more knowledgeable regarding their consumer rights (Campbell, 2001), fuelling the growth of the service user involvement (SUI) movement. Thornicroft and Tansella (2005) remark on the rise of service user groups in the UK from 15 in the 1980s to the 700 estimated to exist in 2005. Despite this laudable progress, there remains a need for significant advancement in the status quo of SUI with regard to levels of participation and the roles afforded to service users. As stated by Tait and Lester (2005) "user involvement is still an essentially minority activity, acknowledged as a 'good thing' by many, but relatively rarely practiced," (p. 168).

1.1 Policy context

SUI is a requirement at both a national and local level (Department of Health; 1999a, 1999b, 2000, 2001). The National Service Framework for Mental Health (DOH, 1999a), which seeks to set national standards for users of working age mental health services and involves service users in setting these standards, make the following specific recommendations:

a) Service users should be involved in developing services so that they are acceptable and culturally sensitive.
b) Performance of mental health services should be examined at a national and local level by the experience of users and carers including those from black, ethnic and minority (BME) groups.
c) Service users and carers should be involved in planning, provision and evaluation of training for all mental health professionals.

In *Saving Lives: Our Healthier Nation*, the Government recognises the expertise that many patients have with regard to managing their illness and the 'the importance of individuals making their own decisions about their health' (DOH, 1999b). The rights of patients, their carers and families to be involved in the planning and the development of services to reflect their needs and preferences is also made clear by the National Health Service's (NHS) Constitution (2009).

Despite this clear mandate of the NHS, a large cross-sectional study carried out in Greater London in 2001 found that none of the mental health trusts' systems of SUI met the national standards (Crawford et al, 2003). It is thus imperative that services embedded in these trusts continue to strive for more and consistent levels of SUI, and avoid tokenistic approaches to involvement.

1.2 What is service user involvement?

Sheldon and Harding (2010; *British Psychological Society: Good Practice Guidelines to support the involvement of Service users and Carers in Clinical Psychology Services*) refer to involvement as 'principles and approaches that lead to individuals having real choices (both in their treatment and in facilities) and their voices heard and heeded both individually and collectively,' (p. 5).

According to Braye (2000), SUI ranges from active participation at the micro-level (e.g. individual decision-making and care plans) to macro-level participation (e.g. service planning and evaluation, training and research). Peck et al (2002) have constructed a useful framework in the form of a matrix from which to consider SUI. They divide involvement along three distinct categories: 1) recipients of care, 2) subjects of consultation, and 3) agents of control, and suggest that these operate at four levels within mental health services. Please refer to Table 1 for examples of SUI, which occur at the intersection between these categories and different levels, as reported by Peck et al (2002).

Table 1. Matrix of service user involvement (Peck et al, 2002)

Levels of interaction	**Recipient of communication**	**Subject of consultation**	**Agent in control**
Between users	-Newsletters -Periodicals	-Advocacy schemes	-Hearing voices -Newsletters -Periodicals
Between users & professionals	-Receiving care plans	-Agreeing care plans	-Direct payments
Management of local services	-Receiving information services	-Patient councils -User surveys -User-focused monitoring	-User-run crisis house -Social firms
Planning of overall services	-Community care plans	-Mental health taskforce membership -Stakeholder conferences -Users on local implementation teams	

A UK study by Diamond et al (2003) examined the extent to which services had introduced user involvement, and found acceptable standards in relation to staff recruitment, regular meetings of users and involvement in the planning and organising of services. However, involvement in the arenas of staff training and teaching and linking with advocacy services were found to be less established. The study's conclusion supported Peck et al's (2002) finding of a clustering of activity at levels of 'between users and professionals' and 'users as subjects of consultation,' but considerable underdevelopment in the area of users as 'agents in control with planning of overall services.'

1.3 Importance and benefits

Thornicroft and Tansella (1999b) outline the principles that guide community mental health services as autonomy, continuity, effectiveness, accessibility, comprehensiveness, equity, accountability, coordination and efficiency – aspects which rely on meaningful SUI. The benefits of involving service users at every level are many and are discussed below.

1.3.1. Improving knowledge and research

It is an accepted truth that professionals' understanding of psychological distress remains limited and incomplete (Bracken & Thomas, 2001; Double, 2002; Smail, 1993); thus, users' knowledge and experience are invaluable resources that can help to build on what is already known. According to May (2001), "user involvement in service provision is an opportunity to contribute to a much-needed change in the value ascribed to their (user's) knowledge of confusion, distress, social exclusion and what helps recovery."

Townend and Braithwaite (2002) advocate for increased user involvement in the research arena, where a partnership between researchers and users could lead not only to greater trust in research agendas by service users, but also to improvements in the quality of research. The University of Birmingham, where the authors are based, employs a research committee made up of 50 percent service users to appraise dissertation proposals. The authors make the observation that as a result of service users' contribution the quality and relevance of the University's research has improved. Moreover, they highlight that greater acceptability and relevance could lead to further gains in terms of quicker recruitment to research studies, better adherence to protocol and a reduction in drop-out rates, leading to better internal validity and external relevance.

Facilitating an atmosphere of collaboration between users and providers is essential for the evaluation and planning of mental health services. In terms of their own care, service users should be positioned as experts about their own illness and influence the approach to their care. They may also contribute to innovative and alternative approaches to mental health. For example, Borrill (2000) points out that users' ability to predict when they become unwell can be used to collaborate on early stage responses in order to manage symptoms and stay well.

1.3.2. Involvement can be therapeutic

SUI may also be therapeutic in itself by targeting the social, occupational and psychological needs of individuals. For example, user involvement can be empowering and can increase confidence, self-esteem, self-belief and provide the user with new skills (Mental Health Foundation, 2003; Davis & Braithwaite, 2001). Paid activity may enhance the feeling of empowerment, as well as addressing the issue of poverty (Sayce and Morris, 1999). Being a valued member of a group or team also promotes social inclusion, countering the effects of social isolation which can lead to poorer mental health outcomes.

Simpson and House (2002) carried out a systematic review of randomised controlled trials (RCTs) and other comparative studies that looked at involving users in the delivery or evaluation of mental health services and found that users can be involved as employees, trainers, or researchers without detrimental effect and it is feasible. The Department of Health (2003c) has recommended the employment of people with 'lived experience of mental illness' in such roles as Graduate Primary Care Mental Health Workers.

The success of some service user roles have been described in the literature, and point to distinct benefits of users' roles. For example, Clark et al (1999) reported on differences in responding on a satisfaction with mental health services survey when clients were interviewed by either a staff member or another client. Though both reported high levels of satisfaction, clients gave significantly more 'extremely negative' responses when being interviewed by client interviewers, which may represent a more accurate and unbiased response. Service users' unique contribution on interviewing panels for clinical psychologist jobs has also been noted (Newnes et al, 2001), as well as their ability to highlight different service user needs relative to those identified by professionals (Thornicroft & Slade, 2002).

1.4 The role of clinical psychologists

Sheldon and Harding (2010) attest to psychology's consummate role in advocating for a consistent and considered approach to SUI by merit of their "expertise in organisational and attitudinal change, relationship building, managing power differentials, management, research, training and leadership," (p. 9), supporting Soffe's (2003) suggestion that clinical psychology in the UK needs to deem involvement its 'business'. As such, clinical psychologists are well positioned in terms of leadership, managerial and research positions to integrate SUI initiatives and culture change at a variety of levels.

Soffe et al (2004) also draws attention to the potential power imbalance in a therapeutic relationship, which by its nature requires an ethos of collaboration and partnership to attain equilibrium. In her research on clinical psychologists' views of SUI in mental health services, she found that the majority of respondents were supportive of SUI, but that SUI was in varying stages of development in differing domains of involvement.

In order to ensure the progression of SUI within mental health services it is essential that clinical psychologists integrate involvement principles into their work at all levels. This requires equipping clinical psychologists with the skills and knowledge necessary for fostering meaningful SUI and with consultation on ways to overcome barriers and obstacles. Sheldon and Harding (2010) assert that organisations should have dedicated resources and forums which can help to cultivate a culture of SUI via leadership, consultation and planned initiatives.

2. Context of the evaluation

South London and The Maudsley (SLaM) NHS Foundation Trust is committed to support service user involvement, as evidenced by the existence of the Trust-wide Involvement Group (TWIG). The Trust includes a special interest group for psychologists interested in service user involvement (Psychology Service User Involvement Group; PSUIG) who, as part of their remit, offer consultation and support to those developing user involvement initiatives. To promote user involvement members provide workshops to psychology teams or services in order to encourage psychologists to embed involvement principles in their work.

2.1 Structure of workshops

The workshops were designed to provide information around SUI to psychologists within the trust in order to build their confidence relevant to involvement and to provide an opportunity to reflect on the benefits of SUI, and suggest possible ways of overcoming obstacles to involvement. They were designed for and targeted at professionals working in Child and Adult Mental Health Services (CAMHS), Mental Health of Older Adults (MHOA), Learning Disability (LD), and an adult Community Mental Health Teams (CMHT).

The workshops were developed by two clinical psychologists and an experienced service user consultant, who were all PSUIG members, and were delivered by at least one of these clinical psychologists and the service user consultant, alongside another member of the PSUIG who was employed in the targeted area.

The workshops followed a consistent format, however, some content was tailored in order to address issues salient to the target audience. The content of the workshops is summarised in Table 2.

2.2 Aims of evaluation

1) To assess participants' satisfaction (usefulness and relevance) with the workshop
2) To assess changes post-workshop in the following:
    a. Confidence in involving service users
    b. Confidence in carrying out or participating in SUI initiatives
    c. Belief in importance of SUI
    d. Knowledge around SUI

    e. Likelihood of becoming involved in SUI initiatives in the future

3) To carry out a long-term follow-up with participants in order to ascertain:
    a. The types of new initiatives created
    b. How much of the initative had been achieved
    c. Any obstacles which made it difficult to carry out or complete initiatives

3. Method

3.1 Design

This evaluation employed a mixed methods design but was primarily a quantitative study which used a repeated measures quantitative questionnaire (5-point Likert scale) for evaluating the workshop's success in influencing five core areas. Participants were also asked to rate usefulness and relevance of the workshop at one time point immediately following the workshop. A follow-up questionnaire assessed participants' long-term success in carrying out their action points. Open-ended questions allowed for qualitative feedback in both the workshop evaluation and follow-up questionnaire.

3.2 Ethics

Approval was sought from South London and the Maudsley research and audit committee, and it was confirmed that the nature of the project did not require formal ethical approval or clinical governance.

3.3 Participants

Participants were psychologists working in CAMHS, MHOA services, LD services and adult CMHTs within the SLaM NHS Foundation Trust. Participants were invited to partcipate in workshops by representatives of the PSUIG working within their area. Fifty-one psychologists participated in the workshops and completed the pre- and post-measures, including eight from MHOA services, seventeen from LD services, thirteen from CAMHS, and thirteen from adult CMHTs. Thirty-eight completed action plans at the end of the workshop (not carried out with adult CMHT group) and agreed to be followed up in order to assess their success in creating their selected initiatives. Prior to the workshop, participants described any previous experience in SUI in an open-ended question. These were transcribed and coded by three raters (author, supervising clinical psychologist and service user consultant). Please see Table 3, below, for details on participants' experience. Please see Appendix B for transcriptions of responses and coding.

Table 2. Generic content of workshops and additional content based on targeted audience

Generic content of workshops	*CAMHS*	*Southwark CMHT*	*Learning Disability*	*MHOA*
Values exercise (see Appendix A)	--------------------------	--------------------------	--------------------------	--------------------------
Locating SUI in the NHS an policy	--------------------------	--------------------------	LD specific legislation	--------------------------
Outlining the objectives of SUI	--------------------------	--------------------------	--------------------------	--------------------------
The ladder of involvement & who needs to be involved	Involving children, young people & parents	--------------------------	--------------------------	--------------------------
Dimensions of involvement	SUI within the CAG	--------------------------	--------------------------	--------------------------
Personal experience of user involvement	Parent service user	--------------------------	--------------------------	--------------------------
Clinical perspectives of SUI: Concerns & benefits	--------------------------	--------------------------	--------------------------	--------------------------
Concerns regarding SUI	--------------------------	--------------------------	--------------------------	--------------------------
Benefits of SUI for clinicians & SUs	--------------------------	--------------------------	--------------------------	--------------------------
Existing examples of SUI in the trust	Existing examples of SUI within CAMHS	--------------------------	Practice example in the context of LD	--------------------------
Where the service is in terms of SUI	--------------------------	--------------------------	--------------------------	--------------------------
How to manage obstacles	--------------------------	--------------------------	NB Communicative and cognitive obstacles	NB Cognitive obstacles
Identifying feasible next steps & action plan	--------------------------	Not carried out	--------------------------	--------------------------

Table 3. Participants' reported previous SUI experience

Amount	*Examples*	*No. of participants*
None	No experience	7
Very limited	e.g. passive recipient of info (lectures/talks)	6
Limited	e.g. surveys/questionnaires	14
Some	e.g. evidence of more direct experience	15
A lot	e.g. a greater number of SUI projects/direct experience	2
Missing	No response given	7

3.4 Workshop evaluation questionnaire

A workshop evaluation questionnaire was developed and piloted prior to the workshops. It was designed to examine participants' previous experience of involvement and specifically assessed their: 1) confidence in involving service users, 2) confidence in carrying out or participating in SUI initiatives, 3) belief in importance of SUI, 4) knowledge around SUI, and 5) the likelihood that they would carry out or participate in SUI initiatives in the future. These aspects were assessed pre- and post-workshop. Responses were presented on a 5-point Likert scale, with 1 indicating the least amount and 5 indicating the most. Post-workshop questionnaires assessed usefulness and relevance of the workshop and provided a space for comments and recommendations for improvement. Please see Appendix C for a copy of the questionnaires.

3. 5 Follow-up questionnaire

At the end of the workshops participants (excluding the adult CMHT group) were asked to develop and draw out a brief plan of a feasible step they could take in their own service to promoting SUI. Participants agreed to being followed up regarding progress with these plans. All participants were contacted by e-mail with an online survey. Within the survey, they were asked to give a brief description of their original action points and to rate how successful they were to date in achieving them on a percentage scale of 0 – 100. They were also asked to share any obstacles they encountered. Participants were also offered the opportunity to share any topic areas that they believed would be useful to cover in future SUI workshops. Please see Appendix D for a copy of the questions.

3.6 Data Analysis

A Wilcoxon Signed Rank Test was used to detect differences between before and after ratings on the workshop evaluation questionnaire. It is the non-parametric equivalent to a repeated measures t-test. Instead of using mean scores, the Wilcoxon test converts scores to ranks to compare Time 1 to Time 2.

Frequencies were used to calculate percentages to show how much each response was endorsed with reference to the questions, before and after the workshop.

Descriptives (means) were used to report responses regarding usefulness and relevance of the workshop.

Qualitative responses were summarised and arranged according to relevant themes.

4. Results

4.1 Workshop evaluation findings

A Wilcoxon Signed Ranks Test showed that the workshop elicited statistically significant changes in the following:

- How confident participants felt about involving service users (Z = -3.8, *P* = 0.000), where the median rating was 3 pre-workshop and 4 post-workshop.
- How confident participants felt about carrying out or participating in service user involvement initiatives (Z = -4.56, *P* = 0.000), where the median rating was 3 pre-workshop and 4 post-workshop.
- How participants rated their knowledge of service user involvement (Z = -4.56, *P* = 0.000), where the median rating was 3 pre-workshop and 4 post-workshop.
- How likely participants felt it was that they would carry out or participate in service user involvement initiatives in the future (Z = -4.15, *P* = 0.000), where the median rating was 4 pre-workshop and 5 post-workshop.

Changes regarding how important participants believe service user involvement to be did not reach statistical significance, where the median rating was 5 both pre- and post-workshop.

Please see Figure 1 for a summary of the before and after mean scores.

4.2.1. Descriptives of response endorsement to five core areas

Question 1: How confident do you feel about involving service users?

	Not all	A little bit	Somewhat	Fairly	Very
Before	2.7%	27.7%	36.1%	30.5%	2.7%
After	0%	2.7%	33.3%	52.8%	11.1%

Question 2: How confident do you feel about carrying out or participating in service user involvement initiatives?

	Not all	A little bit	Somewhat	Fairly	Very
Before	2.2%	26.6%	44.4%	26.6%	0%

After	0%	4.4%	26.7%	66.7%	2.2%

Question 3: How important do you think service user involvement is?

	Not all	A little bit	Somewhat	Fairly	Very
Before	0%	0%	2.2%	17.4%	80.4%
After	0%	0%	0%	8.7%	91.3%

Question 4: How would you rate your knowledge of service user involvement?

	No knowledge	A little bit	Some	A fair bit	A lot of knowledge
Before	0%	33.3%	44.4%	22.2%	0%
After	0%	2.8%	16.7%	77.7%	2.8%

Question 5: How likely is it that you will carry out or participate in service user involvement initiatives in the future?

	Very unlikely	Maybe	Somewhat likely	Fairly likely	Very likely
Before	0%	8.7%	19.5%	43.5%	28.3%
After	0%	0%	6.5%	36.9%	56.5%

4.2.2. Participant satisfaction with workshop

When asked about the usefulness of the workshop, on a Likert Scale of 1 – 5, attendees' mean rating of the usefulness of the workshop was 4.06. When asked about the relevance of the workshop, on a Likert Scale of 1 – 5, attendees' mean rating of the relevance of the workshop was 4.13.

4.2.3. Comments and suggestions

Twenty participants offered comments and suggestions following the workshop. These are summarised below. Please See Appendix E for a transcription of the original comments.

<u>Participants reported the workshop to be:</u>

- Useful/Helpful
- Thought provoking and interesting
- Inspiring with reference to the SU consultant's contribution
- Delivered well and by a knowledgeable facilitator

- Relevant
- Enjoyable

<u>They offered the following recommendations for the delivery of future workshops:</u>

- A reduction of presentation content and more time for discussion, feedback and working on action points
- Use of more small group work before feeding back to larger group
- A longer time slot

<u>Regarding the content of the workshop they suggested the following:</u>

- More information regarding the interface between SUI and community approaches and BME group involvement

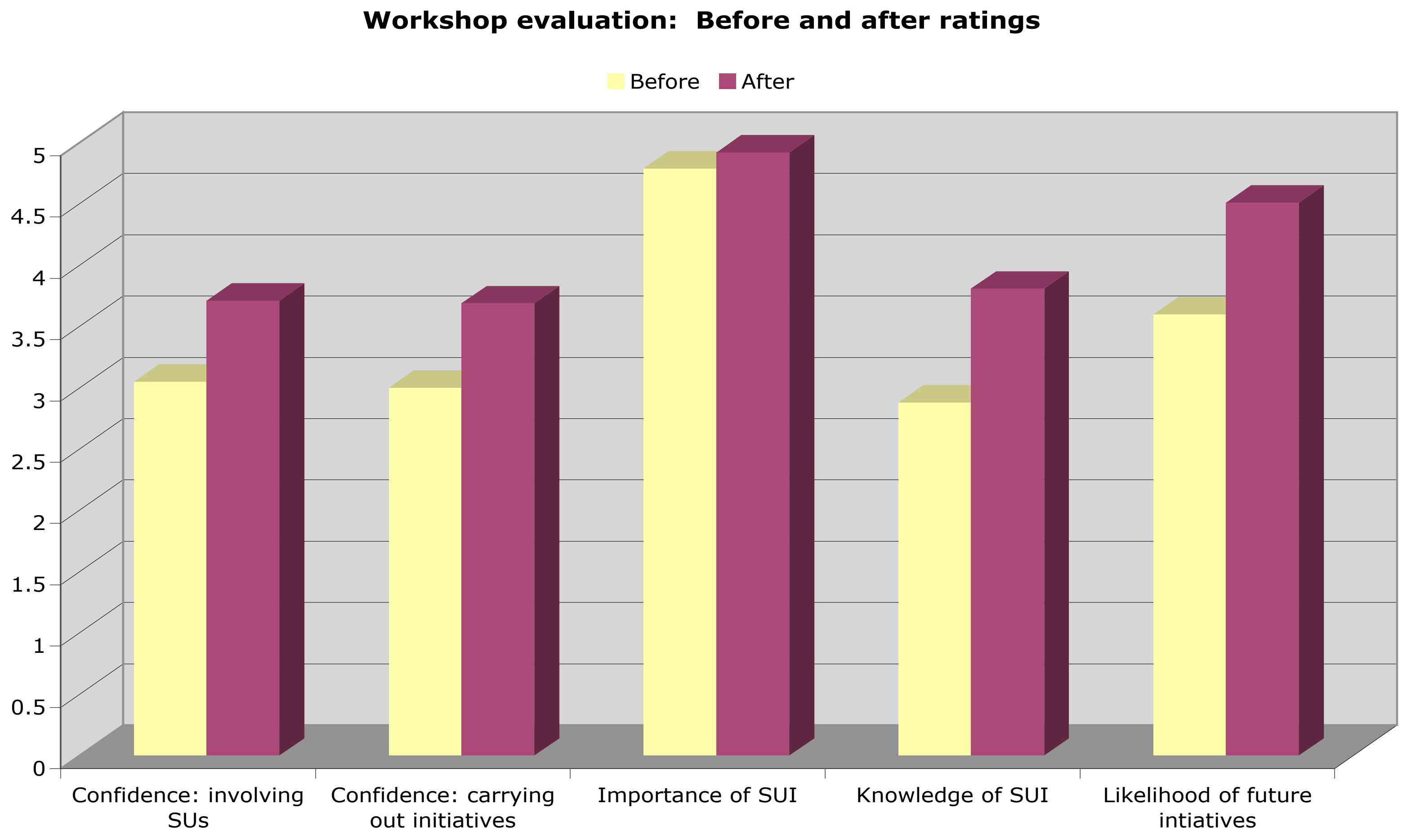

Workshop evaluation: Before and after ratings
Before
After
5
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
Confidence: involving SUs
Confidence: carrying out initiatives
Importance of SUI
Knowledge of SUI
Likelihood of future intiatives

Figure 1

- Advice on how to recruit or involve service users
- How to overcome difficult issues (e.g. confidentiality)
- To include a presentation by a service user who has recently presented to and accessed services
- More examples of SUI
- More focus on how to implement initiatives
- Information on the practical aspects of involving people with learning disabilities

4.2 Follow-up data

Six participants completed the follow-up questionnaire. Three participants worked in LD services, and three worked in CAMHS. There were no respondents from participants working in MHOA services. Table 4, below, summarises the types of initiatives generated and their stage of completion at follow-up. Please see Appendix F for a transcription of participants' open-ended responses.

Table 4. Types of initiatives generated and stage of completion

Service	*Type of initiative*	*Completion*
LD	1) SUI group to assist in training and recruitment	20%
	2) Promotion of SUI involvement and accessible feedback format	10%
	3) Accessible care plan documents	100%
CAMHS	1) Advancing ways to involve users and parents in decision making around services. Involving parents in groups to support 'mutual aid' intervention.	10%
	2) Public survey at a community event and BME event to elicit feedback on services. Service user music project	80%
	3) Focus group mid-intervention and subsequent formal evaluation to shape and evaluate intervention.	50%

4.2.1. Obstacles to involvement initiatives

Participants were also asked to share any obstacles to SUI they encountered. Responses fell into two themes: organisational (N=3) and time demands (N=3). Organisational obstacles included a lack of an appropriate system to support the use of accessible documents in record keeping and the reorganisation of the service and related cuts to front-line provision of staff. Time demand was also mentioned by three participants, with one participant making specific reference to the time required to create accessible documents for users.

4.2.1. Potential support to involvement initiatives

Participants were also given the opportunity to reflect on supports that they believed would have been helpful in overcoming these obstacles. Responses can be grouped into themes of resources, training and support from management.

Supportive resources included access to photosymbol software to create accessible documents, electronic availability of adapted questionnaires (LD services), additional staff (e.g. assistant psychologist), and more time devoted to SUI (e.g. ‘protected time’)

Participants also felt that further training may be useful. This included, staff training on how to use photosymbols to create accessible documents in their everyday work and training on ‘personal and public involvement’ (PPI) techniques, such as facilitating focus groups. One participant reported that support from management would have been helpful in or to further develop their initiatives.

5. Discussion

5.1 Summary of findings

5.1.1. Usefulness and relevance

Findings indicated that participants found the workshop both useful and relevant, suggesting a good level of satisfaction. Further comments indicated that they found the content interesting and well delivered, with the service user consultant's contribution being highly valued. More time for discussion, feedback and focus on action points were suggested.

5.1.2. Confidence in carrying out/participating in SUI initiatives & involving users

Participants' feelings of confidence in carrying out or participating in SUI initiatives and involving service users increased significantly following the workshop, suggesting that the workshop may have successfully targeted aspects of SUI which hitherto may have undermined participants' self-efficacy in integrating SUI principles into their work.

5.1.3. Belief in the importance of service user involvement

It is clear from the findings that prior to the workshop participants already rated the importance of SUI highly with 80.4% endorsing the 'very' response. Though this precluded the possibility of any statistically significant increases following the workshop, the percentage of participants endorsing the highest response category increased to 91.3% following the workshop. These findings resonate with those reported by Soffe et al (2004) who found that in her sample of clinical psychologists working adult mental health services the majority was supportive of service user involvement, despite involvement being in varying stages of development. This may be intuitive based on clinical psychology's stance on collaborative ways of working; however, its significance should not be ignored as professionals' attitudes have been cited as significant in the development of SUI (Williams & Lindley, 1996; Davis et al, 2001) and support the assertion that clinical psychologists are ideally placed to lead on service initiatives (Soffe, 2004; Sheldon & Harding, 2010).

5.1.4. Knowledge

Participants rated their knowledge regarding SUI as significantly higher following the workshop. It is worth noting that prior to the delivery of the workshop, a third of participants reported having only ‘a little bit’ of SUI-related knowledge. This may be indicative of lack of exposure to information and practice regarding involvement in training and post-qualification. Findings from a survey carried out by Jellicoe-Jones (2000) about the nature and extent of service user involvement training in UK clinical training courses suggested it existed on a limited and minimal level.

5.1.5. Likelihood of future SUI participation and initiatives

Following the workshop, participants felt it was more likely that they would integrate service user involvement principles into their work, with the increase being statistically significant. These findings suggest that these workshops are may be an effective method for promoting and supporting trust-wide involvement. The format allows for a large number of professionals to be targeted at once, and grouping professionals according to the population they serve allows for content to be specifically targeted and salient issues explored and discussed.

5.1.6. Follow-up of initiatives and action points

Completion rates varied widely and ranged from 10% to 100%. Initiatives that were more specific and measurable in nature (e.g. developing accessible care plan documents) appeared to have better success rates than less defined action points (e.g. promotion of SUI involvement and accessible feedback format). It is therefore difficult to compare the success of these initiatives, as more broadly defined initiatives rated at 10% completion could also encapsulate the completion of smaller action points rated at 100% completion. This highlights the importance of setting goals that are clearly measurable and actionable. Making goals achievable allows for the opportunity for success, which is an important factor in increasing a sense of efficacy and progress. The long-term goal of achieving a good standard of SUI can seem like a boundless and nebulous task, thus developing feasible and attainable medium-term goals is essential to success.

Initiatives reported by participants reflected that SUI initiatives existed at the levels of 'recipients of care' and 'subjects of consultation', with none placing users as 'agents of control' (as defined by Peck et al, 2002). This is in keeping with findings reported by Diamond et al (2003) and Peck et al (2002) who noted a similar pattern, with neglect at the axis of 'agents of control' and 'planning of overall services'. However, the given the context of the workshop being evaluated, introducing or increasing involvement may initially be more feasible at the levels 'recipients of care' and 'subjects of consultation,' given participants' positions and roles within the organisation.

5.1.6.1. Obstacles and Potential Support Information elicited from participants regarding obstacles in achieving their initiatives were categorised into the themes of organisational obstacles and time demands. Though participants do not elaborate in further detail, these obstacles seem to highlight a clear challenge to SUI in current services where professionals are required to work within an atmosphere of limited staffing and budgeting, but required to meet outcomes that will guarantee future funding of their service. In such a context, SUI is at risk of being relegated in terms of priority, and this may be compounded further if management does not consider SUI an essential service target. This was reflected in one participant's response who commented on their experience of trying introduce meaningful SUI service initiatives, "[it] feels as if there's a tick box culture though, and the managers are only interested in simple things that allow them to say that they are active in gaining the opinions of and involving service users (simple questionnaire feedback). It feels hard to ask for anything that requires any more feedback, as both the service and fellow workers are under so much pressure." Participants also cited the importance of resources (e.g. software and systems) and the availability of salient training to support SUI, which also indicate the need for more funding and appropriate allocation of resources. Pilgrim and Waldron (1998) stress the significance of resources in order to effectively support SUI, and argue "just as the status quo of mental health services cannot be maintained without finance, any change in such services would also require stable financial backing," (Pilgrim & Waldron, 1998). Integrating SUI in the fabric of mental health services at every level will thus be hindered without acknowledging the requirement for further resources and allocating funding respective of this.

5.2 Implications and Recommendations

5.2.1. Workshops

An examination of the findings of this evaluation reveals that psychologists believe service user involvement to be an important and worthwhile activity, as also reflected in previous research. The evaluation affirms the usefulness and relevance of SUI workshops to psychologists working in mental health services, and suggests that such endeavours to enhance knowledge and understanding around SUI can positively impact on confidence and likelihood of developing projects and integrating principles effectively. The implications of these findings are positive and it is hoped that as a result SUI will become increasingly imbedded in the service.

The scope of the presently evaluated workshop was relatively broad and intended to re-familiarise participants with involvement, its benefits and to explore ways to overcome obstacles and implement principles in services. Following the workshop, participants indicated that there were a number of areas and aspects of SUI that they would like to know more about (e.g recruiting users, practicalities of involving users with LD, involving BME users, community approaches, etc). A series of workshops that target specific areas of interest or particular challenges may helpful in this regard. It may also be useful to present in detail a successful series SUI initiatives carried out at each level, as this would allow for a closer analysis of the steps required and the opportunity to field questions around practical responses to obstacles.

5.2.2. Improving knowledge

In light of the widespread recognition of the importance and value of SUI, and the call to see it as the 'business' of clinical psychology (Soffe, 2000), it is surprising that prior to the workshop participants rated their knowledge 'a little bit'. Establishing user involvement early on in training programmes may beneficial in a number of ways including, helping to challenge stigma and myths surrounding mental illness, providing a healthy challenge to current views and traditional assumptions, and not least ensuring that SUI is built into the foundations of future mental health care. Training courses and SUI interest groups could also work together to increase the amount and level of user input into courses, as well as facilitating the role of users in the development and review of doctoral research proposals, as evidenced by Townend and Braithwaite (2002).

5.3 Areas for further evaluation

The evaluation highlighted the difficulty of trying to implement SUI in the context of widespread austerity measures. Further evaluation of how management level professionals view SUI in the context of the current financial climate of the NHS may allow for a better understanding of how decisions are made regarding the appropriation of funds and staffing.

5.4 Limitations

One of the main limitations of our approach was the small sample size from which our follow-up findings have emerged due to the low rate of response. The implication here is that it becomes difficult to make widespread generalisations, and as such, we may have to retain a level of caution with respect to the recommendations detailed above. There is also a possibility that there exists a degree of response bias in that those psychologists willing to complete our follow-up were those who felt most engaged with the process of service user involvement, both in relation to this audit, and more generally.

A further limitation worthy of mention is the extent to which our questionnaire provides detailed information regarding which particular elements of the workshop were most influential in peoples’ thinking. The rationale for greater specificity here would be that we may be in a better position to inform improvement to future workshops, rather than simply to say that they are “useful” or “relevant”, broadly speaking.

References

Borrill, J. (2000). Developments in treatment for people with psychotic experiences. *Updates, 2 (9),* 1 – 4.

Bracken, P. & Thomas, P. (2001). Postpsychiatry: a new direction for mental health. *British Medical Journal, 322,* 724 – 727.

Braye, S. (2000). Participation and involvement in social care: an overview. In *User Involvement and Participation in Social Care: Research Informing Practice* (eds H. Kemshall & R. Littlechild), pp. 9 – 28. London: Jessica Kingsley.

Campbell, P. (2001). The role of users of psychiatric services in service development -influence not power. *Psychiatric Bulletin, 25,* 87 – 88.

Clark, C.C., Scott, E.A., Boydell, K.M. & Goering, P. (1999). Effects of client interviews on client-reported satisfaction with mental health services. *Psychiatric Services, 50(7),* 9613.

Crawford, M. J., Aldridge, T., Bhui, K., Rutter, D., Manley, C., Weaver, T., Tyrer, P., & Fulop, N. (2003). User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. *Acta Psychiatrica Scandinavica*, *107*, 410–414.

Davis, A. & Braithwaite, T. (2001). In our own hands. *Mental Health Care, 41,* 13 – 414.

Davis, F., Holden, L. & Sutton, R. (2001) User involvement and psychosocial rehabilitation. *Clinical Psychology Forum 150* 34-42

Department of Health. (1999a). *The National Service Framework for Mental Health*. Crown Copyright.

Department of Health. (1999b). *Saving Lives: Our Healthier Nation.* Crown Copyright.

Department of Health. (2000). *The NHS Plan. A Plan for Investment, a Plan for Reform*. Crown Copyright.

Department of Health. (2001). *Mental Health National Service Framework (and the NHS Plan) Workforce Planning, Education and Training Underpinning*

Programme: Adult Mental Health Services: Final Report by the Workforce Action Team. Crown Copyright.

Department of Health. (2003). *Into the Mainstream: Analysis of responses to the Consultation Document.* Crown Copyright.

Department of Health. (2009). NHS Constitution. Crown Copyright.

Diamond, B., Parkin, G., Morris, K., Bettins, J and Bettesworth, C. (2003). User Involvement: Substance or spin? *Journal of Mental Health 12(6),* 613-626.

Double, D. (2002). The limits of psychiatry. *British Medical Journal, 324,* 900 – 904.

May, R. (2001). Crossing the "them and us" barriers: an inside perspective on user involvement in clinical psychology. *Clinical Psychology, 150,* 14 – 18.

Mental Health Foundation. (2003). *Surviving User-led Research: Reflections on Supporting User-led Research Projects*. London: Mental Health Foundation.

Newnes, C., Long, N. & MacLachlan, A. (2001). Recruits you, sir. *Open Mind, 108*, 12.

Peck, E., Gulliver, P. and Towel, D. (2002). Information, consultation or control: User Involvement in mental health services in England at the turn of the century. *Journal of Mental Health, 11(4),* 441-451.

Pilgrim, D. & Waldron, L. (1998) User involvement in mental health service development: How far can it go? *Journal of mental health 7, 1* 95-104

Sayce, L. & Morris, D. (1999). *Outsiders Coming In? Achieving Social Inclusion for People with Mental Health Problems*. London: Mind Publications.

Sheldon, K. & Harding E. (2010). *Good Practice Guidelines to support the involvement of Service Users and Carers in Clinical Psychology Services.* British Psychological Society, Division of Clinical Psychology.

Simpson, E.L. & House, A.O. Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal, 325,* 1265 – 1269.

Smail, D. (1993). *The Origins of Unhappiness.* London: Harper Collins.

Soffe, J. (2003). Clinical Psychology and Service User Involvement: Our Business? Clinical Psychology, 37, 15-18.

Soffe, J., Read, J. and Frude, N. (2004). A survey of clinical psychologists' views regarding service user involvement in mental health services. *Journal of Mental Health, 13(6),* 583-592.

Tait, T. and Lester, H. (2005). Encouraging user involvement in mental health services. Advances in Psychiatric Treatment (2005), vol. 11, 168–175.

Thornicroft, G. & Tansella, M. (1999b). Translating ethical principles into outcome measures for mental health service research. *Psychological Medicine, 29,* 761 – 767.

Thornicroft, G. & Tansella, M. (2005). Growing recognition of the importance of service user involvement in mental health service planning and evaluation. *Epidemiologia e Psichiatria Sociale, 14(1),* 1 – 3.

Thornicroft, G. & Slade, M. (2002). Comparing needs assessed by staff and by service users: paternalism or partnership in mental health. *Epidemiologia e Psichiatria Sociale, 11,* 186 – 191.

Townend, M. & Braithwaite, T. (2002). Mental health research – the value of user involvement. *Journal of Mental Health, 11(2),* 117 – 119.

Williams, J. & Lindley, P. (1996) Working with mental health service users to change mental health services *Journal of community & applied social psychology 6,* 1-14

APPENDIX A

Values exercise script from workshop

We work within a number of discourses (unspoken cultural values, assumptions and practices), which pull us away from the values and principles (and practices) that brought us into this work in the first place. These assumptions shape how we act and our actions maintain prevailing assumptions. One of these is the medical discourse, which works on a deficit model and values us playing the role of the expert. Another is the management discourse, which values the collection of information and managing risk.

Many clinicians (including myself) state that it is the organisational aspects of their work that cause the most stress and the client work, hard as it might be at times, that brings some relief and reconnection with the values and principles that brought them into this work.

In pairs, interview each other about a moment in your work when you have amplified the client's voice. This may be a formal piece of work you carried out, such as a satisfaction survey, or a moment in your clinical work where the client was placed in the expert position. Spend a few minutes talking about what happened and what led you up to that point. Elicit the strengths in the interviewee that enabled them to do that and then go on to identify the principles and values that under pinned that action.

(Interviewer could use post-its to write the strengths, etc., on and then stick them on interviewee!)

Hold on to these values and principles throughout the rest of the day and consider what you would want to take from the day that would enable you to hold these values close to you in your future work

APPENDIX B

Transcription and rating of participants' experience

Key	
Very limited (VL)	e.g. passive recipient of info (lectures/talks)
Limited (L)	e.g. surveys/questionnaires
Some (S)	e.g. evidence of more direct experience
A lot (AL)	e.g. a greater number of SUI projects/direct experience

Part. No.	*Previous Experience*	*Coder 1*	*Coder 2*	*Coder 3*	*Final Code*
O1	Feedback from SUs on feasibility/sensitivity of outcome measures	L	L	S	L
O2	Developing a SU evaluation tool; involving SUs in teaching/training; involving SUs in meetings	S	AL	S	S
O3	None	N	N	N	N
O4	None	N	N	N	N
O5	no direct clinical experience post qualification	N	N	N	N
O6	being interviewed by some SUs volunteering in MIND, setting up and running user advisory groups	S	S	S	S
O7	Council of advisors meetings in MHOA; user satisfaction questionnaire	S	S	N	S
O8	Little	L	L	L	L
ID1	focus groups	S	L	S	S
ID2	Missing	Missing	Missing	Missing	Missing
ID3	Clinical experience involving SUs in clinical work, e.g. training their own staff teams/families re the support they need to manage their CB/symptoms. Also auditing their experience of having been a SU following therapeutic (systemic family) intervention	S	S	N	S

ID4	Missing	Missing	Missing	Missing	Missing
ID5	to date none	N	N	N	N
ID6	Missing	N	N	N	N
ID7	teaching on DClinPsy course	VL	VL	S	VL
ID8	20 year but not LD, only 3 yrs LD	S	S	N	S
ID9	always involved SUs	S	L	N	L
ID10	Very limited	VL	VL	N	VL
ID11	not within a research context	L	L	N	L
ID12	I was interviewed by a panel including a SU in a previous job	VL	VL	N	VL
ID13	Using SU reps to review research protocol; completing a needs analysis via post with SUs wit ASD and LD and their families with telephone follow-up	S	S	N	S
ID14	just started new training for supporting people with LDs; we work with people first to deliver. Otherwise, no experience outside current clinical work	S	L	N	L
ID15	None	N	N	N	N
ID16	Some, e.g. co-presenting trust conference in previous job	L	L	S	L
ID17	Very little	VL	VL	N	VL
C1	I have been a member of Lewisham CAMHS PPI (SU group) and the psychology group in the past. As such I have been part of various initiatives getting SUI in service provision	AL	AL	N	AL
C2	S with LAC children in previous service and with parents and YP using GP services (autism)	S	S	S	S
C3	evaluative work in therapy/service involvement. Exploring views of SUs and carers about perspective service changes	S	S	N	S
C4	currently acting as co-lead/support for people at Croydon CAMHS adolescent team	S	L	N	L
C5	limited; use of feedback	L	L	L	L

	questionnaires such as CHI				
C6	small amount previously - e.g. running focus group at leaflet development	S	L	S	S
C7	not much except S feedback and satisfaction questionnaires post therapy	L	L	N	L
C8	feedback sessions from CHASE	L	L	N	L
C9	I have experience working with SUs in setting up mental health service projects supporting people into education and employment. More recently, I am in the process of recruiting patient representatives	AL	AL	N	AL
C10	Just a little. Grant application. Carer/SU groups on ward	S	L	N	L
C11	general feedback from Chase, etc. currently running a PPI group for 16 - 18s at service	S	S	N	S
C12	designing and administering satisfaction surveys (treatment/assessment)	L	L	S	L
C13	Missing	Missing	Missing	Missing	Missing
S1	Working on a SU initiative trying to encourage Tamil asylum seekers to access service and train as trainers to hold community groups with psychoeducation	S	S	N	S
S2	Very little	VL	VL	N	VL
S3	I have been involved in gathering SU perspectives to use in training and in delivering training alongside SUs	S	S	S	S
S4	running training days for staff with SUs as co-facilitators in the past, in another trust	S	S	S	S
S5	not as much as I would like to have. Very sporadic. However, I build it in to my clinical work by asking clients re their experience	L	L	N	L
S6	not much	VL	VL	N	VL
S7	None	N	N	N	N
S8	feedback surveys; committee work	L	L	S	L
S9	participated in some seminars where a user was present last	S	S	S	S

	year. Attended a user forum to talk re therapies in SLaM				
S10	Missing	Missing	Missing	Missing	Missing
S11	Missing	Missing	Missing	Missing	Missing
S12	Missing	Missing	Missing	Missing	Missing
S13	Missing	Missing	Missing	Missing	Missing

APPENDIX C

Workshop evaluation questionnaire – Before

1) What experience do you have have with service user involvement?

____

____

____

2) How confident do you feel about involving service users?

1	2	3	4	5
Not all	A little bit	Somewhat	Fairly	Very

3) How confident do you feel about carrying out or participating in service user involvement initiatives?

1	2	3	4	5
Not all	A little bit	Somewhat	Fairly	Very

4) How important do you think service user involvement is?

1	2	3	4	5
Not all	A little bit	Somewhat	Fairly	Very

5) How would you rate your knowledge of service user involvement?

1	2	3	4	5
No knowledge	A little bit	Some	A fair bit	A lot of knowledge

6) How likely is it that you will carry out or participate in service user involvement initiatives in the future?

1	2	3	4	5
Very unlikely	Maybe	Somewhat likely	Fairly likely	Very likely

Workshop evaluation questionnaire – After

1) How confident do you feel about involving service users?

1	2	3	4	5
Not all	A little bit	Somewhat	Fairly	Very

2) How confident do you feel about carrying out or participating in service user involvement initiatives?

1	2	3	4	5
Not all	A little bit	Somewhat	Fairly	Very

3) How important do you think service user involvement is?

1	2	3	4	5
Not all	A little bit	Somewhat	Fairly	Very

4) How would you rate your knowledge of service user involvement?

1	2	3	4	5
No knowledge	A little bit	Some	A fair bit	A lot of knowledge

5) How likely is it that you will carry out or participate in service user involvement initiatives in the future?

1	2	3	4	5
Very unlikely	Maybe	Somewhat likely	Fairly likely	Very likely

6) How useful was the workshop for you?

1	2	3	4	5
Not useful	A little bit	Somewhat	A fair bit	Very useful

7) How relevant was the workshop to you?

1	2	3	4	5
Not relevant	A little bit	Somewhat	A fair bit	Very relevant

Any comments on how we could improve the workshop?

____

____

____

APPENDIX D

Follow-up Questionnaire

1. Under which type of service were you employed when you attended the Service User Involvement (SUI) Workshop?

    - Child and Adolescent Mental Health Services
    - Intellectual Disability Services
    - Mental Health of Older Adults Services

2. Can you please provide a brief summary of the action points/goals that were developed?

3. Approximately, how successful have you been to date in achieving these goals?

    0% - 10% - 20% - 30% - 40% - 50% - 60% - 70% - 80% - 90% - 100%

    Further comments:

4. What, if any, obstacles did you encounter along the way?

5. What types of supports or resources would you have found helpful, if any?

APPENDIX E

Transcription of participant comments on the workshop evaluation questionnaire

MHOA
I'd suggest reducing the presentation as I think psychologists are fairly well acquainted with the argument/issues. More time for discussions/implementations
Hearing about X's work was the best part; very inspiring
Extremely useful workshop; very knowledgeable facilitator
Thank you very much, very thought provoking
LD
Very interesting and helpful-thank you
A bit clearer focus at the end on the way forward. Perhaps a bit more of an action plan
It would be useful to have more directives around how to go about involving SUs and approach staff. Also, it would be helpful to think about the practical aspects of getting people with LDs involved.
Great delivery - thanks. Perhaps break into small groups to brainstorm what we could start to do and then feedback to large group
CAMHS
I still do feel that BME involvement (especially since all boroughs are so culturally diverse) and thinking about community approaches is vital - I wonder what the interface between that and SUI is.
Excellent and relevant
I would have valued more time to think about applications to clinical practice and planning. Very informative, thank you!
More time for discussion and feedback. Powerpoints too detailed to absorb, but great content anyway.
Perhaps more examples
Adult CMHTs
I think it needs to be longer
Introduction in the beginning is useful. Clarifying length of time for exercise and making sure instructors are clear. Overall, v clear and good. Like the SU contribution - was inspiring
More about recruitment - how to effectively recruit SUs. How to tackle difficult

issues that come up - e.g. issues of confidentiality. Have a SU who has just accessed PCS - feedback on their involvement
Longer…
Very useful and enjoyable - thank you
A very well thought out and interesting session - lots of food for thought
I'd suggest reducing the presentation as I think psychologists are fairly well acquainted with the argument/issues. More time for discussions/implementations
Hearing about X's work was the best part; very inspiring
Extremely useful workshop; very knowledgeable facilitator
Thank you very much, very thought provoking

APPENDIX F

Transcribed responses to follow-up questionnaire

Service	Level of completion	Description of initiatives	Obstacles	Potential supports
LD	20%	Encourage more people with LD to be registered on the service user group to assist in training and recruitment I believe that there are still no servcie users with LD on this group though this may not be the case as I am not involved directly in this myself	Organisational record keeping constraints that suggests that easy read correspondence with picture and adapted outcome measures cannot easily be pput on the electronic system which still values a more medical approach to record keeping	Updated photosymbols for all and training for all staff on how to use as part of their everyday work and letter writing Our adapted outcome measures being available to complete electronically
	10%	Promoting involvement by service users with LD within the service and developing an accessible feedback format.	Availability of time to create accessible documents	More staff in the service with time to meet and develop initiatives
	100%	Accessible care plan documents – all plans are now in use and in accessible format	Finding time	Protected time to devote to involvement
CAMHS	10%	Setting up service user involvement goals for the short term to long term Advancing ways to involve service users (esp parents) in our services (they're involvement in helping with groups to encourage "mutual aid" type interventions; involving service users and parents in decision making around our service)	Service has been in a massie state of flux ("reorganisation" and, effectively, cuts in front line provision) so it has been difficult to implement changes or create the thinking space that would allow this.	Support from management for developing these initiatives. Feels as if there's a tick box culture though and the managers are only interested in simple things that allow them to say that they are active in gaining the opinions of and involving service users (simple questionnaire feedback). it feels hard to ask for anything that requires any more feedback as both the service and fellow workers are under so much pressure
	80%	I think the goals would have been to continue to develop our servcie user initiatives here in CAMHS There have been several initiatives, including our annual presence and survey at Lewisham People's day to get feedback on our service from the public, annual event for BME families in lewisham and a successful project in which service users participated in a music project which resulted in a song being written performed and recorded.	Other demands on our time	A psychology assistant
	50%	Use PPI to meaningfully shape intervention and evaluate it We've conducted focus group and in middle of intervention - we will finish and use for evaluation also.	some organisational, not insurmountable	training on good PPI techniques - facilitating focus groups etc.

Volume II

Clinical Case Studies

Erin Tehee

Thesis submitted in partial fulfilment of the degree of
Doctorate in Clinical Psychology

Institute of Psychiatry, King’s College London
June 201

Table of Contents

CASE STUDY 1

ACCEPTANCE AND COMMITMENT THERAPY FOR COMPLEX ANXIETY WITH A 37-YEAR OLD WOMAN

Erin Tehee

Supervised by Dr Katja Windheim

1. Introduction

1.1 Prevalence and classification of anxiety disorders

Anxiety disorders represent the most common mental health disorder, with lifetime prevalence estimated at 28.8% (US figures; Kessler et al, 1994). Compared to other disorders, they are also more likely to perpetuate in the absence of effective treatment (Goisman et al, 1998; Wittchen et al, 2001) and lead to further co-morbid conditions (Barlow et al, 2004), compounding the level of mental and social disability to sufferers. On account of their prevalence, chronicity and potential for complexity, such disorders pose not only economic and social costs (Barlow, 2002), but also substantial personal costs.

Anxiety disorders span a spectrum of different conditions which are defined by the current diagnostic systems of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; APA, 2000) and International Classification of Diseases (ICD-10; WHO, 1993) and include panic disorder, phobic disorders (e.g. specific phobia, social phobia and agoraphobia), generalised anxiety disorder (GAD), obsessive-compulsive disorder (OCD) and post-traumatic stress disorder (PTSD). Despite differences in the way these disorders present, their development and maintenance share the common features of avoidance, control and escape behaviour.

Barlow et al (2004) acknowledges the merit of classifying anxiety presentations into discrete disorders in terms of reliability; however, he also criticises this nosology for lack of validity, where he suggests categories are formed inappropriately and unnecessarily rather than considering these presentations under a broader umbrella of an underlying syndrome. Third wave approaches (e.g. mindfulness, ACT and DBT) tend to embrace the latter, where the focus is to change one’s relationship with thoughts and feelings rather than to work directly on specific content.

1.2 Acceptance and Commitment Therapy – working with process over content

According to Hayes et al (1999), Acceptance and Commitment Therapy (ACT) is a third wave and empirically based psychological intervention that uses acceptance and mindfulness strategies, together with commitment and behaviour change strategies, to increase psychological flexibility. Psychological flexibility can be described as being in contact with the present moment fully and consciously, and based on what a situation affords, changing or continuing with behaviour in line with one's chosen values.

ACT's theory draws heavily on the idea that our well-being can be negatively affected by the way language and cognition interact with circumstances in our lives (Luoma et al, 2007). From an ACT perspective, anxiety becomes disordered via experiential avoidance when persons:

1. Do not accept the reality that they will experience certain negative emotions, thoughts, memories or sensations
2. Are unwilling to be in contact with these experiences
3. Take deliberate steps to alter circumstances that are likely to trigger negative emotional experiences
4. Do the above rigidly and inflexibly leading to significant costs to their personal life

(Forsyth & Eifert, 1996)

Proponents of ACT emphasise the similarities and high degree of functional and symptom overlap between anxiety disorders, rather than ascribing to disorder specific treatments. CBT approaches to anxiety treatment have been criticised by ACT for colluding with the anxiety sufferer, through their agenda of control and mastery (Hayes, Strosahl & Wilson, 1999; Eifert & Forsyth, 2005). ACT positions the process of control as the mechanism by which normal anxiety becomes pathological and one's main goal, to the neglect of other important life goals. Despite its criticisms of CBT, however, ACT does retain a number of CBT approaches, which can be applied transdiagnostically (e.g. exposure and cognitive restructuring).

Unlike CBT, which focuses on symptom alleviation, ACT outcomes are defined by behavioural change and changes in processes related to psychological inflexibility. In ACT, psychological inflexibility is targeted by six core processes. These are commonly illustrated by a 'hexaflex' (see Figure 1), whose points correspond with the processes and interact to create greater psychological flexibility. These processes are defined in Table 1.

Table 1. Definitions of the six core processes of ACT (Luoma et al, 2007)

Process	**Definition**
Acceptance	A continuing willingness to experience difficult thoughts, feelings, body sensations, and memories without defence
Cognitive defusion	An ability to watch and observe thoughts without being unnecessarily dominated or ruled by them
Self as context	A perspective on self that is unchanged by time or experience
Contact with the present moment	An ability to be aware of how thoughts often have a past or future quality and to be able to more frequently connect with the present
Values	Clarity and the capacity to follow what is most personally important
Committed action	Sustained, sustainable, and flexible behaviour in the direction of values

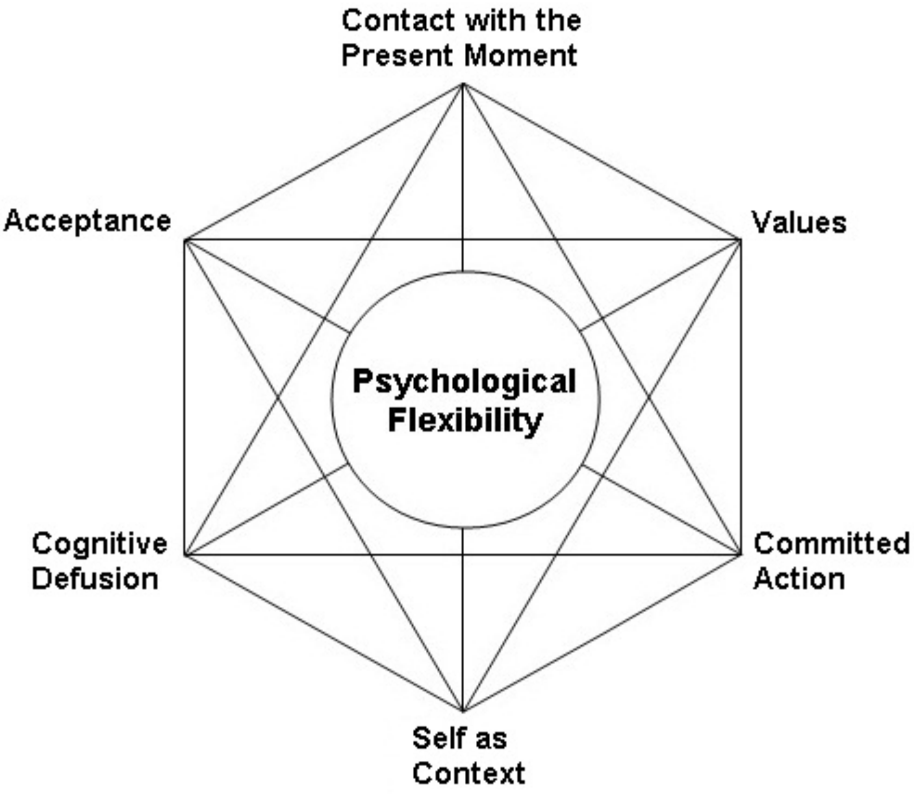


Figure 1. 'Hexaflex' (Luoma et al, 2007)

1.3 Empirical evidence for ACT

ACT has been found to be effective for a range of disorders (e.g. depression, substance misuse, chronic pain, psychosis, OCD, etc.) with reviews suggesting medium to large group effect sizes (Hayes et al, 2006; Ruiz, 2010). Processes of change research has also shown that ACT alters 'psychological flexibility' (Hayes et al, 2006; Wicksell et al, 2011). Forman et al (2007) reported on an a randomised controlled trial (RCT) of outpatients with moderate to severe levels of anxiety or depression randomly assigned to cognitive therapy (CT) and ACT and found that participants in both treatment groups benefited from large improvements in anxiety, depression, quality of life and functioning. It was noted that though improvements were equivalent, the mechanisms for change appeared to be different, where 'observing' and 'describing' experiences mediated outcomes in CT relative to ACT, and changes in experiential avoidance, 'acting with awareness and acceptance' and 'acceptance' contributed to outcomes in the ACT group. In a study of ACT for obsessive compulsive disorder (OCD), Twohig et al (2006) found clinically significant reductions in compulsions by the end of treatment and at 3-month follow-up. Process changes in experiential avoidance, believability of obsessions and need to respond were also noted.

2. Background to case

2.1 Referral

Michelle was referred to her community mental health team (CMHT) in March 2007 with chronic and pervasive anxiety. She engaged in four sessions of CBT at home, but this ended when the psychologist left the service and Michelle decided to discontinue therapy on account of beliefs that it caused her to develop irritable bowel syndrome (IBS). She was not discharged, however, and a year later she was re-assessed by the team psychologist, with whom she then engaged for CBT. Due to Michelle's lack of response to traditional CBT, difficulties with psychological inflexibility and unwillingness to expose herself to feelings of anxiety, ACT was introduced.

2.2 Personal history

Michelle was a 37-year-old lady of White British origin. She was born and raised in South-East London by both parents, along with her younger brother. She described being an anxious young child, and reported a further worsening of her distress when she entered secondary school and became the target of bullying. As a result of the emotional difficulties this caused her, she left school prematurely at the age of fifteen with only two GCSEs, despite having been an academically bright student. She later regretted not having more qualifications.

Following her departure from schooling, she completed an administration skills course, and subsequently worked in administration for a solicitor and law stationary company for eleven years. She described interpersonal difficulties with colleagues which added to the emotional strain she was under at the time as a result of her poorly managed anxiety and low self-esteem.

In her mid-twenties, Michelle lost her father and grandfather. She reported a very close relationship to her grandfather, but a difficult relationship with her father. Regarding the latter, she described feeling 'traumatised' by his death and reported many unresolved feelings around the loss. She thus had a very difficult time coping and processing these events. At this time, Michelle felt she was no longer able to manage her anxiety and, feeling overwhelmed, she quit her job. This was closely followed by a fear of leaving the house which eventually led to her refusal to go outside at all, including the enclosed back garden.

Michelle had never had any romantic relationships, and reported feeling very anxious around men and that she avoided social interaction with male colleagues at her place of work as much as possible.

Michelle lived at home with her mother. Her grandmother and brother visited daily, but contact with other family and friends was considerably limited. Michelle described feeling rejected by her extended family, whom she believed avoided her. Michelle's relationship with her mother was characterised by features of enmeshment, where both found it difficult to separate from one another and assert developmentally appropriate boundaries. Her mother would often communicate Michelle's emotional and physical states to others on her behalf, which appeared to maintain Michelle's avoidance of interpersonal interactions.

3. Assessment and Aims

3. 1 Assessment of difficulties

Michelle presented with a complex anxiety disorder, which was premorbidly preceded by separation difficulties, interpersonal difficulties, avoidance and a shy and anxious temperament, but was exacerbated in adolescence by bullying and further compounded in her mid-twenties by bereavement. As her lifestyle became increasingly restricted the presentation of anxiety expanded and by the time of her referral she had chronic and pervasive difficulties, which spanned a number of diagnostic categories including: panic disorder (PD), obsessive compulsive disorder (OCD), health anxiety, generalised anxiety disorder (GAD), social phobia, agoraphobia and co-morbid depression, secondary to anxiety.

Approximately ten years prior to engaging in therapy, Michelle stopped leaving her home for fear that she would be unable to cope with what she believed would be an inevitable and catastrophic escalation of her anxiety, in an environment that would be unpredictable and unsympathetic to her. Michelle also described suffering from constantly elevated physiological symptoms of anxiety, in addition to memory and concentration difficulties, poor energy levels, poor sleep and periods of significantly low mood. In an attempt to try to control her anxiety, she was living an extremely limited lifestyle, and reported feeling cut off from the world. She was completely unable to leave the home and was dependent on the support of her mother. Her limited contact with others also left her feeling lonely and excluded. She described feelings of regret around the loss of opportunities and life experiences she had suffered as a result of shutting herself off from the world.

Due to the complex presentation of her anxiety, it was hypothesised that a transdiagnostic approach, such as ACT, would be effective in targeting the processes that maintained Michelle's psychological inflexibility and prevented her from acting in accordance with her values and life goals.

3.2 Aims

The aim of this case study was to assess the effectiveness of ACT in improving specific behavioural (i.e. leaving the house) and psychosocial outcomes, and more generally decreasing experiential avoidance. This was assessed using an A-B single case study design.

3.3 Measurement of outcomes

3.3.1. Psychosocial outcomes

The Health of the Nation Outcomes Scales (HoNOS) is comprised of 13 scales which are used to rate the mental and social health of mental health service users before and after interventions to assess outcomes. Each scale is rated from 0 to 4, where 0 indicates 'no problem' and 4 indicates a 'severe to very severe problem'. Orrell et al (1999) found the HoNOS to be a valid and reliable measure for rating the mental and social health of psychiatric patients in the community. See Table 2, below, for pre-intervention scores.

Table 2. Pre-intervention HoNOS scores

Scale	Scores
1) Overactive, aggressive, disruptive or agitated behaviour	2
2) Non-accidental self-injury	2
3) Problem-drinking or drug-taking	0
4) Cognitive problems	1
5) Physical illness or disability problems	1
6) Problems associated with hallucinations and delusions	0
7) Problems with depressed mood	4
8) Other mental and behavioural problems	4
9) Problems with relationships	2
10) Problems with activities of daily living	0
11) Problems with living conditions	0
12) Problems with occupation and activities	0
13) Strong unreasonable beliefs occurring in non-psychotic disorders only	3
Total	19

3.3.2. Behavioural outcomes

Behavioural outcomes were assessed by Michelle's success in completing specified treatment goals which were graded and included:

1. To be able to go into the back garden and stand without needing to lean on a wall
2. To get to the furthest point away from the house in the back garden
3. To leave the house through the front door
4. To be able to walk down to the corner of the road to window shop

3.3.3 Experiential avoidance

Changes in experiential avoidance were assessed by Michelle’s ratings of willingness to accept feelings of anxiety in the context of completing exercises to bring her closer to achieving her valued life goals. These were measured weekly and recorded on Weekly Life Goal Activities form (See Appendix A)

1. ACT Formulation

4.1 Case Conceptualisation Framework

A collaborative formulation was generated with Michelle in order to effectively tailor her treatment plan. It followed Lillis and Luoma's (2005) ACT Case Conceptualisation Framework, and explored the following areas:

1. *Experiential avoidance of thoughts, emotions, and memories*
- **Thoughts**: The world is unpredictable; I am helpless; I might lose control; my life is a failure; I will end up on my own without anyone; people are judging me; thoughts that I might faint or have a panic attack
- **Emotions**: Anxiety; shame; grief; physiological symptoms of anxiety
- **Memories:** Grandfather dying; father dying; bullying at school, panic attack at work
- **Other:** Sources of external stimulations (e.g. noise, space, poor weather conditions, too much sunshine)

2. *How anxiety gets in the way*
- **Overt behavioural avoidance:** Not going outside house/open spaces; avoiding 'over-stimulation'; avoiding exercise or strain on the body; avoiding people and relationships other than those with whom I am very familiar
- **Internal and external emotional control strategies:** Checking physical symptoms; distraction; rumination; reassurance seeking; procrastination; neutralising behaviour
- **In-session avoidance or emotional control patterns:** Saying I will become ill if I am pushed too far; changing topic/distraction; avoidance of mindfulness

3. *Costs of behaviour in terms of daily life*
- Restricted mobility
- Dissatisfaction and depression
- No independence (e.g. job, living arrangements, finance)
- Lack of meaningful relationships (e.g. friendships, romantic relationships)
- Physical health and self-care are deteriorated (e.g. muscle weakness, severe dental problems)

4. *Environmental barriers*
- Interdependent relationship with mother

- Missed developmental experiences and milestones
- Genuine physical frailty (e.g. muscle atrophy, fatigue, compromised immune system)

5. *Obstacles to Psychological Flexibility*

- **Cognitive fusion:** Talking about things, e.g. panic symptoms, will make it happen or make things worse
- **Strongly held beliefs:** If I step outside my comfort zone I won't be able to cope; others will judge me negatively
- **Excessive reason-giving:** I am fragile/prone to illness; circumstances are not perfect
- **Comparisons with others:** I feel I have missed too many milestones (e.g. using 'shoulds')
- **Strong ambivalence to change:** Gaps seem too wide to bridge now; I am uncomfortable with uncertainty; if I improve I would be pushed further; if I succeed then I will have to face the loss of what I have missed out on
- **Avoids engaging in present moment:** Active awareness of present is too aversive; distracting self with 'boring' and non-stimulating thoughts

Table 3. Reformulation of presenting problem

Presenting problems in clients own words	I can't go out because I am afraid to be overwhelmed by fear and to be judged by others
ACT reformulation of presenting problem	My efforts to control the "nerves" and avoid fearful situations are preventing me from living a full life and pursuing what I value
Client initial goal	To be able to leave the house and move towards valued goals such as being active and healthy and willingly experience what there is to be experienced in my life
Hypothesis	By increasing psychological flexibility and willingness to accept anxiety, Michelle would be able to overcome avoidance and achieve her goals.

2. Intervention

The psychological intervention included family therapy and the ACT intervention presently described. Family therapy was included as the enmeshment with her mother was hypothesised to be a significant maintaining factor and it was deemed important to address this alongside an individual intervention.

Michelle was seen for 14 weekly sessions at home for an hour, parallel to the weekly individual therapy sessions delivered by the supervising psychologist. In the initial sessions a Life Compass (see Figure 2) was completed with Michelle in order to identify her valued goals and to consider the barriers to accessing these goals, as informed by the Case Conceptualisation. The barriers are listed in Table 4, below, alongside the targeted interventions and exercises of the treatment plan. As Michelle's phobic avoidance of leaving the house presented as the main barrier to her value-driven goals it was positioned as the primary target of intervention using exposure work, which was complemented by exercises to develop greater psychological flexibility and openness to her experiences. It was hoped that gains made and skills developed during this intervention would generalise to other domains, which could be targeted in future work with successive trainees joining the service.

Table 4. Treatment plan for targeting barriers to valued life goals

Barrier	**Intervention and exercises**
Strong ambivalence to change	Creative hopelessness; Exercises (Chinese Finger Trap, Tug of War, Life Bus) Reviewing valued life goals
Excessive reason-giving	Buts vs. Ands; Willingness vs. Struggle
Avoidance & emotional control	Exposure work
Strongly held beliefs	Exposure work; behavioural experiment
Avoids engaging in present moment	Mindfulness scripts & exercises

Cognitive fusion	‘Thoughts Drift By’ mindfulness script
Comparisons with others	Acceptance

5.1 Specific treatment goals

5. To be able to go into the back garden and stand without needing to lean on a wall
6. To get to the furthest point away from the house in the back garden
7. To leave the house through the front door
8. To be able to walk down to the corner of the road to window shop
9. To accept feelings of anxiety and increase willingness

5.2 Summary of sessions

Sessions 1 – 3

- Case conceptualisation – Formulation review

- Review of valued goals
  - Life Compass (Figure 2)

- Setting of specific time-limited goals

- Rationale of ACT
  - Control is the problem and letting go of control is the alternative
  - Showing that past attempts to control and avoid anxiety have not worked (unworkability)
  - Encouraging ‘creative hopelessness’ (i.e. past solutions are hopeless, but encouraging motivation to try new and ‘creative’ approaches to relating with anxiety)
  - Experiential metaphorical exercises used to illustrate unworkability of old solutions (see Appendix B for copy of exercises)
    - Chinese Finger Trap

        - Tug of War
        - Bus Driver Exercise

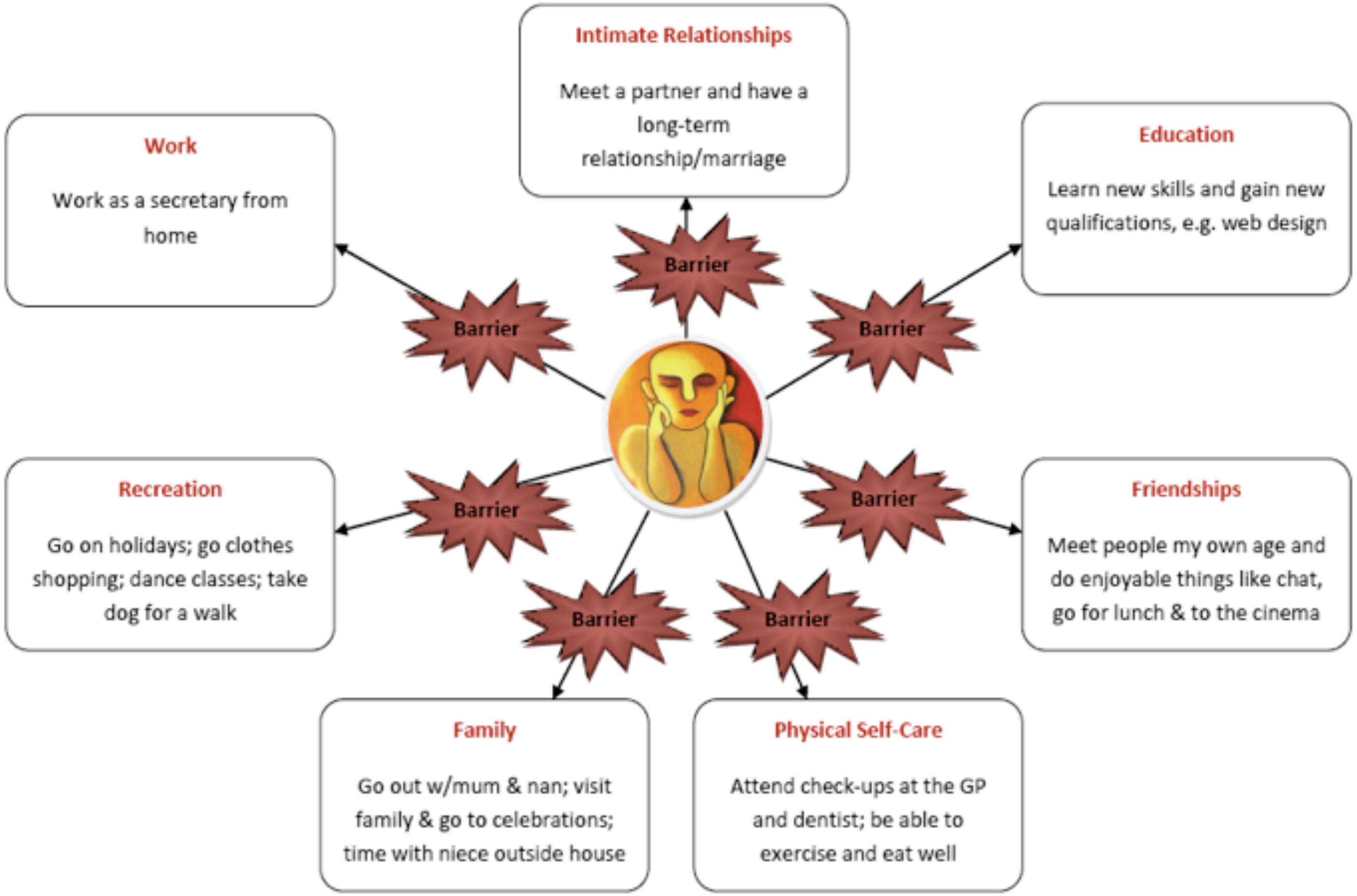
- Mindfuless (see Appendix B for copy of exercises)
    - Centering Exercise
    - Acceptance of Anxiety Exercise

- Exposure work (starting at Session 3)
    - Reviewing the concept of 'Emotional Willingness'
        - Pen exercise (see Appendix B)
    - Completed Weekly Valued Life Goals Activities form and rating anxiety, willingness and struggle (see Appendix A)
    - Areas completed:
        - Patio area of back garden leaning against the wall

- Homework
    - Mindfulness exercises and exposure practice
    - Weekly Valued Life Goals Activities form

Session 4 - 6

- Introduction of exposure to feared sensations with FEEL exercises (Feeling Experiences Enriches Living)
    - The aim was to prepare for exposure to feared sensations
    - Rationale was explored with Michelle (i.e. it will help her remove the barriers to her valued directions)
    - Hierarchy of 'most feared' sensations were collaborated on
    - Michelle was not willing to begin with FEEL exercises, and stated that she felt it was 'too much' to work with at that time, requesting that we wait until she has become comfortable with going out side first.
- Mindfulness
    - Tactile mindfulness exercises (e.g. washing up, ironing)
    - Watching Thoughts Drift By Exercise (Davis et al, 2000; Hayes et al, 1999; see Appendix B for a description)
    - Mindful eating and drinking



The Life Compass – a behavioural compass of valued life domains, intentions in each area, and potential barriers to reaching those goals (adapted from Association for the Advancement of Behavior Therapy, ©2004)

Figure 2

- Exposure work
    - Working with resistance and excuse-making
        - Defusion exercise – the language trap of ‘yes-butting’
            - Acknowleding the role of ‘but’ in excuse-making
            - Encouraging the replacement of the word ‘but’ with ‘and’ to remove feeling of ‘stuckness’ (e.g. ‘I want to go out, but I am afraid I will have a panic attack’ to ‘I want to go out, and I am afraid I will have a panic attack’).
    - Completed Weekly Valued Life Goals Activities form
    - Further areas completed:
        - Middle of patio, not holding onto the wall
        - Reaching as far as the gate opening onto the grass (middle of back garden)
        - Standing on the grass
        - Looking at (not avoiding) neighbours and builders in her line of sight from garden

- Homework (as before)

Session 7 – 9

- Progress Review

Michelle described feeling proud of her achievements, and was pleased that her family had noticed the effort she was making. However, she also expressed fear around improving further, because that meant that she would be pushed to do more and would end up farther outside her comfort zone. We explored this in the context of her valued life goals and considered the pros and cons of choosing to stop now and stay in her ‘safe place’, returning to the Case Conceptualisation to re-examine the costs of this to her life. We also identified this fear as the ‘voice’ of her anxiety, and returning to the Bus Driver metaphor we explored whether she would choose to stay on her own valued life course, or choose to take directions from her anxiety.

- Mindfulness
    - Centering Exercise
    - Acceptance of Anxiety Exercise
    - Thoughts Drifting By Exercise
    - Mindfully walking in garden

- Exposure
    - Completed Weekly Valued Life Goals Activities form
    - Further areas completed:
        - Middle of grass without leaning on wall
        - Walking mindful circuits in the grass
        - Leaving front door and standing on front step

- Homework (as before)

Sessions 10 – 12

- Mindfulness
    - Centering Exercise
    - Acceptance of Anxiety Exercise
    - Thoughts Drifting By Exercise
    - Mindfully walking in garden
- Exposure
    - Completed Weekly Valued Life Goals Activities form
    - Areas completed:
        - Continued exposure on front porch
        - Looking at passersby without distracting self or looking at ground

- Working with resistance to progress

  Michelle's progress in exposure sessions halted during these weeks, and she reported significant worry around dealing with and interacting with the public if she progressed beyond the front gate. She reported a strong fear around having a panic attack if she were walking along the street and that others would evaluate her negatively.

To work with these beliefs a behavioural experiment was planned and collaborated on in these sessions. Michelle did not want to participate in the behavioural experiment herself, and instead it was suggested that this would be done by proxy, with the therapist acting out a panic attack in the street and Michelle observing the reactions of passersby from her window. It was scheduled for our final session with her other psychologist (supervisor) attending and acting in the role of Michelle's mother (a supporter).

- Homework (as before)

Sessions 13 – 14

- Ending

We explored Michelle's feelings around ending. Given that Michelle had very little contact with people outside her immediate family, she reported feeling very sad at the loss of this relationship and felt like she was losing a friend. Michelle felt that she had learned a lot from therapy, specifically that she could push herself past her comfort zone. She was pleased with her progress, but continued to worry about failing in the long-term.

- Behavioural experiment

Prediction: 'People will stare and whisper to one another. Neighbours might come over and have a look'.

Outcome: She reported being surprised that others did not pay too much attention and that many people walked past without even turning around. She also noticed that neighbours did not come out of their house, though she could not tell if they were looking out of the window with the view from her own window. We re-explored the option of taking part in the behavioural experiment herself in the future, but she remained resistant to this.

4. Clinical outcome

6.1 Treatment goals

Goal 1: By Session 4, Michelle was able to stand in the middle of the patio without leaning on the wall of the house or fence.

Goal 2: By Session 7, Michelle reached the back wall of the garden, and was able to stand in the middle of the grass without leaning on a wall and to walk mindful circuits when accompanied by a therapist or her mother.

Goal 3: By Session 9, she was able to leave the house via the front door and stand on the front step. At Session 10, she was able to step off the front porch.

Goal 4: Michelle did not reach the stage where she was willing to walk further than the front gate of the house.

Goals 5 & 6: Michelle showed a gradual increase (2 to 6) in her willingness to accept anxiety over the course of exposure sessions. See Figure 3.

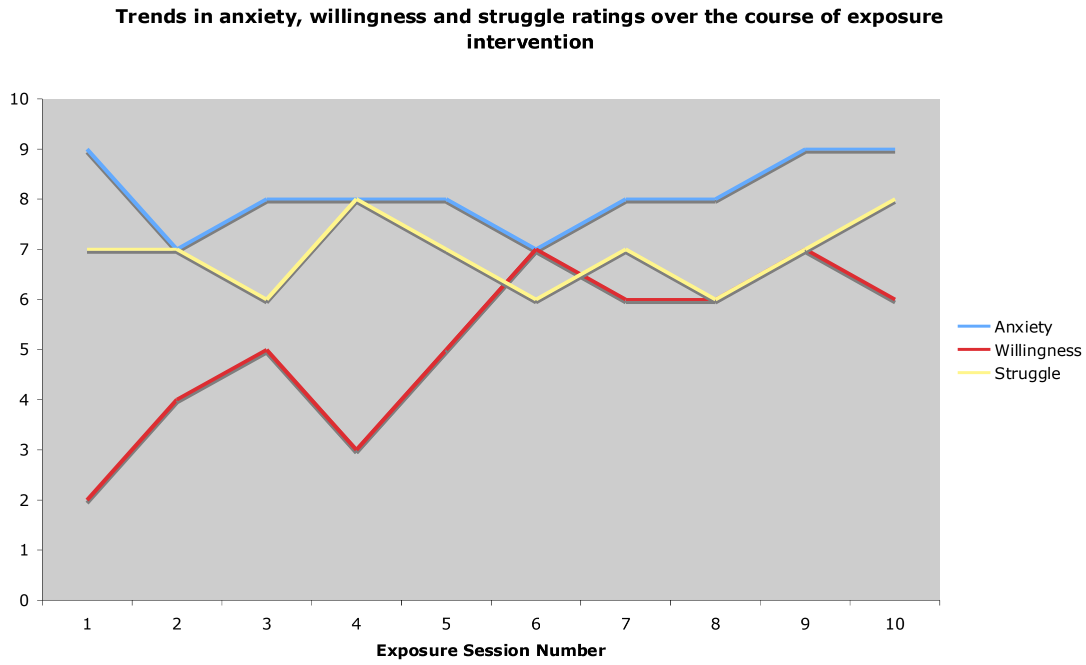


Figure 3

6.2 HoNOS ratings

Comparison in pre- and post-intervention HoNOS ratings identified a slight improvement in Michelle's overall mental and social health. Please see Table 5.

Table 5. Pre- and Post-intervention HoNOS scores

Scale	Before	After
1) Overactive, aggressive, disruptive or agitated behaviour	2	1
2) Non-accidental self-injury	1	0
3) Problem-drinking or drug-taking	0	0
4) Cognitive problems	1	0
5) Physical illness or disability problems	1	0
6) Problems associated with hallucinations and delusions	0	0
7) Problems with depressed mood	4	3
8) Other mental and behavioural problems	4	4
9) Problems with relationships	2	2
10) Problems with activities of daily living	0	0
11) Problems with living conditions	0	0
12) Problems with occupation and activities	0	0
13) Strong unreasonable beliefs occurring in non-psychotic disorders only	3	3
Total	18	13

7. Discussion

Over the course of therapy, Michelle's willingness to accept anxiety increased. This willingness served to increase the amount of control she had in terms of making decisions of how she would like to live her life rather than the amount of control she needed to have over anxiety itself. Michelle was able to consistently build on her goals and it was hypothesised that the processes targeted in the intervention (acceptance, cognitive defusion, self as context, contact with the present moment, values and committed action) would continue to lead to greater psychological flexibility over time and further improvement. Achievement of her specific and short-term goals also brought her closer to her valued life course, which narrowed the wide gap that existed between her starting point and long-term goals. She did not reach the stage where she was willing to walk further than the front gate of the house, but her success with other goals had fuelled her motivation to continue to build on these gains in future therapeutic work. Related to these achievements, more meaningful interactions and improvements to her behavioural repertoire also helped her to reconnect with her life, energising her and creating hope for the future.

This single case study provides support to the growing evidence for ACT for anxiety disorders by illustrating how improvements in psychological flexibility and shifting focus from content to process can aid a client to become 'unstuck' in the context of chronic and pervasive difficulties.

Michelle's presentation of anxiety was complex and covered a range of diagnostic categories. Following on from the suggestion by Barlow (2002) that it may be more useful to consider what is similar between anxiety disorders than what is distinct, it was thought that a transdiagnostic approach would be best indicated whereby the common process of experiential avoidance could be targeted. This approach allowed for goals to be simplified, stream-lined, and given meaning. In the context of such complexity this proved useful in undermining a sense of overwhelm for both the client and therapist and fostered hope and a renewed sense of self-efficacy.

The severity and chronicity of Michelle's difficulties had led to a sense of hopelessness and a life that was devoted exclusively to managing symptoms of anxiety to the detriment of her life beyond the symptoms. A careful evaluation of these processes suggested that a non-symptom focused approach could be more effective in helping Michelle to shift her focus from symptom management to reconnecting with her life goals and values. This process was not without difficulties, however. Owing to the chronicity of her difficulties, by dropping her avoidance and getting in touch with her values she inevitably faced loss. Confronting unchangeable facts, such as the loss of a decade of her youth, was understandably difficult for Michelle and triggered low mood, self-criticism and guilt. To defend against this she would often retreat from these experiences through avoidance, which presented in therapy as resistance. At these times, acceptance, mindfulness and a compassionate and non-judgemental approach was emphasised, reorienting Michelle to the present and inviting her to make the choice to take a stance on where she wanted to take her life.

7.1 Limitations

The assessment of the outcomes of this study was somewhat limited by lack of relevant outcome measures. Unlike other therapies (e.g. CBT), which focus on symptom alleviation, the aim of ACT is to foster psychological flexibility and acceptance in order for the client to make contact with their life beyond their symptoms. As such, in retropsect the outcomes of the HoNOS do not convey the specific processes targeted by ACT. The behavioural outcomes and willingness ratings, however, are more relevant to the goals of the intervention. In future work it would be preferable to measure outcomes with standardised measures such as the Mindfulness Attention Awareness Scale (MAAS; Brown & Ryan, 2003), which assesses mindfulness across cognitive, emotional, physical, interpersonal and general domains, and the Acceptance and Action Questionnaire (AAQ; Hayes et al, 2004), which a includes a Willingness scale (measuring willingness to accept undesirable thoughts and feelings) and an Action scale (measuring the congruence between the client's actions and their values and goals).

7.2 Reflections

Michelle's relative isolation meant that she had little contact with the outside world and people other than her family. Therapy presented a chance for her to build a new relationship with someone outside her inner circle and protected world. She would often ask personal questions regarding my life, such as my interests, if I could drive a car and if I was in a romantic relationship. It was important to consider the function of these questions in thinking of how to deal with challenges to traditional therapeutic boundaries. Through discussions in supervision it was thought that some level of disclosure may be useful in providing Michelle with a glimpse of the outside world that she had shut herself off from and with a measure of social comparison that could act as a catalyst for change and encourage commited action.

The theme of loss was also implicated in the therapeutic relationship. At the time, I was the exact age that Michelle was when she had stopped leaving the house, and therefore there was a degree of identification between me and this younger Michelle, with the years between us representing loss of opportunity and potential. Though this was difficult for her, it challenged Michelle's avoidance of negative emotions and facilitated a degree of acceptance.

Rapport, humour and therapeutic use of self was also helpful in engaging Michelle in therapy and building her trust when trying out an approach to anxiety that was new and frightening for her.

This case is an example of the usefulness of considering aspects of the therapeutic relationship in intervention. Flexibility around boundaries and disclosures proved effective in this case, however, such disclosure might not be useful or appropriate with other clients and should be carefully evaluated in the context of the formulation.

References

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

Barlow, D.H. (2002). *Anxiety and Its Disorders: The Nature and Treatment of Anxiety and Panic* (2nd Ed). New York: Guilford.

Barlow, D.H., Allen, L.B., & Choate, M.L. (2004). Towards a unified treatment of emotional disorders. *Behaviour Therapy, 35(2),* 205- 230.

Eifert, G.H. & Forsyth, J.P. (2005). *Acceptance and Commitment Therapy for Anxiety Disorders.* Oakland, CA: New Harbinger Publications.

Forman, E.M., Herbert, J.D., Moitra, E., Yeomans, P.D., & Geller, P.A. (2007). A randomized controlled effectiveness trial of acceptance and commitment therapy and cognitive therapy for anxiety and depression. *Behav Modif. 31(6),* 772-99.

Forsyth, J.P. & Eifert, G.H. (1996). The language of feeling and the feeling of anxiety: Contributions of the behaviourisms towards understanding the function-altering effects of language. *The Psychological Record, 46,* 607 – 649.

Goisman R.M., Allsworth J., Rogers M.P., Warshaw M.G., Goldenberg I., Vasile R.G., Rodriguez-Villa F., Mallya G., & Keller M.B. (1998). Simple phobia as a comorbid anxiety disorder. *Depress Anxiety, 7(3),* 105-12.

Hayes, S.C., Strosahl, K.D. & Wilson, K.G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behavior change.* New York: Guilford.

Hayes, S.C., Luoma, J.B., Bond, F.W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes. *Behaviour, Research and Therapy, 44,* 1 – 25.

Kessler R.C., McGonagle K.A., Zhao S., Nelson C.B., Hughes M., Eshleman S., Wittchen H.U, & Kendler K.S. Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States. Results from the National Comorbidity Survey. *Arch Gen Psychiatry, 51(1*), 8-19.

Luoma, J.B., Hayes, S.C., & Walser, R.D. (2007). *Learning ACT: An Acceptance and Commitment Therapy Skills Training Manual.* Oakland, CA: New Harbinger Publications.

Lillis, J. & Luoma, J. (2005). *ACT Initial Case Conceptualization Form.*

Orrell, M., Yard, P., Handyside, J. & Schapira, R. (1999). Validity and reliability of the Health of the Nation Outcome Scales in psychiatric patients in the community. *British Journal of Psychiatry, 174,* 409 – 412.

Ruiz, F.J. (2010). A review of Acceptance and Commitment Therapy (ACT) empirical evidence: correlational, experimental psychopathology, component and outcome studies. *International Journal of Psychology and Psychological Therapy, 10, (1),* 125-162.

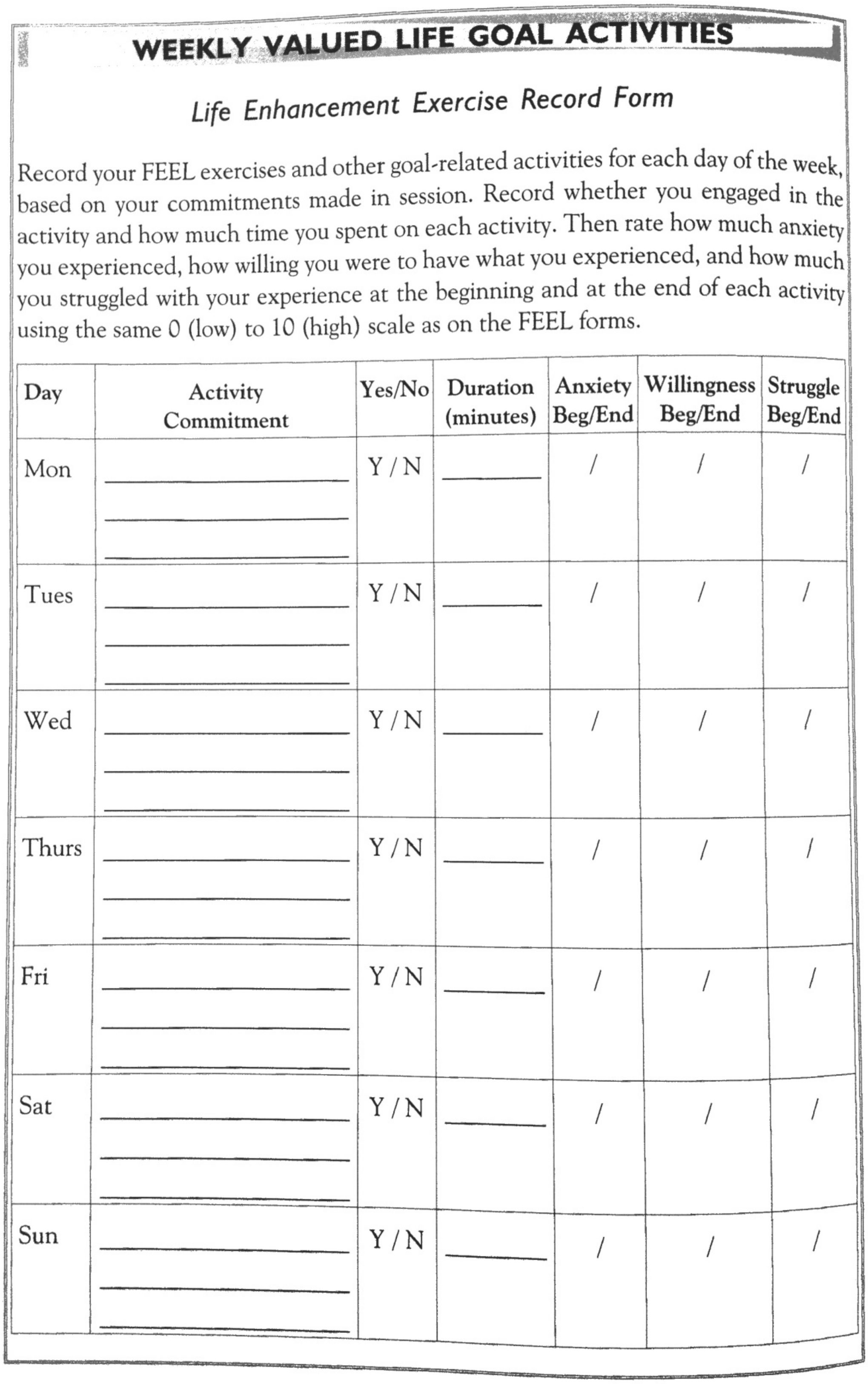
Twohig, M.P., Hayes, S.C., Plumb, J.C., Pruitt, L.D., Collins, A.B., Hazlett-Stevens, H., Woidneck, M.R. (2010). A randomized clinical trial of acceptance and commitment therapy versus progressive relaxation training for obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology, 78(5),* 705 – 716.

Wicksell, R.K., Olsson, G.L., & Hayes, S.C. (2011). Mediators of change in Acceptance and Commitment Therapy for pediatric chronic pain. *Pain, 152(12),* 792-801.

Wittchen, H.U., Schuster P, & Lieb R. (2001). Comorbidity and mixed anxiety-depressive disorder: clinical curiosity or pathophysiological need? *Hum Psychopharmacol. 6(1),* 21-30.

World Health Organisation (1993). *The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research*. Geneva: Author

Appendix A



WEEKLY VALUED LIFE GOAL ACTIVITIES

Life Enhancement Exercise Record Form

Record your FEEL exercises and other goal-related activities for each day of the week, based on your commitments made in session. Record whether you engaged in the activity and how much time you spent on each activity. Then rate how much anxiety you experienced, how willing you were to have what you experienced, and how much you struggled with your experience at the beginning and at the end of each activity using the same 0 (low) to 10 (high) scale as on the FEEL forms.

Day	Activity Commitment	Yes/No	Duration (minutes)	Anxiety Beg/End	Willingness Beg/End	Struggle Beg/End
Mon	____________________ ____________________ ____________________	Y / N	________	/	/	/
Tues	____________________ ____________________ ____________________	Y / N	________	/	/	/
Wed	____________________ ____________________ ____________________	Y / N	________	/	/	/
Thurs	____________________ ____________________ ____________________	Y / N	________	/	/	/
Fri	____________________ ____________________ ____________________	Y / N	________	/	/	/
Sat	____________________ ____________________ ____________________	Y / N	________	/	/	/
Sun	____________________ ____________________ ____________________	Y / N	________	/	/	/

Appendix B

1) Experiential and metaphorical exercises:

   a. *Chinese Finger Trap*

      The purpose is to illustrate how a counterintuitive behaviour (i.e. pushing fingers together, rather than pulling out) can sometimes be the best solution.

   b. *Tug of War*

      The purpose is to illustrate 'letting go of struggle'. It involves playing a tug-of-war with the 'anxiety monster' (played by therapist). It highlights the amount of energy and focus it takes to pull against the 'anxiety monster', to the point where they are unable to do anything else.

   c. *Bus Driver Exercise*

      Client is asked to imagine driving their bus called 'My Life', which picks up noisy and bullying passengers along the way that shout and tell the bus driver to change course and go where they want to go (representing thoughts and feelings). The idea is that clients can choose to drive the course they want to drive (valued directions) regardless of what the passengers say.

   d. *Pen exercise*

      The aim of this exercise is to illustrate the idea of 'emotional willingness' and draw a distinction between 'trying' and 'doing'. It demonstrates that willingness is an all-or-nothing action. The exercise requires the client to 'try' to write with a pen, making the point that 'trying' really means 'not doing'. Therefore, willingness becomes a 'yes or no' (i.e. if you are willing then you will be doing).

2) Mindfulness exercises
   a. *Centering Exercise (Eifert & Forsyth, 2005)*

      This is a brief mindfulness exercise which is designed to help clients focus on the here and now.

   b. *Acceptance of Anxiety Exercise (Eifert & Forsyth, 2005, adapted from Segal et al, 2002).*

      The aim of this exercise to change the client's relationship with anxiety. It encourages the acceptance of anxiety as it is (e.g. physical sensations and difficult feelings), not what the mind says it is (e.g. something dangerous or a warning sign for catastrophe). It focuses awareness on thoughts and bodily sensations related to anxiety and enlists the client to stay with the feelings until they feel they are no longer dominating their need for attention. The client is encouraged to be with these feelings and sensations without needing to change or fix them.

   c. *Watching Thoughts Drift By Exercise (Davis et al, 2000; Hayes et al, 1999)*

      This exercise is designed to help clients see thoughts as thoughts, and as phenomena that can be observed without the need to engage with their content. It involves using imagery to place one's thoughts on leaves as they drift downstream, encouraging the acknowledgement their presence with curiosity and compassion and without trying to force them to go away.

CASE STUDY 2

NEUROPSYCHOLOGICAL ASSESSMENT OF MEMORY AND EXECUTIVE FUNCTIONING IN THE CONTEXT OF TRAUMATIC BRAIN INJURY 25 YEARS ON

Erin Tehee

Supervised by Professor Robin Morris

1. Introduction

1.1 The Nature of Traumatic Brain Injury

Traumatic brain injury (TBI) occurs when there is physical damage to the brain as a result of a head injury. TBI is commonly incurred by sudden motion in the brain due to either blunt impact or rapid acceleration and deceleration (Richardson, 2000). The repercussions of such forces may cause tearing of cranial nerves and blood vessels, loss of oxygen, loss of blood and intracranial pressure. The majority of TBIs are classed as closed head injuries where there is no penetrating wound, but where damage is caused by a blow to the head or the forces of acceleration or deceleration causing the brain to make contact with the skull (Richardson, 2000), the nature of which leaves the frontal and temporal lobes most vulnerable to damage.

According to Jennett (1976), the severity of TBI can be defined by the duration of its initial characteristics, the nature of complications arising from injury and long-term sequelae. Coma severity at the initial stages is measured by the Glasgow Coma Scale (GCS), which ranges from mild to moderate to severe (Teasdale & Jennett, 1974). Recovery from a coma is determined by the length of the post-traumatic amnesia (PTA) period, a time when patients are confused and unable to encode new memory. PTA which lasts longer than 24 hours is classed in the severe range (Russell & Smith, 1961).

1.2 Incidence and risk factors

In Europe, the incidence of TBI in the adult popultion has been estimated to vary between 150 to 300 per 100,000 per year (Tagliaferri et al, 2006) with the variation owed to the heterogeneity in definition of mild TBI. A review by Cassidy et al (2004), has suggested that the vast majority (70 – 90%) of TBI cases fall into the mild range of severity.

Road traffic accidents (RTAs) are the most common cause of TBI (Langlois-Orman et al, 2011). Risks factors for TBI include being male (Jennett et al, 1977; Richardson, 2000), being an adolescent or young adult (Kraus et al, 1984; Kraus & McArthur, 1996) and being of lower socioeconomic status (Kerr et al, 1971; Field, 1976).

1.3 Cognitive implications of TBI

1.3.1. Memory

Memory loss is the most common cognitive impairment following TBI (McCullagh & Feinstein, 2011), including loss of old memories and difficulty retaining new memories. It is particularly evident in declarative memory, where memory is consciously recalled (Richardson, 2000). Structurally, memory impairment is connected to damage incurred to the temporal lobes (Kolb & Whishaw, 2003), but may also be impacted on by secondary processes carried out in the frontal lobes, such as working memory.

1.3.2. Executive Functioning

According to Burgess and Alderman (2004), "executive functions refer to those abilities that enable a person to determine goals, formulate new and useful ways of achieving them, and then follow and adapt this proposed course in the face of competing demands and changing circumstances, often over long periods of time." Damage to the frontal lobe may directly impact these processes resulting in a range of symptoms which are collectively referred to as dysexecutive syndrome (Baddeley & Wilson, 1988). This syndrome is characterised by difficulties in a number of key processes including: 1) planning and problem solving, 2) initiation and inhibition, 3) rule detection and maintenance or shifting in set, 4) perseveration, 5) sustained attention, 6) multitasking, and 7) disinhibition (Burgess & Alderman, 2004).

1.3.3. Language

Frontal and temporal lobe damage may also lead to language impairment (Kolb & Whishaw, 2003), such as aphasia, naming difficulties and problems interpreting emotional prosody in speech.

1.3.4. Attention

Problems with attention are one of the most common deficits noted following TBI (Auerbach, 1986; Levin & Goldstein, 1989) and are related to damage to the white matter connecting frontal, parietal and striatal structures of the brain (Friedman et al, 1998; Garnett et al, 2000). This is evident in TBI patients' tendency to drift from goals (Shallice & Burgess, 1991) and in the preponderance of complaints regarding attention and concentration reported by patients post-injury (McKinlay, 1981; VanZomeren & Burg, 1985).

1.4 Psychosocial sequelae

Lishman (1973) drew a distinction between direct and indirect consequences of TBI and suggested that brain damage factors explained only a fifteenth of later psychiatric difficulties. He highlighted the role of other factors in outcome including emotional consequences of injury, pre-morbid personality, environmental factors, response to intellectual impairment, and compensation and litigation. Kendall and Terry (1996) acknowledge the role of these variables, but also emphasise the role of mediating factors such as coping strategies and cognitive appraisals.

In terms of psychiatric morbidity, people with TBI are more vulnerable to developing co-morbid psychiatric disorders including generalized anxiety disorder, depression and post-traumatic stress disorder (Holsinger et al, 2002; Rogers & Read, 2007) and their suicide risk is increased three to four fold compared to that of the general population (Simpson & Tate, 2007).

The nature of brain damage may also lead to changes in personality, which varies considerably between individuals but can include blunted affect, disinhibition, increased aggression, decreased self-control, inappropriate sexual behaviour and emotional lability (Prigatano, 1992). This may be particularly difficult for friends and family to accept and manage post-injury, which may compound adjustment difficulties.

In summary, in addition to the direct consequences of TBI, it is also important to consider the indirect impact of injury as well at the coping resources, strategies and beliefs one uses to manage and make sense of their difficulties.

1.5 Long-term psychosocial outcome of TBI

A study by Thornhill et al (2000) found that over half of individuals studied at one-year post-injury remained moderately to severely disabled. The literature has also examined the longer-term (>10 years) psychosocial outcome of TBI, though the number of studies is relatively few. A study by Sbordone et al (1995) suggested that recovery continues in the years following injury and the authors noted improvements over a 10 year post-injury period in motor, behavioural, cognitive, vocational and interpersonal functioning. Longitudinal research carried out by Thomsen (1974, 1984, 1992) identified psychosocial sequelae as more debilitating than physical disability at two and a half years, and found that these problems persisted at initial follow-up; however, later improvement was noted subsequently at 10 to 15 year follow-up for a number of cases. At 20 year follow-up, Thomsen (1992) reported 23% of the sample to have ‘good’ to ‘very good’ psychosocial outcomes. Findings from a study of very long-term outcomes following serious head-injury (10- 32 years post injury) by Wood and Rutterford (2006) also support the potential for considerable recovery of functioning over time. The authors found that 72% of their sample was able to live independently and 41% were in employment, leading them to conclude that later outcomes may be better than those predicted at earlier stages of recovery.

2. The Case of Mr W

2.1 Reason for Referral

Mr W was referred for neuropsychological assessment following a review from his consultant neurologist who identified Mr W as experiencing chronic and significant issues in relation to his memory and performance following a road traffic accident (RTA) which took place in 1984. The referrer also highlighted possible psychosocial stressors in the context of Mr W's work environment. It was noted that Mr W had undergone neuropsychometric testing at some point in the 1980s, but it was not possible to locate the results of these assessments at the time of testing.

2.2 Assessment

2.2.1 Aims

The current assessment sought to clarify the impact of Mr W's head injury incurred as a result of a RTA in 1984, in terms of memory and performance difficulties with a view to providing salient recommendations.

2.2.2 Clinical interview

Mr W was seen together with his wife for a brief clinical interview in order to gain a more comprehensive understanding of his current difficulties and their impact on his day-to-day life, in addition to assessing his mood and well being. The Hospital Anxiety and Depression Scale (HADS) was used as a standardised clinical screening measure of affective symptoms.

2.2.3 Cognitive functioning

Following the clinical interview, Mr W was seen individually and underwent an assessment of his premorbid IQ, current intellectual abilities, memory, working memory, processing speed and executive functioning. See Table 1 for a summary of the assessment battery.

Table 1. Assessment Battery

Area to be assessed	*Test*
Premorbid IQ	National Adult Reading Test (NART)
Current Intellectual Functioning	Wechsler Abbreviated Scale of Intelligence (WASI)
Memory	Logical Memory (WMS-III)*
	Verbal Paired Associates (WMS-III)
	Auditory Recognition (WMS-III)
	Visual Reproduction (WMS-III)
Working Memory	Digit Span (WAIS-III)**
	Letter-Number Sequencing (WAIS-III)
Processing Speed	Digit Symbol-Coding (WAIS-III)
	Symbol Search (WAIS-III)
Executive Functioning	Hayling Sentence Completion Test and Brixton Spatial Anticipation Test
	Verbal Fluency (D-KEFS)***
	Trail Making Test (D-KEFS)
	Color-Word Interference Test (D-KEFS)
	Sorting Test (D-KEFS)
	Twenty Questions Test (D-KEFS)
	Word Context Test (D-KEFS)
	Tower Test (D-KEFS)

*Wechsler Memory Scale-III

**Wechsler Adult Intelligence Scale 3rd Edn

***Delis-Kaplan Executive Function System

2.3. Presenting Problem

Mr W reported a number of memory difficulties at the time of assessment. At work, he stated that he had difficulty remembering dates and tended to forget what he was doing in the middle of a task. He believed that writing things down helped him to remember things, but stated that he often did not engage in note-taking as he preferred to trust himself to remember. If he forgot to do something, he reported that he was sometimes accused of deliberately not doing it, and that even when he forgot something small, his colleagues might bring it up with him. On occasions, Mr W believed colleagues would highlight his shortcomings in order to "point score", an experience which he found frustrating. As a result of his memory difficulties and the working environment, Mr W reported experiencing a certain degree stress at work. When asked if his colleagues were aware of his TBI, he reported that he did not share this with them in case they would use it against him.

Overall, Mr W felt that he was able to perform effectively at work as it involved routines and patterns that he was able to remember. In terms of employment-related difficulties, he reported that when going for interviews for promotion in the past he had received feedback that he tended to "talk too much" and often digressed from the question at hand. Mr W agreed with this feedback, saying that he often found himself going off on a tangent. He also reported word finding difficulties where he described "feeling the word" but being unable to "pull it out of [his] head". Additionally, he described difficulties doing two things at once and that he often became distracted by competing noises or conversations, particularly when trying to have a telephone conversation.

With regard to home life, Mr W reported performing better when in routine and when prompted by notes or reminders left by his wife. He stated that he could remember routines, but had difficulty updating this information with changes or alterations to the pattern. If the pattern changed he tended to continue with the old pattern and thus make mistakes, which he found "infuriating". His wife, whom he described as very organised, conscientiously placed notes around the house to prompt him to remember things. She also managed the preparation of his meals and reminded him about events such as birthdays, holidays and when to buy greeting cards, but he would forget when not prompted (e.g. not remembering his wife's own birthday). With regard to managing his memory difficulties, he stated that a lot of what he did was "guess work" and that he preferred to take a chance at a correct answer or response rather than saying he did not know or could not remember.

2.4. History

Mr W reported being involved in a road traffic accident in 1984 at the age of 19 years. As the result of the RTA, he reported sustaining a head injury, which left him in a coma for 12 days. According to Mr W, he was informed that he may have sustained a frontal lobe injury as a result of the accident and that a scan (not available at the time of assessment) revealed injury and scarring to his brain, though he was not sure what part of the brain had been affected. Mr W also sustained paresis in his left arm as a result of the trauma, which he reports as now atrophied due to disuse. Mr W reported undergoing some neuropsychological testing as a participant in a research study approximately six years ago, but stated that he did not receive the results.

Mr W was right-handed. He left school at 17 years, having completed his CSEs and GCSEs in Mathematics, English, and Physics in addition to woodwork, art/design and technology. He reported his best subject to have been Mathematics and he went on to take up an apprenticeship in precision engineering. In the second year of his apprenticeship he was involved in the RTA, as described above. He returned to college in 1988 to take up studying electronics service and repair; however, he left the course as he found it too challenging at the time due to the disability of his left arm. Concurrently, he had begun a job at a bingo hall, which he enjoyed as it allowed him to work with people whilst also bringing in a good income. Following this job, Mr W took up a variety of other jobs, which ranged from manual/technical in nature to hosting a visitors' centre. In terms of his job performance in the past, he reported some "absent mindedness", where he would sometimes lose track of his schedules and confuse plans. However, he reported that this did not have a significant effect on his ability to carry out his work effectively. He took up his most recent post in 2003, as a support attendant within a government building, which he was still working in at the time of assessment. This post involved managing a number of facilities such as the post and meetings, in addition to organising the business of the day. He described the job as repetitive, mundane, boring and frustrating. He also reported feeling that he was being treated unfairly and discriminated against by colleagues, and not being offered the same opportunities as others. Reflecting on his employment history, he described feeling that all his jobs were below what he was capable of achieving, and this frustrated him. This coupled with perceived unfair treatment, according to Mr W, left him feeling angry and resentful towards his current colleagues from time to time.

Before the accident, Mr W described himself as an active young man, with a particular interest in martial arts. At the time of assessment, he described a great deal of regret at not being able to continue practicing this and considered it a loss in his life. However, following the RTA Mr W had remained active and was a member of a running club, and continued to enjoy challenging himself, having completed the London Marathon close to the time of the current assessment. He reported feeling proud of this achievement as it was something he was able to put his mind to and succeed at.

2.5 Presentation

In the assessment, Mr W presented as a well-dressed and talkative gentleman. In response to questions, he tended to be tangential and anecdotal in his responses, often digressing from the focus of the question.

3. Assessment Findings

Mr W's current performance on neuropsychological tests will be outlined in each of the following sections. Please see the appendix for further details of results obtained on the neuropsychological tests.

3.1. Intellectual Functioning

Mr W's current intellectual functioning was assessed using the Wechsler Abbreviated Scale of Intelligence (WASI). On this test, he achieved a Full Scale IQ score of 110 (75th percentile) placing him within the average range on this assessment. He obtained a Performance IQ (PIQ) score of 114 (82nd percentile), and his Verbal IQ (VIQ) score was 106 (66th percentile), placing his performance in these subtests in the high average and average range, respectively. The discrepancy between his Verbal and Performance intelligence is statistically significant and suggests a particular strength in his performance abilities, but this difference is relatively common and found in a normative sample (25%).

3.2. Memory

Mr W's verbal and visuo-spatial memory abilities were tested using the following subtests of the Wechsler Memory Scale III (WMS-III): Logical Memory I & II, Verbal Paired Associates I & II and Visual Reproduction I & II. His working memory was assessed using the Digit Span and Letter-Number Sequencing tasks of Wechsler Adult Intelligence Scale, 3rd Edition (WAIS-III).

3.2.1 Verbal memory

On the Logical Memory subtests, Mr W scored in the low average range for immediate recall, delayed recall, and retention. On the Verbal Paired Associates subtests, he scored in the borderline range for immediate recall, delayed recall, and moderate range for retention. His total performance for delayed auditory recognition in both verbal memory tasks placed him in the low average range. Overall, his verbal memory performance is significantly lower than can be expected from his Verbal IQ range of average, with mild to moderate impairment.

3.2.2 Visuo-spatial memory

On the Visual Reproduction subtests, Mr W scored in the low average range for immediate recall, borderline for delayed recall, and in the average range for retention. Compared to his Performance IQ, which is in the high average range, his overall performance on these tests was significantly lower than what can be predicted from his non-verbal intellectual abilities, again suggesting mild to moderate impairment.

There was a tendency for him to do better when there was meaning and structure in the material and he also tended to remember information that he had been able to initially register.

3.3.3 Working memory

Mr W scored in the average range on both the digit span and letter-number sequencing tasks, which suggests the absence of a significant deficit in his working memory in the context of his average Verbal IQ score.

3.4 Processing speed

Mr W's processing speed was assessed using the digit symbol-coding and symbol search tasks of the WAIS-III. Mr W scored in the low average range on both tests suggesting a mild to moderate impairment, when compared to his high average Performance IQ.

3.3. Executive Functioning

3.3.1 Delis-Kaplan Executive Function System (D-KEFS)

3.3.1.1 Verbal Fluency Mr W's word generation abilities were assessed using the Verbal Fluency test of the D-KEFS. On the letter fluency, category fluency and category switching tests Mr W performed in the average range.

3.3.1.2 Trail Making Mr W's cognitive flexibility was assessed using the Trailmaking test of the D-KEFS. He performed in the average range in all conditions, which relative to his Performance IQ suggests mild impairment.

3.3.1.3 Sorting Mr W's conceptual-reasoning, problem solving skills, and initiation of problem solving was assessed using the Sorting test of the D-KEFS. He scored in the average range for correct sorting and correct descriptions, but in the low average range for sort recognition, suggesting a mild to moderate impairment in these areas, respectively.

3.3.1.4 Twenty Questions Logical thinking, abstraction, deduction and hypothesis testing was assessed using the Twenty Questions test of the D-KEFS. He scored in the average range in this test suggesting that these abilities were intact.

3.3.1.5. Word Context Mr W's deductive reasoning, flexibility of thinking, and his ability to integrate multiple pieces of information and to hypothesis test was measured using the Word Context test of the D-KEFS. He scored in the average range on this test suggesting these abilities were intact.

3.3.1.6 Tower Rule learning, spatial planning, inhibition of perseverative responding, inhibition of impulsive responding, and the ability to establish and maintain a cognitive set were assessed by the Tower test of the D-KEFS. Mr W scored in the average range, suggesting a mild deficit relative to what can be expected based on his high average Performance IQ.

3.3.1.7 Colour-Word Interference Test The two baseline conditions of this test require the naming of colour patches and reading words that denote colours (printed in black ink). The interference tasks measure inhibition (Condition 3) and inhibition and cognitive flexibilty (Condition 4). Mr W scored in the average range for the baseline conditions and the inhibition condition, but in the low average for the inhibition/switching condition, which suggests a deficit in cognitive flexibility.

3.3.2 The Hayling Sentence Completion Test

Mr W completed the Hayling Sentence Completion Test which is a measure of response initiation and response suppression. Overall, he scored in the poor range on the test. More specifically, for the response initiation subtest he scored in the low average range and the for the response suppression subtest he achieved a score in the average range, however his level of category error in the latter task placed him in the impaired range.

4.3.3. The Brixton Spatial Anticipation Test

In the Brixton Spatial Anticipation Test he scored within the high average range.

3.4. Mood

On the Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994), Mr W scored 11 for anxiety and 5 for depression, suggesting that he is in the moderate range on the anxiety subtest.

4. Conclusions

4.1. Memory

Mr W's performance on verbal and visuo-spatial memory tasks indicate mild to moderate memory impairment relative to what can be expected from his performance on verbal and performance IQ tests. His working memory scores, however, were in line with his verbal ability.

4.2. Executive functioning and processing speed

His performance on tests of executive function suggests a mixed picture, with some areas showing deficit whilst others remained intact. His Tower Test scores indicated a mild overall deficit in executive functioning, and his performance on sub-tests of the Colour-Interference and Trailmaking tests suggested mild difficulties with cognitive flexibility. His performance on response suppression tasks suggested significant impairment in this area. Conceptual reasoning and recognition of new patterns also appeared to have been affected. Tests of processing speed showed mild to moderate impairment.

Mr W's performance on tests of executive functioning reflects the difficulties he described in his everyday life. For example, he reported taking longer to learn new information and to start new routines, which may be due to speed of processing new information, recognising new patterns and changing his behaviour in light of new information. Mr W also found it difficult to multitask, and would become easily distracted from tasks and thus find it difficult to see them to completion. His difficulties with inhibition also appear to fit with his tendency to be tangential in conversation.

4.3 Psychosocial considerations

Mr W appeared to present with some difficulty adjusting to and accepting the cognitive sequelae of his TBI, and this may have been affecting his ability to cope at his place of work. On the screening measure for anxiety and depression, Mr W scored in the moderate range for anxiety. He also described anger and frustration in terms of his current work situation, where he felt he was being criticised by colleagues. The nature of Mr W's work required him to organise and coordinate meetings and facilities, tasks which carried a heavy memory and executive functioning load. Mr W felt he was able to do his job effectively once he had learned off a routine as he could then remember it and carry it out without difficulty; however, whenever new information was introduced he had trouble remembering it and incorporating it into existing routines. Mr W would get angry at these times, both at himself and at anyone who mentioned his mistakes. He was unwilling to disclose the nature of his difficulties to colleagues or to employ memory aids that could improve his performance at work, such as note taking. Furthermore, though it was the repetitiveness of the job that helped Mr W to work effectively, he also felt frustrated by the monotony of his day-to-day work and felt resentful when he was passed up for more demanding jobs. At home, Mr W also remained heavily dependent on his wife to provide him with reminders rather than taking a more proactive role to managing his memory difficulties.

5. Psychoeducation Session

Following the initial assessment, Mr W was invited to attend for a feedback and psychoeducation session with his wife where the results of assessment were explained and potential strategies for his difficulties were introduced and discussed.

5.1. Goal Management Training

In order to support Mr W in working effectively both in his job and at home, Goal Management Training (Levine et al, 2000) was introduced. In order to achieve a specific goal, it was suggested that Mr W break the process down into five steps using the following statements:

- *"Stop – what am I doing?"*
- *"Define the goal"*
- *"List the steps"*
- *"Learn the steps"*
- *"Check – am I doing what I planned".*

5.2 Memory strategies

Memory aides were also discussed to encourage Mr W to be more proactive and independent in managing his memory, both at home and at work. The following recommendations were discussed:

- Allowing for a slower pace of learning
- Setting a specific time each day or week to programme one's mobile phone with important reminders
- As his visual memory was slightly less impaired, the use of visual memory aides such as diaries and notice boards was encouraged.

5.3 Cognitive Behaviour Therapy

In order to develop more adaptive ways of managing any ongoing anxiety and stress, cognitive behaviour therapy (CBT) was recommended. Mr W was sign-posted to the Improving Access to Psychological Therapies (IAPT) service, or if he preferred, to his GP who could then refer him to the appropriate service.

6. Limitations

The comprehensiveness of this assessment would have benefited from the addition of neuroimaging, which could have confirmed the areas of the Mr W's brain that had been damaged. These had been done in the past, but were not available at the time of assessment. Mr W was able to confirm the presence of long-term damage from these previous scans, and believed that part of his frontal lobe had been compromised, but without the images it is difficult to draw any conclusions.

7. Reflection

Other than an assessment completed as part of a research protocol, Mr W had not undergone any formal clinical neuropsychological testing following his TBI or thereafter, which I found interesting in light of his persistent difficulties. Mr W presented as optimistic about his abilities, and his tendency to challenge himself had brought him great success in physical challenges, such as the London Marathon; however, this approach seemed less adaptive in the context of irreparable neuropsychological deficits. From a stress-appraisal coping framework (Lazarus & Folkman, 1984), his expectations for what he could achieve seemed to outweigh his resources, resulting in significant stress. Furthermore, because his manager or colleagues were not aware of his difficulties, their expectations may have also been unrealistically high, compounding the pressure he was experiencing. He also appeared to lack insight into possible reasons why he was not being offered jobs with a more varied remit which required novel thinking and flexibility. Despite the attempt at developing a rudimentary formulation of his difficulties, this was not done collaboratively or shared. Though in another case it may have been appropriate and useful to tentatively explore this formulation, Mr W's presentation suggested that he was not willing to consider these processes in the context of this assessment. In addition to this, the feedback session was more challenging than I expected as Mr W was somewhat dismissive of the strategies I suggested, particularly the possibility of engaging in CBT. This was disappointing on my part, as I was hoping that providing him with information around his difficulties and strategies on how to best manage them would help to foster more acceptance and diminish his avoidance. Nevertheless, I was able to empathise with his position and his feelings of frustration and the loss of potential, which he faced on a daily basis. I could acknowledge that this 'unrealistic' optimism may have been the driving force behind his remarkable recovery and any attempts to introduce flexibility in a strategy that had served him so well for and for so long would be difficult and beyond the scope of this piece of work. On reflection, in future work it may be beneficial to spread feedback over a number of sessions in order to sufficiently engage a client who may have difficulty accepting limitations brought about by TBI.

References

Auerbach, S.H. (1986). Neuroanatomical correlates of attention and memory disturbances in traumatic brain injury: an application of neurobehavioural subtypes. *Journal of Head Trauma Rehabilitation, 1,* 1 – 12.

Baddeley, A. & Wilson, B. (1988). Frontal amnesia and the dysexecutive syndrome. *Brain Cognition, 7(2),* 212- 230.

Burgess, P.W. & Alderman, N. (2004). Executive dysfunction. In Goldstein, L. & McNeil, J.E. (eds). *Clinical Neuropsychology: A practical guide to assessment and management for clinicians* (p. 185 – 209). London: Wiley.

Cassidy, J.D., Carroll, L.J., Peloso, P.M., Borg, J., von Holst, H., Holm, L., Kraus, J., & Coronado, V.G. (2004). Incidence, risk factors and prevention of mild traumatic brain injury: results of the WHO collaborating centre task force on mild traumatic brain injury. *Journal of Rehabilitation Medicine, 36 (43), 8–60.*

Field, J.H. (1976). *Epidemiology of head injuries in England and Wales.* London: Her Majesty's Stationary Office.

Friedman, S.D., Brooks, W.M., Jung, R.E., Hart, B.L. & Yeo, R.A. (1998). Proton MR spectroscopic findings correspond to neuropsychological function in traumatic brain injury. *American Journal of Neuroradiology 19 (10),* 1879–1885.

Garnett, M.R., Blamire, A.M., Corkhill, R.G., Cadoux-Hudson, T.A.D., Rajagopalan, B. & Styles, P. (2000). Early proton magnetic resonance spectroscopy in normal-appearing brain correlates with outcome in patients following traumatic brain injury. *Brain, 123,* 2046– 2054.

Holsinger, T., Steffens, D.C., Phillips, C., Helms, M.J., Havlik, R.J., Breitner, J.C., Guralnik, J.M. & Plassman, B.L. (2002). Head injury in early adulthood and the lifetime risk of depression. *Archives of General Psychiatry, 59,* 17 – 22.

Jennett, B. (1976). Assessment of the severity of head injury. *Journal of Neurological and Neurosurgical Psychiatry, 39,* 647 – 655.

Jennett, B., Murray, A., Carlin, J., McKean, M., MacMillan, R., Stran, I. & Hawthorne, V. (1977). Head injuries in Scottish hospitals: Scottish Head Injury Management Study. *Lancet, 2,* 696 – 698.

Kendall, E. & Terry, D.J. (1996). Psychosocial adjustment following closed head injury. A model for understanding individual differences and predicting outcome. *Neuropsychological Rehabilitation, 6,* 101 – 132.

Kerr, T.A., Kay, D.W.K. & Lassman, L.P. (1971). Characteristics of patients, type of accident, and mortality in a consecutive series of head injuries admitted to a neurosurgical unit. *British Journal of Preventative and Social Medicine, 25,* 179 – 185.

Kolb, B. & Whishaw, I.Q. (2003). *Fundamentals of human neuropsychology (5th ed.).* New York: Worth.

Kraus, J.F. & McArthur, D.L. (1996). Epidemiological aspects of brain injury. *Neurological Clinics, 14,* 435 – 450.

Kraus, J.F., Black, M.A., Hessol, N., Ley, P., Rokaw, W., Sullivan, C., Bowers, S., Knowlton, S. & Marshall, A. (1984). The incidence of acute brain injury and serious impairment in a defined population. *American Journal of Epidemiology, 119,* 186 – 201.

Langlois-Orman, J.A., Kraus, J.F., Zaloshnja, E. & Miller, T. (2011). Epidemiology. In Silver, J.M., McAllister, T.W. & Yudofsky, S.C. (eds). *Textbook of traumatic brain injury (2nd Ed).* (p. 3 -23). Arlington, VA: American Psychiatric Publishing.

Lazarus, R.S. & Folkman, S. (1984). *Stress Appraisal and Coping.* New York: Springer.

Levin, H.S. & Goldstein, F.C. (1989). Neurobehavioural aspects of traumatic brain injury. In P. Bach-y-Rita (Ed.). *Comprehensive Neurologic Rehabilitation* (p. 53 - 72) Demos: New York, NY.

Levine, B., Robertson, I.H., Clare, L., Carter, G., Hong, J., Wilson, B.A., et al. (2000). Rehabilitation of executive functioning: An experimental-clinical validation of Goal Management Training. *Journal of International Neuropsychological Society, 6,* 299 – 312.

Lishman, W.A. (1973). The psychiatric sequelae of head injury: a review. *Psychological Medicine, 3,* 304 – 318.

McCullagh, S. & Feinstein, A. (2011). Cognitive changes. In Silver, J.M., McAllister, T.W. & Yudofsky, S.C. (eds). *Textbook of traumatic brain injury (2nd Ed).* (p. 279 - 295). Arlington, VA: American Psychiatric Publishing.

McKinlay, W.M. (1981). The short-term outcome of severe blunt head injury as reported by relatives of the injured persons*, Journal of Neurology, Neurosurgery, and Psychiatry, 44*, 527–533.

Prigatano, G.P. (1992). Personality disturbances associated with traumatic brain injury. *Journal of Consulting and Clinical Psychology, 60,* 360 – 368.

Richardson, J. T. E. (2000). *Clinical and Neuropsychological Aspects of Closed Head Injury (2nd ed.)*. Hove: Psychology Press

Rogers, J.M. & Read, C.A. (2007). Psychiatric comorbidity following traumatic brain injury. *Brain Injury, 21,* 1321 – 1333.

Russell, W.R. & Smith, A. (1961). Post-traumatic amnesia in closed head injury. *Archives of Neurology, 5,* 4 – 17.

Sbordone, R.J., Liter, J.C., Petter-Jennings, P. (1995). Recovery of function following severe traumatic brain injury: a retrospective 10-year follow-up. *Brain Injury, 9,* 285-299.

Shallice, T. & Burgess, P. (1991). Deficits in strategy application following frontal lobe damage in man. *Brain, 114,* 727–741.

Simpson, G. & Tate, R. (2007). Suicidality in people surviving traumatic brain injury: Prevalence, risk factors and implications for clinical management. *Brain Injury, 21,* 1335 – 1351.

Snaith, R.P. & Zigmond, A.S. (1994). *HADS: Hospital Anxiety and Depression Scale.* Windsor: NFER Nelson.

Tagliaferri, F., Compagnone, C., Korsic, M., Servadei, F., & Kraus, J. (2006). A systematic review of brain injury epidemiology in Europe. *Acta Neurochir, 148,* 255–268.

Teasdale, G. & Jennett, B. (1974). Assessment of coma and impaired consciousness. A practical scale. *Lancet, 2,* 81 – 84.

Thomsen, I.V. (1974). The patient with severe head injury and his family. *Scand J Rehabil Med, 6,* 180-183.

Thomsen, I.V. (1984). Late outcome of very severe blunt head trauma: a 10-15 year second follow-up. *J Neurol Neurosurg Psychiatry, 47,* 260-268.

Thomsen, I.V. (1992). Late psychosocial outcome in severe traumatic brain injury. *Scand J Rehabil Med, 26*, 142-152.

Thornhill, S., Teasdale, G.M., Murray, G.D. *et al.*. (2000). Disability in young people and adults one year after head injury: prospective cohort study. *BMJ, 320,* 1631-1635.

VanZomeren, A.H. & Burg, W.V.D. (1985). Resdidual complaints of patients two years after severe closed head injury. *Journal of Neurology, Neurosurgery, and Psychiatry, 48,* 21– 28.

Wood R.Ll & Rutterford, N.A. (2006). Psychosocial adjustment 17 years after severe brain injury. *J Neurology Neurosurg Psychiatry, 77,* 71-73.

Appendices

1) Pre-morbid Intellectual Functioning

National Adult Reading Test (NART)

Number of errors	25
Predicted FSIQ	100 (Average)
Predicted VIQ	100 (Average)
Predicted PIQ	99 (Average)

2) Current Intellectual Functioning

Wechsler Abbreviated Scale of Intelligence (WASI)

IQ	*Standard Score*	*Percentile*	*Description*
Full Scale (FSIQ)	110	75th	Average
Verbal (VIQ)	106	66th	Average
Performance (PIQ)	114	82nd	High Average

	Subtests	*T-Scores*	*Scaled Scores*	*Description*
VIQ	Vocabulary	50	10	Average
	Similarities	57	12	Average
PIQ	Matrix Reasoning	56	11	Average
	Block Design	61	13	High Average

3) Memory Functions

Wechsler Memory Scale-III

Subtests	*Scaled Score*	*Description*
Logical Memory		
Immediate	7	Low Average
Delay	6	Low Average
Retention	6	Low Average
Verbal Paired Associates		
Immediate	4	Borderline
Delay	4	Borderline
Retention	3	Moderate

Auditory Recognition		
Delayed Total	6	Low Average
Visual Reproduction		
Immediate	6	Low Average
Delay	5	Borderline
Retention	8	Average

4) Executive Functioning

Brixton Spatial Anticipation Test: High Average

The Hayling Sentence Completion Test

Test	*Range*
Sensible Completion	Low Average
Unconnected completion	Average
Category A + B error	Impaired
Overall	Poor

Delis-Kaplan Executive Function System

Test	*Subtest*	*Scaled Score*	*Description*
Verbal Fluency	Letter Fluency	12	Average
	Category Fluency	10	Average
	Category Switching	12	Average
Trailmaking	Visual Scanning	9	Average
	Number Sequencing	9	Average
	Letter Sequencing	10	Average
	Number-Letter Switching	8	Average
	Motor Speed	11	Average
Sorting Test	Correct Sorts	10	Average
	Description Score	11	Average
	Sort Recognition	7	Low Average
Twenty Questions	Initial Abstraction	11	Average

	Total Questions Asked	10	Average
	Total Weighted Achievement	12	Average
Word Context	Consecutively Correct	10	Average
Tower Test	Total Achievement	11	Average
Color-Word Interference	Color Naming	10	Average
	Word Reading	11	Average
	Inhibition	12	Average
	Inhibition/Switching	1	Very Poor

5) Working Memory

Wechsler Adult Intelligence Scale, 3rd Edition (WAIS-III)

Subtests	*Scaled Score*	*Description*
Digit Span	11	Average
Letter-Number Sequencing	8	Average

6) Processing Speed

Wechsler Adult Intelligence Scale, 3rd Edition (WAIS-III)

Subtests	*Scaled Score*	*Description*
Digit Symbol Coding	6	Low Average
Symbol Search	6	Low Average

7) Mood

Hospital Anxiety and Depression Scale (HADS)

Scale	*Score*
Anxiety	11
Depression	5
Total	16

CASE STUDY 3

GROUP COGNITIVE BEHAVIOUR INTERVENTION FOR POST-TRAUMATIC STRESS SYMPTOMS WITH THREE GIRLS AGED 6 – 10 YEARS FOLLOWING THE 2009 CAMBERWELL AND PECKHAM FIRES

Erin Tehee
Supervised by Dr Eleanor Leigh

1. Introduction

With growing research on child reactions to traumatic events and diagnostic criteria reflecting new findings, we now know that children can develop post-traumatic stress disorder (PTSD), and that those who do are at greater risk of developing a range of affective and anxiety disorders (Copeland et al, 2007; Bolton et al, 2000). For those children who develop PTSD there is also a risk of substantial impairment in social and academic functioning (Giaconia et al, 1995), which may be particularly detrimental given the developmental and psychosocial demands of childhood and adolescence, where prolonged distress may have a considerable negative impact on a child's fulfillment of their potential and their trajectory through life. Thus, effectively identifying and treating PTSD in children and young people is of utmost importance.

1.1 Diagnosing PTSD in children

To meet criteria for a PTSD diagnosis the DSM-IV (APA, 1994) requires that the child has experienced, witnessed, or been confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of oneself or others, and that their response involved intense fear, helplessness, or horror, noting that in children it may be expressed instead by disorganised or agitated behavior. The child must also present with at least one symptom of persistent re-experiencing, at least three symptoms of persistent avoidance associated with the trauma, and at least two symptoms of arousal. The duration of these symptoms must last for longer than one month and distress must be deemed clinically significant or impairing to social, occupational or other important areas of functioning.

The DSM-IV (APA, 1994) recognises that compared to adults, children may react differently at the time of exposure to a trauma, as well as differing in the way that their re-experiencing symptoms present. For example, children may engage in repetitive play characterised by themes of the trauma, or where aspects of the trauma are expressed. Like adults, children may have frightening dreams, but their content may not be as clearly trauma-related. Additionally, young children may be more likely to engage in specific trauma reenactment when they feel like the event is occuring again. Scheeringa et al (1995, 2003) have proposed alternative criteria (PTSD-AA) to provide a more developmentally appropriate way of assessing for PTS symptoms in very young children (e.g. those aged less than seven years). The PTSD-AA criteria require only one symptom from each cluster, and the requirement for distress or agitation at the time of the trauma is dropped. Additional symptoms are also considered, such as a new presentation of separation anxiety, fear or aggression, the latter of which is to be introduced in the DSM-V.

1.1.1. Co-morbidity

Co-morbidity is common in presentations of PTSD; with anxiety, affective and substance misuse disorders being the most prevalent. Giaconia et al (1995) found that in a sample young people, those with PTSD were seven times more likely to meet DSM-III-R (APA, 1987) criteria for another co-morbid disorder than those who had not experienced trauma.

1.2 Risk factors

There are a number of factors that are associated with the increased likelihood of a child developing PTSD, including subjective appraisal of the severity of the traumatic event (Foy et al, 1996) and parental reaction to the traumatic event (Foy et al, 1996; Wolmer et al, 2000; Meiser-Stedman 2006). Studies have also found that the level of family support and parental coping can impact on the severity of PTS symptoms (Green et al, 1991; Copeland et al, 2007). If a child has experienced traumatic events in the past, he or she is likely to be more vulnerable to developing PTSD (Copeland et al, 2007). Long-term adjustment and trauma-related reactions may also be related to ongoing trauma reminders (Pynoos, Steinberg & Wraith, 1995).

1.3 Treating PTSD in Children

Compared to what is known about treating trauma in adults, the evidence base for psychological interventions for trauma in children has been slower to develop, but recent years have been more fruitful, with studies following similar theoretical routes (Fletcher, 1996), thus attracting analogous approaches to treatment (Brewin et al, 1996; Ehlers & Clark, 2000).

Memory and unhelpful coping strategies have been widely recognised in the PTSD literature as key maintaining factors of symptoms and thus a target of clinical intervention. These include cognitive and behavioural factors such as rumination (e.g. Ehlers et al. 1998; Ehring et al., 2008), attempts to suppress memories of the trauma (e.g. Ehlers et al. 1998), mental disengagement, wishful thinking, counterfactual thoughts (e.g. Clohessy & Ehlers, 1999), and high levels of initial avoidance (Lawrence et al., 1996). Such strategies, though intended to control the sense of threat, paradoxically exacerbate the sense of threat and keep it going by preventing elaboration of the trauma memory (Ehlers & Clark, 2000).

When applying psychological interventions for PTSD to children, Meiser-Stedman (2002) and Salmon and Bryant (2002) argue the importance of taking developmental (e.g. language, memory and emotional regulation ability) and family factors (e.g. parental disress/PTS symptoms, family reactions, coping and other stressors) into account in order to tailor interventions successfully for this population.

1.3.1. Evidence for CBT Interventions with Children

Support for individual CBT for single-incident trauma in young people has been building (Saigh et al, 1996; Deblinger et al, 1990; Kolko, 1996; Chemtob et al, 2002; Stein et al, 2003). NICE Guidelines (2005) recommend that trauma-focused CBT should be offered to adults, young people and children who present with PTSD. Smith et al's (2007) randomised controlled trial (RCT) of CBT for PTSD (based on the model of Ehlers & Clark [2000]) for children aged 8 – 18 years following a single trauma, found the intervention to be effective at significantly improving symptoms of PTSD, depression, and anxiety, in addition to improving functioning, compared to a wait list control group.

1.3.2. Group Interventions

Group CBT has been shown to be an effective intervention for PTSD in children (March et al., 1998; Saigh, Yule, & Inamdar, 1996) and allows for the provision of treatment to a larger number of children at the same time. Groups are a useful format for the delivery of psychoeducation, as well as the delivery of therapeutic ingredients of CBT for PTSD symptoms. With reference to the latter, groups have the added benefit of facilitating the normalisation of symptoms through the process of sharing of similar experiences between members. Furthermore, this collective approach allows ideas to be shared and explored in a safe environment. Previous studies have noted that children may be more likely to complete group treatment over individual therapy (e.g. Chetomb et al, 2002).

Children and Disaster: Teaching Recovery Techniques (Smith et al, 2008) is a manual designed to teach children skills and techniques which can help them to cope with psychological effects of traumatic events, such as natural and man-made disasters. It is a six-session group treatment to be delivered for two hours on a weekly basis. Sessions focus on dealing with intrusive thoughts and feelings, coping with arousal, and targeting avoidance. The format of sessions is comprised of a combination of education work and practical group activities, intended to encourage children to be more pro-active and to promote self-help and mutual support.

The manual has a growing evidence base, and the authors continue to encourage the feedback of results from those who use it. Giannopoulou, Dikaiakou and Yule (2006) used the manual when treating twenty 8 – 12 year olds following the 1999 Athens earthquake. Statistically significant improvements were found for PTSD symptoms, as well as improvements in depression and psychosocial functioning. Improvements were noted at 18 month follow up and gains were maintained at four year follow up. Other (unpublished) findings from the use of the manual following the Bam earthquake in Iran in 2003, suggested that 85% of the children and young people involved benefited in terms of reduced distress.

2. Description of the cases

2.1. Description of the events: the Camberwell and Peckham fires

In July 2009, a fire broke out in a tower block of flats in an estate in Camberwell in south east London, in which six people lost their lives. Nearly five months later, in November 2009, another fire occurred in a block of flats in Peckham. Over 300 families were forced to leave their homes following the incident, but fortunately there were no serious casualties.

2.2. Brief background and presenting problems

2.2.1. Cara

Cara was aged six years. She was an only child born in London to a Caribbean father and French mother. Cara's referral to CAMHS was prompted by her mother, who noticed her persistent distress related to the Camberwell fire. Of the people who died in the tragedy, one was a young friend of Cara's. Her mother reported some of Cara's symptoms to have improved over time, but that she continued to present with a strong emotional response to reminders, and reported nightmares and intrusive images related to the event. The family was re-housed following the fire, and was happy with their new accommodation. They reported feeling well supported by friends and those in their community. Other than her distress following the fire, Cara did not present with any significant physical or emotional problems. She had not experienced any other trauma in the past.

2.2.2. Jennifer

Jennifer was aged ten years. She was born in London to a white British mother and Ghanaian father. Jennifer's parents were separated, but her father lived just outside London and remained supportive. Her mother initiated a referral to CAMHS following concerns for her children's well-being following the family's ordeal during the Peckham fire. She reported particular difficulties regarding her sleep. This was impacting on Jennifer's ability to concentrate at school. Jennifer had also stopped playing outside in the vicinity of their estate. She reported no history of trauma other than the fire. The family was not re-housed following the fire, and was still residing on the estate at the time of referral. At the time of referral her mother was appealing to the council for relocation as she felt the environment, which included charred and derelict parts of the estate, served as a constant reminder to the children and was obstructing their recovery.

2.2.3. Vanessa

Vanessa was aged ten years. She was born in Canada to Mexican parents. She was originally assessed by Targeted Mental Health in Schools (TaMHS) following the Peckham fire. At the time of referral, Vanessa was performing very well in school and presented with no other issues other than her distress related to the fire. She reported having experienced no previous traumas, though her mother described a history of domestic violence and alcohol and drug abuse by Vanessa's father. The family lost many of their possessions in the fire. They were temporarily placed in hotel accommodation but were then transferred to new council accommodation. Vanessa's mother reported the new flat to be cramped and uncomfortable.

3. Assessment

3.1. Scales and questionnaires

Each child completed the following questionnaires at assessment:

(i) *Mood and Feelings Questionnaire (MFQ; Angold et al, 1995)*

(ii) *Self Report for Child Related Anxiety Disorders (SCARED; Birmaher et al, 1997)*

(iii) *Child PTSD Symptom Scale (CPSS; Foa et al, 2001)*

Table 1, below, summarises the results of the self-report measures.

Table 1

Pre-intervention self report measure results

	MFQ	SCARED	CPSS
Cara	5	5	14
Jennifer	31*	42*	32*
Vanessa	18	36*	28*

*Indicates clinical significance

Parents completed the parent report versions of the MFQ and SCARED at assessment. Table 2, below, summarises the scores for these parent-report measures.

Table 2

Pre-intervention parent report measure results

	MFQ	SCARED
Cara	2	4
Jennifer	18	15
Vanessa	7	40*

*Indicates clinical significance

3.2 Clinical Interviews

Clinical interviews with the children and parents were carried out separately using the PTSD subsection of the Anxiety Disorders Interview Schedule for Children for DSM-IV: Child and Parent Versions (ADIS-CP; Silverman & Albano, 1996; Silverman, Saavedra & Pina, 2001). The ADIS-CP is designed to assess the presence of anxiety disorders based on DSM-IV criteria. In the case of Cara, who was younger than the other two group members, Scheeringa criteria, as described earlier, informed the clinical interview and diagnostic formulation. The results of these assessments are summarised in Table 3.

Table 3

Diagnoses and symptoms secondary to PTSD

	Diagnostic Formulation	Symptoms secondary to PTSD
Cara	Scheeringa criteria – PTSD (mild)	none
Jennifer	F43.1 PTSD	Depressive symptoms
Vanessa	F43.1 PTSD	Separation anxiety

3.3. Parental Distress

Parental anxiety and depression was measured pre-intervention using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Jennifer's mother scored 18, indicating distress in the severe and clinical range. Cara's mother scored 5, placing her in the normal range. Vanessa's mother did not return the questionnaire.

4. Formulation

4.1 PTSD formulation

Due to the fact that this was a group intervention, idiographic formulations were not developed with each individual child. Instead a more universal approach was taken to formulating the children's PTSD symptoms, based on the idea that the nature of memory and unhelpful coping strategies can maintain symptoms.

4.2 Co-morbid symptoms

Both Jennifer and Vanessa presented with co-morbid symptoms of depression and separation anxiety, respectively, though did not meet diagnostic criteria. Both presentations occurred following the fire and in the context of a PTSD diagnosis. They were thus formulated as secondary to PTSD and were hypothesised to abate following treatment for PTSD.

5. Intervention

5.1 Intervention and aims

The group intervention was based on the manual *Children and Disasters: Teaching Recovering Techniques* (Smith et al, 2008), which has been used with success in other settings (e.g. Giannopoulou et al, 2006). It was delivered in one hour weekly sessions over six weeks. The intervention focused on introducing and practicing copings skills for PTSD, with the aim of reducing the children's PTS symptoms,. The group also provided a forum for normalising the children's experiences and for the provision of child appropriate psychoeducation around the cognitive model for PTSD.

5.2 Working with parents

Following each group session, parents were invited to attend a brief meeting where they were provided with information on what their child was learning in the group and what homework they would be completing for the week. The children were encouraged to share their homework with their parents, who could serve as co-therapists outside therapy, by encouraging their child to complete tasks, by supporting behavioural activation work, and by helping them to troubleshoot in the event of obstacles. Including parents also served to open up communication about the event and thus counteract any possible avoidance in the parent-child dyad or family atmosphere. The space also allowed for parents to share their feelings with one another in an open and supportive environment, which served to normalise their own experiences.

5.3 Summary of sessions

Jennifer and Vanessa attended all sessions. Cara attended the first three sessions before deciding to terminate therapy early.

5.3.1. Session 1

(a) Getting to know each other

The children were encouraged to introduce themselves and share something about themselves, such as their favourite food or activity.

(b) Introducing the group

The facilitators introduced the purpose of the group and what this session and the next five sessions would involve. Ground rules were collaborated on together and covered the topics of confidentiality, respect for other members of the group, turn taking when listening and talking, and not having to talk if one did not want to share.

(c) Normalising and educating

The children were provided with psychoeducation about known reactions to frightening experiences and to reassure them that there were ways of making these experiences more manageable. A strong message was communicated to the children that their experiences were common and could happen to anyone who experienced something as frightening as they had. Sharing these experiences with one another also facilitated the normalising process.

A list of traumatic reminders was also collaborated on and psychoeducation was provided around the connection between the reminders, intrusions and upsetting emotions.

(d) Safe place techniques

In order to prepare the children for future work and to introduce a technique for coping with their distress, children were encouraged to use their imagination and all their senses to create a ‘safe place’ where they could retreat to should they feel they need to reduce difficult emotions.

(e) Homework

The children were encouraged to practice safe place techniques.

5.3.2. Session 2

(a) Imagery techniques

The aim of introducing imagery techniques was to give children more control over distressing and intrusive images. The techniques were designed to counter the lack of control that children can often experience following a traumatic event, which can potentially lead to distress. During the exercises the children were encouraged to explore and try out different techniques in order to find what worked best for them.

The children practiced the following exercises in vivo:

(i) *Superimposing the image on to a television screen.* Children were provided with a laminated flashcard of a blank television (see Appendix A). They were encouraged to practice changing their superimposed image using the television controls, e.g. freeze frame, rewind, speed up, change the focus, and 'switch off'.

(ii) *Imagining the image on the palm of their hand.* Children were again encouraged to change the image by moving their palm (with image) closer and then further away from them, thus changing the size. At the end, children were asked to move their palm and image further and further away and then quickly close it in their fist and move it behind their back.

(b) Activity scheduling/behavioural activation

To support work on reclaiming life, the children were asked to consider previously enjoyed activities that had been dropped since the time of the fire and were asked to write these down on the 'Favourite Activities' worksheet (see Appendix B).

(c) Homework setting

(i) Practice imagery techniques

(ii) Do at least one favourite activity and record activities and mood in the 'Fun Activity Diary' (see Appendix C).

5.3.3. Session 3

(a) Introducing arousal

Before introducing relaxation techniques, psychoeducation was provided around the connection between fear and bodily sensations. Group members were encouraged to describe the types of bodily sensations they experienced, e.g. rapid breathing, racing heart, wobbly legs, dizziness, etc. These reactions were normalised in the context of their evolutionary role, i.e. a response to danger.

(b) Fear thermometer

A 'fear thermometer' (see Appendix D) was introduced to support the children in being able to monitor their own fear reactions. The children were asked to use the thermometer as an analogue measure of their fear, e.g. the hotter the thermometer the more fear. They were asked to personalise it with their own experience of fear to anchor the top and bottom of the scale.

(c) Relaxation

A muscle relaxation and deep breathing exercise was carried out with the children within the session.

(d) Guided imagery

Drawing on previous work on using imagery to create a 'safe place', guided imagery was introduced to combine these imagery skills with the above deep breathing exercises.

(e) Homework setting

(i) Practice relaxation and/or imagery

(ii) Do fun activities

5.3.4. Session 4

The purpose of this session was to prepare the children for how they can carry out an imaginal exposure to their feared stimulus/situation.

(a) Introducing avoidance and exposure

Work from the first session regarding the role of reminders and avoidance on the maintenance of symptoms was recapped on. In order to build on their sense of control and mastery, group members were reminded of the skills they had learned in managing intrusive images and physiological arousal.

(b) Grading traumatic reminders

Work on traumatic reminders from the first session was reviewed socratically with the group. The list from the first session was presented and the children were given the opportunity to add to the list. Group members were then asked to write down a list of their own personal reminders.

Using the example of a simple phobia, e.g. of dogs, the children were questioned socratically on how one may overcome this fear, i.e. overcome avoidance and to confront the feared stimulus. Personalised examples of when the children overcame other fears not associated with the trauma were also sought. The anxiety/avoidance curve was presented graphically to the children to highlight the effect of avoidance on keeping fear going. The children were also asked to think about the techniques that they had learned and what they thought might be most useful in helping them to confront their fears.

(c) Homework setting

The children were asked to share their hierarchy with their parents and to choose an easy goal at the bottom of their hierarchy to target over the next week. Children were asked to rate their fear using the thermometer before and after, and asked to stay in the feared situation until their fear came down to 2 or 3. They were also reminded to use their preferred relaxation technique before and after.

5.3.5. Session 5

(a) Introduction to cognitive avoidance

The purpose of this session was to demonstrate how trauma memories can be recalled and communicated in a controlled way and that it is not as scary as might be predicted. The session also explored the role of cognitive avoidance in maintaining PTS symptoms.

(b) Drawing about memories/trauma

The children were asked to draw a specific and salient memory about the trauma using as much detail as possible. Following the exercise, group members were asked to volunteer to talk through their drawing.

(c) Writing about memories/trauma

The children were asked to work individually and to write a short description in the first person about what happened during the fire.

(d) Relaxation/Imagery

A 'safe place' exercise was carried out with the children following the above exercises in order to reinstate a sense of control and safety.

(e) Homework setting

To target avoidance of talking about the event, the children were encouraged to read through their narrative of the event with a parent and then to use relaxation/imagery techniques.

5.3.6. Session 6

(a) Review of techniques and skills

Work from the previous five sessions was reviewed with the children socratically to consolidate the knowledge they had gained. The children were asked to share their successes in terms of overcoming avoidance and reclaiming their life, in addition to reflecting on the techniques they had found most helpful. Each child was given a certificate for their achievements in the group.

(b) Looking to the future

The group members were encouraged to think about building on their gains and to continue to work up their graded exposure hierarchy.

6. Outcomes

6.1 Post-traumatic stress symptoms

Figure 2 provides a summary of group members' PTS scores over the course of the intervention and at follow-up, as measured by the CPSS.

Cara finished the group at session 3, and by that time was no longer reporting PTS symptoms. These gains were maintained at one- and three-month follow-up.

Jennifer's PTS symptoms did not show improvement by session six. She was subsequently offered five individual sessions of trauma-focused CBT and by one- and three-month follow-up she presented with a significant improvement in her symptoms.

Vanessa's PTS symptoms showed a notable improvement by session six, and she continued to make progress at one- and three-month follow-up, by which time she was no longer endorsing any PTS symptoms.

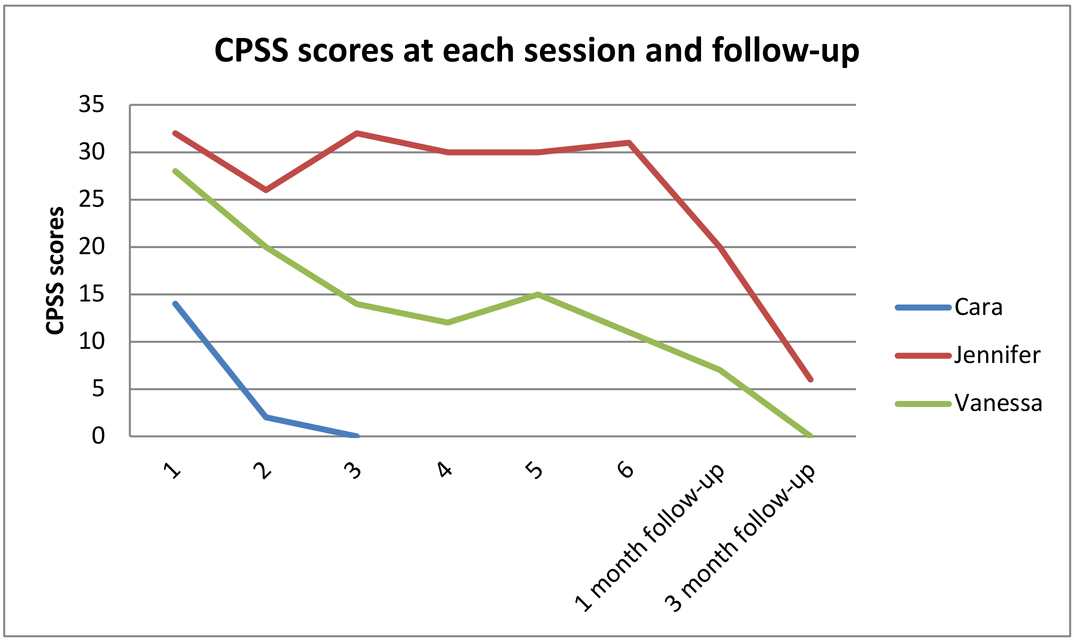


Figure 2

6.2. Mood

Figures 3 and 4 provide a summary of mood scores as reported on the MFQ by children and parents, respectively.

Prior to intervention, Cara did not endorse elevated scores for mood disturbance and her scores remained low when measured at the sixth session and again three months later.

Jennifer presented with significant scores on the MFQ prior to the group and showed some improvement by the end of the group, with more significant improvements at three-month follow-up to below cut-off.

Vanessa's mood symptoms were raised prior to the group, improved to below cut-off by the end of the group and again at three-month follow-up.

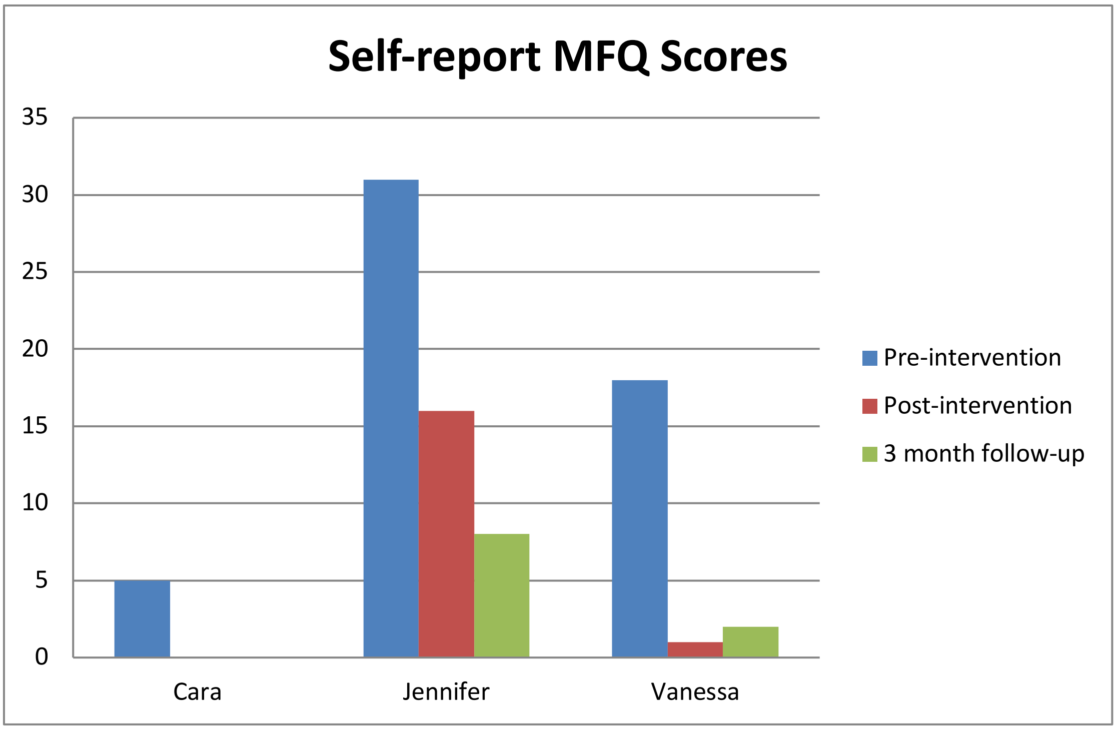


Figure 3

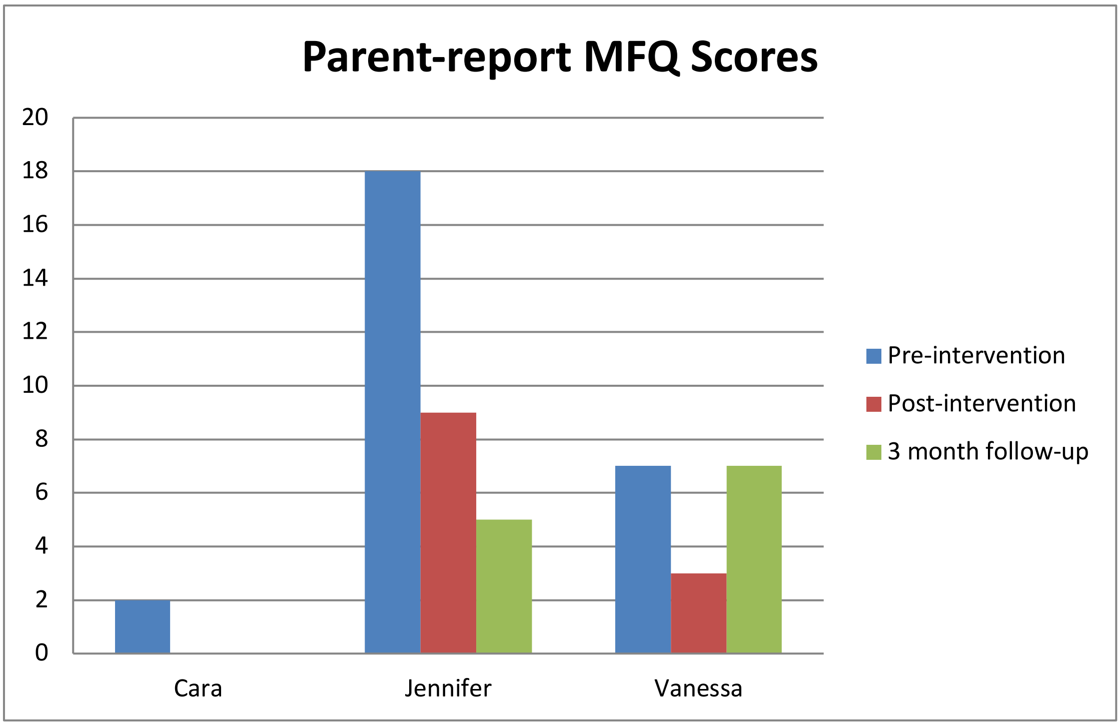


Figure 4

6.3. Anxiety

Figures 5 and 6 provide a summary of anxiety scores as reported on the SCARED by children and parents, respectively.

Cara presented with low levels of anxiety prior to the intervention and this continued to decrease when measured at session six, and again three months later.

Jennifer initially presented with significantly raised levels of anxiety, which did not show meaningful improvement by the end of the six weeks. However, at three month follow-up, and following individual sessions, symptoms were significantly improved.

Vanessa also presented with significantly raised levels of anxiety prior to intervention, and by the end of the group and at three-month follow-up her symptoms showed significant improvement.

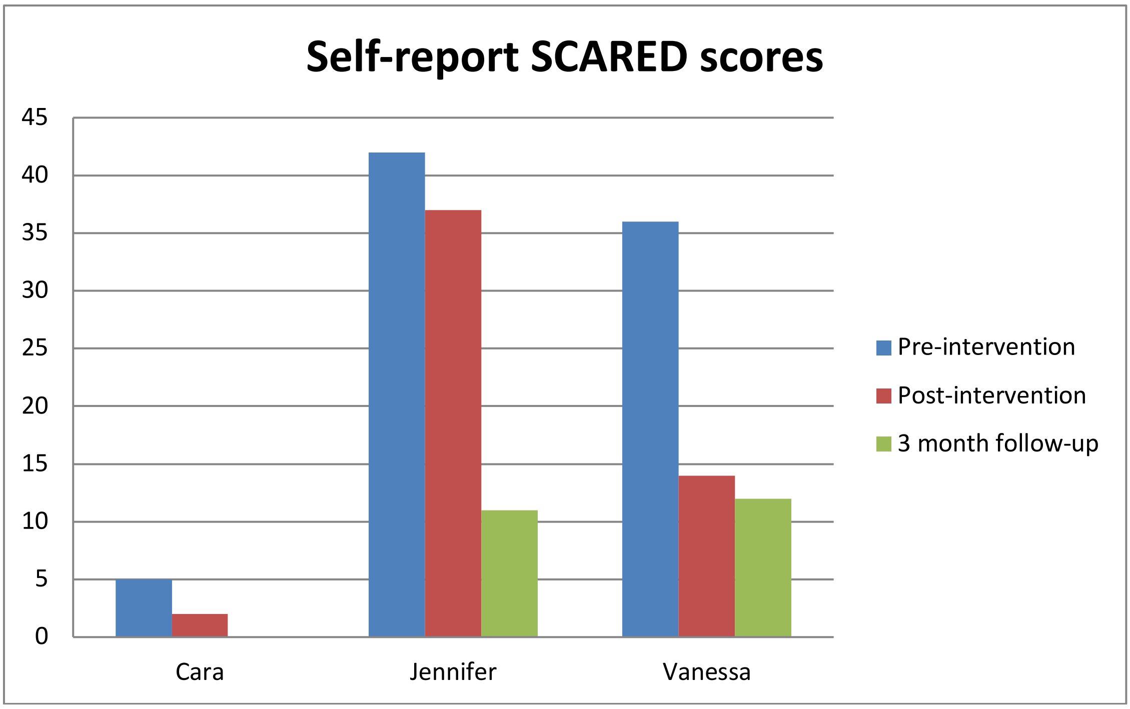


Figure 5

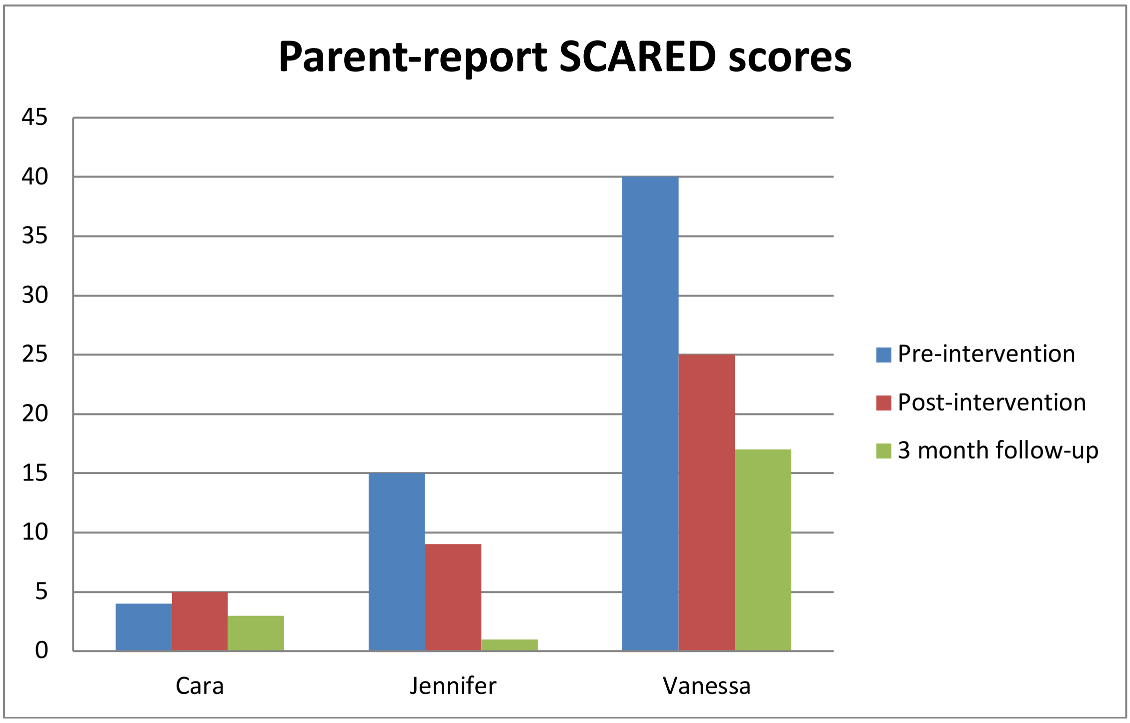


Figure 6

7. Discussion

7.1 PTS symptoms

Cara and Vanessa showed significant decreases in self-reported PTS symptoms by the end of the group intervention and continued to show improvement at one and three month follow-up. However, Jessica's PTS symptoms remained raised but responded to further individual CBT sessions, showing improvement at one and three month follow-up.

7.2 Mood symptoms

For all children, self-reported mood symptoms significantly improved following the group and continued to show improvement or stability at three-month follow-up.

7.3 Anxiety symptoms

Improvements in self-reported anxiety varied more widely between the children. Cara's anxiety was minimally raised prior to the group, and therefore improvements were more modest but, nevertheless, were evident following the intervention and at follow-up. Vanessa showed significant improvements in anxiety by the end of the intervention, and further improvement at follow-up. Jessica's anxiety on the other hand, showed little change following the intervention, but appeared to respond to the additional individual therapy sessions, showing significant improvement at three month follow-up.

The outcomes of this group CBT intervention point to some variability between individuals, which warrants further discussion.

7.4 Outcomes: the role of family and social factors

Cara's outcome illustrates the quickest improvement and a near total alleviation of PTS, anxiety and mood symptoms. Despite terminating the intervention early, her PTS symptoms had completely remitted by this time and her mother reported back to clinicians that she felt Cara had reaped full benefit from the three sessions she attended. Vanessa showed improvement over the six weeks of the group, and continued show improvements in the three months afterwards. In contrast to Cara and

Vanessa, Jennifer’s anxiety and PTS symptoms were maintained post-intervention, though she did show some improvement in mood symptoms.

A review of family and social factors may help to explain the different treatment response trajectories of the group members. Jennifer’s case was characterised by high parental distress and less family support; both have been highlighted as risk factors for poorer outcome (Green et al, 1991; Copeland et al, 2007). Following the trauma, Jennifer’s family was not assessed or re-housed, which exacerbated their distress and feelings of helplessness. This was particularly evident in her mother’s loss of confidence and her feelings of guilt related to the trauma. Remaining at the site of the fire may have also impeded recovery, as Jennifer was constantly faced with reminders of the fire.

Cara’s case was surrounded by different circumstances. Her parents were coping well and her mother did not present with elevated symptoms of distress. The family was re-housed immediately following the fire in accommodation which they described as an improvement on their previous flat. Overall, the family reported feeling that they had moved on with their life.

Time since the event is another factor to consider (e.g. Kessler et al, 1995). The Camberwell fire occurred almost five months previous to the Peckham fire that Jennifer was involved in. This would have allowed for a longer period of time wherein natural recovery may have taken place. Cara’s low scores at the beginning of the intervention may also be evidence of this.

Taking into account the additional difficulties faced by Jennifer and her family, during the course of therapy her mother was supported in pursuing an application for the family to be re-housed. Jennifer was also offered five further individual sessions of trauma-focused CBT, which were successful in significantly reducing her PTS and anxiety symptoms.

7.5 Post-intervention improvement

Despite the variance in final outcomes, all three cases continued to show improvements at follow-up. This may highlight the effect of parental involvement in treatment as noted in previous studies (e.g. Giannopoulou et al, 2006), whereby parents were recruited as co-therapists to support their child between sessions and following intervention. The additional support provided by parents in this intervention may have benefited the children by helping them to practice their newly acquired skills, thus fostering a process of consolidation and generalisation, concurrent to the therapeutic intervention and thereafter.

7.6 Conclusion

This case study supports the effectiveness of CBT interventions for treating PTS symptoms and anxiety and mood symptoms co-morbid to PTSD in children, and emphasises the importance of involving parents and/or family members throughout the intervention. Group CBT formats may be more acceptable to children (e.g. Giannopoulou et al, 2006), and are ideal for supporting the process of normalisation. This particular group allowed children to share experiences of the same or similar event and fostered an environment where children were able to feel safe to speak about their experiences. Parents were also able to share experiences and practical information (e.g. re-housing process) with one another in the parent feedback sessions, which may have been a secondary benefit in terms of support. As the literature suggests, taking account of factors such as parental coping and distress is important in the formulation of more distal maintaining factors (Meiser-Stedman, 2002; Salmon & Bryant, 2002). Practical support to families struggling with the aftermath of trauma is also important so that families can move on and begin to reclaim their lives.

8. Reflections

The initial plan for the group was to involve 6 to 8 members in order to allow for a more even spread of ages and characteristics. Of the eight children offered the intervention, only three took up the offer of this type of treatment. This left the group imbalanced in terms of age, where Cara was aged four years younger than Jennifer and Vanessa, both aged ten. The format and content of the sessions was sometimes difficult to balance given this age difference. Additionally, both Jennifer and Vanessa had been involved in the Peckham fire whereas Cara was involved in the Camberwell fire. This meant that, as well as being the same age, Jennifer and Vanessa had shared similar experiences and memories, which Cara may have found difficult to relate to. A larger and more heterogeneous group may have had better potential for the sharing of a wider range of narratives, and therapeutically may have been more effective in normalising the children's experiences.

Reflecting on the dynamics of this group has helped to highlight the importance of thinking about members' characteristics when planning a group. However, this case study also demonstrates that in spite of these issues, group CBT interventions for children with PTS symptoms can still be effective.

References

American Psychiatric Association (APA). (1980). *Diagnostic and Statistical Manual of Mental Disorders* (3rd Ed.). Washington, DC: Author

American Psychiatric Association (APA). (1987). *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed. - Revised). Washington, DC: Author

American Psychiatric Association (APA). (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th Ed.). Washington, DC: Author

Angold, A., Costello, E. J., Messer, S. C., Pickles, A., Winder, F. & Silver, D. (1995) The development of a short questionnaire for use in epidemiological studies of depression in children and adolescents. *International Journal of Methods in Psychiatric Research*, 5, 237 - 249.

Birmaher, B., Khetarpal, S., Brent, D., Cully, M., Balach, L., Kaufman, J. & Neer, S.M. (1997). The Screen for Child Anxiety Related Emotional Disorders (SCARED): scale construction and psychometric characteristics. *Journal of the American Academy of Child and Adolescent Psychiatry, 36(4),* 545 – 553.

Bolton, D., O'Ryan, D., Udwin, O., Boyle, S. & Yule, W. (2000). The long-term psychological effects of a disaster experienced in adolescence: II. General psychopathology. *Journal of Child Psychology & Psychiatry, 41,* 513 – 523.

Naomi Breslau, N., Lucia, V.C. & Alvarado, G.F. Intelligence and Other Predisposing Factors in Exposure to Trauma and Posttraumatic Stress Disorder: A Follow-up Study at Age 17 Years. *Arch Gen Psychiatry. 63*, 1238-1245.

Brewin, C.R., Dalgleish, T. & Stephen, J. (1996). A dual representation theory of posttraumatic stress disorder. *Psychological Review, 103(4),* 670-686.

Chetomb, C.M., Nakashima, J.P. & Hamada, R.S. (2002). Psychosocial intervention for postdisaster trauma symptoms in elementary school children: a controlled community field study. *Archives of Pediatric and Adolescent Medicine, 156,* 211 – 216.

Clohessy, S. & Ehlers, A. (1999). PTSD symptoms, response to intrusive memories and coping in ambulance service workers. *British Journal of Clinical Psychology, 38*(3), 251–265.

Copeland, W.E., Keeler, G., Angold, A. & Costello, J. (2007). Traumatic Events and Posttraumatic Stress in Childhood. *Arch Gen Psychiatry, 64(5),* 577-584.

Deblinger, E., McLeer, S.V. & Henry, D. (1990). Cognitive behavioural treatment for sexually abused children suffering from posttraumatic stress: Preliminary findings. *Journal of the American Academy of Child and Adolescent Psychiatry, 19,* 747 – 752.

Ehlers, A. & Clark, D.M. (2000). A cognitive model of posttraumatic stress disorder. *Behavioural Research and Therapy, 38,* 319 – 345.

Ehlers, A., Mayou, R. A. & Bryant, B. (1998). Psychological predictors of chronic posttraumatic stress disorder after motor vehicle accidents. *Journal of abnormal psychology*, *107*(3), 508.

Ehntholt, K.A., Smith, P.A. & Yule, W. (2005). School-based cognitive-behaviour therapy group intervention for refugee children who have experienced war-related trauma. *Clinical Child Psychology and Psychiatry, 10,* 235 – 250.

Fletcher, K. (1996). The management of released hostages. *Advances in Psychiatric Treatment, 2,* 232 – 240.

Foa, E.B., Johnson, K., Feeny, N.C. & Treadwell, K.R. (2001). The Child PTSD Symptom Scale (CPSS): preliminary psychometrics of a measure for children of PTSD. *Journal of Clinical Child Psychology, 30,* 376 – 384.

Foy, D, Madvig, B., Pynoos, R. & Camilleri, A. (1996). Etiologic factors in the development of post-traumatic stress disorder in children and adolescents. *Journal of School Psychology, 34(2),* 133 – 145.

Garmezy, N. & Rutter, M. (1985). Acute reactions to stress. In M. Rutter & L. Hersov (Eds.) *Child and adolescent psychiatry: Modern approaches* (2nd ed., pp. 152 – 176). Oxford: Blackwell.

Giaconia, R.M., Reinherz, H.Z., Silverman, A.B., Pakiz, B., Frost, A.K. & Cohen, E. (1995). Traumas and posttraumatic stress disorder in a community population of older adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 34,* 1369 – 1380.

Giannopoulou, I., Dikaiakou, A. & Yule, W. (2006). Cognitive-behavioural group intervention for PTSD symptoms in children following the Athens 1999 Earthquake: A pilot study. *Clinical Child Psychology and Psychiatry, 11(4),* 543 – 553.

Green, B.L., Korol, M., Grace, M.C., Vary, M.G., Leonard, A.C., Glesser, G.C. & Smithson-Cohen, S. (1991). Children and disaster: Age, gender, and parental effects on PTSD symptoms. *Journal of the American Academy of Child and Adolescent Psychiatry, 30,* 945 – 951.

Kessler, R. C., Sonnega, A., Bromet, E., Hughes, M. & Nelson, C. B. (1995). Posttraumatic stress disorder in the National Comorbidity Survey. *Archives of general psychiatry*, *52*(12), 1048.

Kolko, D.J. (1996). Clinical monitoring of treatment course in child physical abuse: psychometric characteristics and treatment comparisons. *Child Abuse and Neglect, 20,* 23 – 43.

Lawrence, J.W., Fauerbach, J. & Munster, A. (1996). Early avoidance of traumatic stimuli predicts chronicity of intrusive thoughts following burn injury. *Behaviour Research and Therapy, 34(8),* 643 – 646.

March, J.S., Amaya-Jackson, L., Murray, M.C. & Schulte, A. (1998). Cognitive-behavioural psychotherapy for children and adolescents with post-traumatic stress disorder after a single-incident stressor. *Journal of the American Academy of Child and Adolescent Psychiatry, 37,* 585 – 593.

Meiser-Stedman, R. (2002). Towards a cognitive-behavioural model of PTSD in children and adolescents. *Clinical Child and Family Psychology Review, 5(4),* 217 – 232.

Meiser-Stedman, R., Yule, W., Dagleish, T. Smith, P. & Glucksman E. (2006). The role of the family in child and adolescent posttraumatic stress following attendance at an emergency department. *Journal of Pediatric Psychology, 31,* 397 – 402.

Pynoos, R.S., Steinberg, A.M. & Wraith, R. (1995). A developmental model of childhood traumatic stress. In D. Cicchetti & D.J. Cohen (Eds.) *Manual of developmental psychopathology* (pp. 72 – 95). New York: Wiley.

Saigh, P.A., Yule, W. & Inamdar, S.C. (1996). Imaginal flooding of traumatized children and adolescents. *Journal of School Psychology, 34,* 163 – 188.

Salmon, K. & Bryant, R.A. (2002). Posttraumatic stress disorder in children: The influence of developmental factors. *Clinical Psychology Review, 22,* 163 – 188.

Scheeringa, M.S., Zeanah, C.H., Drell, M.J. & Larrieu, J. (1995). Two approaches to the diagnosis of postraumatic stress disorder in infancy and early childhood. *Journal of American Academy of Child an Adolescent Psychiatry, 34,* 191 – 200.

Scheeringa, M.S., Zeanah, C.H., Myers, L. et al. (1995). New findings on alternative criteria for PTSD in preschool children. *Journal of American Academy of Child an Adolescent Psychiatry, 42,* 561 – 570.

Silverman, W. & Albano, A. (1996). *Anxiety Disorders Interview Schedule (ADIS-IV) Child/Parent version.* San Antonio, TX: Psychological Corporation.

Silverman, W.K., Saavedra, L.M. & Pina A.A. (2001). Test-retest reliability of anxiety symptoms and diagnoses with the Anxiety Disorders Interview Schedule for DSM-IV: child and parent versions. *J Am Acad Child Adolesc Psychiatry, 40(8),* 937- 944.

Smith, P., Yule, W., Perrin, S., Tranah, T., Dalgleish, T. & Clark, D.M. (2007). Cognitive-Behavioural Therapy for PTSD in children and adolescents: A preliminary randomised controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry, 46(8),* 1051 – 1061.

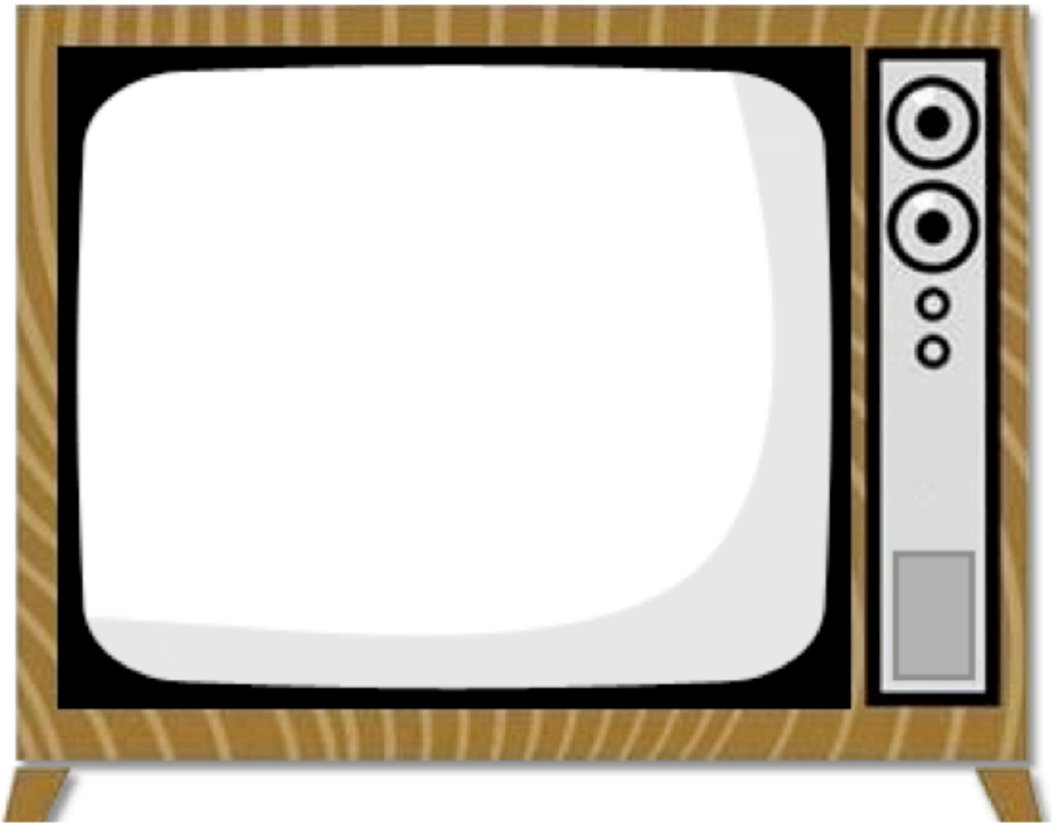
Smith, P., Perrin, S., Yule, W., Perrin, S., Gjestad, R. & Gupta, L. (2008). *Children and war: Teaching recovery techniques*. Bergen, Norway: Foundation for Children and War.

Stein, B.D., Jaycox, L.H., Kataoka, S.H. et al (2003). A mental health intervention for schoolchildren exposed to violence: a randomised controlled trial. *Journal of the American Medical Association, 290,* 603 – 611.

Wolmer, L., Laor, N., Gershon, A., Mayes, L.C. & Cohen, D.J. (2000). The mother-child dyad facing trauma: a developmental outlook. *J Nerv Ment Dis, 188(7),* 409 – 415.

Zigmond, A.S. & Snaith, R.P. (1983). The hospital anxiety and depression scale. *Acta Psychiatr Scand, 67(6),* 361 – 370.

Appendix A



Appendix B

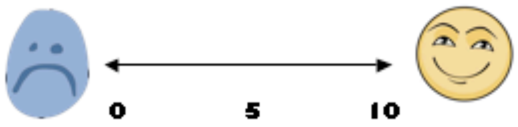
My Favourite Activities

Appendix C

Fun Activity Diary

During the week record the fun activities you take part in and rate how happy they made you feel.

0 = not at all happy, 10 = very happy



	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning 	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**
Afternoon 	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**
Evening 	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**	**Rate:**

Appendix D

Feelings Thermometer

CASE STUDY 4

COGNITIVE-BEHAVIOUR THERAPY FOR LOW SELF-ESTEEM WITH AN 18 YEAR-OLD YOUNG WOMAN WITH A MILD INTELLECTUAL DISABILITY

Erin Tehee

Supervised by Dr Nadja Alim

4.1 Introduction

4.1.1 Psychological morbidity in people with ID

People with intellectual disabilities (ID) are more vulnerable to developing mental health problems relative to the general population (Sevin & Matson, 1994) with prevalence estimated at 30 – 75% (Borthwick-Duffy, 1994). According to research by Richards et al (2001), people with ID were at four times greater risk of affective disorders not accounted for by social or material disadvantage or by a medical disorder. It is thus important to recognise that psychological functioning may be a significant obstacle to quality of life and optimum functioning for people with ID.

The prevalence of depression in people with ID is approximately 3- 4% compared to 1.7% found in the general population (Meltzer et al, 1995). In the general population, risk factors for depression include stress, life events, lower socioeconomic status, older age, being female and lack of social support. Though research relevant to ID populations is more limited, there is some evidence to suggest similar relationships, e.g. less social support (Meins, 1993), higher stress (Lunsky, 2003) and female gender (Hastings et al, 2004). People with ID may be at increased risk to developing psychological difficulties in the presence of such circumstances as a result of having limited coping skills and resources, in addition to more experiences of rejection, discrimination, abuse and stigma.

4.1.2 The role of social comparison and stigma

According to Festinger (1954), social comparison is an active process by which we evaluate ourselves through comparison with others. Negative social comparison is a process implicated in psychological difficulties (Allen & Gilbert, 1995; Swallow & Kuiper, 1998), and may be particularly relevant to people with ID and the construction of their identities. Research with people with ID has highlighted the role of social comparison as a mediator in depression (Swallow & Kuiper, 1998). Dagnan and Sandhu (1999) found that social comparison is associated with self-esteem and depression in people with ID via the same processes as those without ID. Specifically, they found that lower depression was associated with more favourable social comparisons on social attractiveness and group belonging dimensions, in addition to positive self-esteem. Crocker and Park (2004) found that instability of self-esteem may predict depression particularly in domains of self-worth. Self-esteem may be further compromised when an individual has a limited repertoire of alternative roles or areas of self-worth (Oatley & Boulton, 1985; Champion & Power, 1995). According to Linville (1981), a wider range of roles lends itself to 'psychological complexity' which is protective against the impact of negative social comparison. Due to restricted opportunities and roles afforded to those with ID, self-esteem may be more readily comprised by negative comparisons in this group.

Stigma may also play an important role in the development of psychological problems. A study by Szvios-Bach (1993) found that awareness of stigma was related to low self-esteem in adolescents with ID. Dagnan and Waring (2004) found that greater perception of stigma was related to increasingly negative social comparisons and more specifically that stigma was found to directly impact social comparison processes as mediated by evaluative beliefs.

Based on the evidence of cognitive process in the development and maintenance of low self-esteem, social comparison and depression in people with ID, Dagnan and Sandhu (1999) suggest that cognitive therapy techniques that target these processes may be useful in psychological interventions for this population. They also emphasise social comparison as an important focus for formulation on account of its relevance to the social context and social processes shaping the lives of people with ID.

4.1.3 CBT with individuals with ID

Cognitive Behavioural Therapy (CBT) is an effective treatment for a wide range of mental health problems; however, historically studies of effectiveness have tended to focus on its application in the general population to the exclusion of the populations with ID. Nevertheless, evidence supporting the use of CBT with people with ID has been growing with results indicating that it can be effective in treating a range of psychological difficulties (Kroese et al, 1997; Lindsay, 1999) including anger (Black, Cullen & Novaco, 1997; Benson, 1994; Black & Novaco, 1993; Taylor et al, 2002), anxiety (Lindsay, Neilson & Lawrenson, 1997), depression (Lindsay, Howells & Pitcaithley, 1993; Dagnan & Chadwick, 1997), and psychosis (Haddock et al, 2004; Kirkland, 2005). Furthermore, research examining the processes underlying psychological disorders in ID found that they do not differ from those found in studies that did not include a population with ID. For example, psychological distress in people with people with ID, as in the general population, has been found to be linked to 'negative self-concept' (Benson & Ivins, 1992), negative social comparisons (Dagnan & Sandhu, 1999), feelings of hopelessness (Nezu, Nezu, Rothenburgh, DelliCarpini, & Groag, 1995), low self-esteem (Dagnan & Sandhu, 1999) and poor social support (Reiss & Benson, 1985).

The use of CBT in people with ID has been disputed on account of the impact impairments in verbal skills, poor memory, difficulties with abstract thinking, and executive functioning may have on a person's ability to self-report (Voelker et al, 1990) and grasp abstract concepts (Sams et al, 2006). However, Dagnan, Chadwick and Proudlove's (2000) research on developing an assessment of suitability of people with ID for cognitive therapy argue that individuals with ID may have the necessary skills to use cognitive therapy effectively, but may require additional support in grasping the concept of cognitive mediation. For example, where understanding and skills are lacking, a structured intervention may be necessary to facilitate improvement. Reed and Clements (1989) suggest that the ability to recognize emotions with the support of visual aides (e.g. cartoons, modelling emotions, etc.) is related to language ability requirement of four years and five months and above. Dagnan et al's (2000) study also found that language ability had a significant influence on individuals' ability to link situations with either emotions or beliefs. A step-wise approach to assessment of skills necessary for CBT is therefore recommended (Dagnan et al, 2000; Joyce, Globe & Moody, 2006) to inform and facilitate appropriate targeting of individuals' needs.

4.1.4 Cognitive model of low self-esteem

Fennell's (1998) cognitive model for low-esteem draws on methods and concepts previously developed from work on depression (Beck et al, 1979) and acute anxiety (Beck et al, 1985) which have a strong and well-validated evidence base. The model also utilises more experimental ideas and interventions used in the treatment of personality disorders (Beck et al, 1990). Fennell (1998) elaborates on these cognitive models of emotional disorders in order to provide an understanding of low-self esteem. The model proposes that the roots of low self-esteem lie in global ('me as a person') negative core beliefs about the self, which are arrived at during an interaction between inherent temperamental factors and later experience, for example, of neglect, abuse, bereavement or absence of sufficient warmth, affection and praise.

Fennell's model summarises the relationship between early experiences, core beliefs, dysfunctional assumptions and the salience of the critical incident, and then outlines the maintaining role of negative predictions and maladaptive behaviour on psychological distress (anxiety and depression) via the 'confirmation' of core beliefs and self-criticism. An idiographic formulation using the model is presented later in the formulation section of the study.

To inform the treatment of low self-esteem, Fennell (1998) outlines a number of key interventions, which are summarized in Box 1, below.

Figure 1
Key in interventions in CBT for self-esteem

Overall treatment objectives

- Weaken old, negative core beliefs about the self
- Establish and strengthen more positive, realistic news beliefs about the self
- Encourage kindly self-acceptance, 'warts and all'

Understanding the problem

- Developing an individually tailored case conceptualisation

Modifying perceptual bias

- Directing attention to positive qualities, assets, skills and strengths
- Keeping regular written records of examples of positive qualities
- Seeking evidence which is inconsistent with negative core beliefs about the self
- Recording incidents inconsistent with negative core beliefs about the self
- Acting against the old belief and observing the results

Modifying interpretative bias

- Re-evaluating the evidence that apparently supports the old belief
- Questioning associated negative automatic thoughts
- Testing negative predictions through behavioural experiments
- Breaking down black and white thinking through contiuum work
- Re-evaluating dysfunctional assumptions and formulating more realistic and helpful alternatives

4.2 Description of the case

4.2.1 Reason for referral

Anna was referred to the community team for adults with learning disabilities for psychological intervention following a deterioration in her behaviour which was characterised by ‘tantrums’ and ‘outbursts’, in addition to ritualistic behaviours. Anna was also distressed by sweating symptoms, feelings of ‘hotness’ and dizziness which were ruled out by endocrinology as having a physical aetiology. The referral also noted that Anna had particular difficulties with expressive language.

4.2.2 Personal and developmental history

Anna was an 18 year-old young woman with mild ID. She was the youngest of three siblings, with an older sister aged 21 years and brother aged 24 years. Anna was born in the UK to Ghanaian parents. She lived at home with her mother, sister and brother. Her father and mother were separated and though her father resided outside the home, he visited a number of times a week.

Anna’s birth followed a full term pregnancy, which was without complications. Regarding her early development, her mother describes Anna as having been a ‘floppy’ baby and as a result she was difficult to hold and feed. Her development was marked by delays in language acquisition and comprehension. She was also late to develop fine and gross motor skills, and tended to slide herself from one place to another rather than crawl. She attended mainstream school with extra support until the age of fourteen when she was transferred to a school which catered specifically for students with additional learning needs, including learning disability and speech and language difficulties. This transfer was instigated by deterioration in Anna’s well-being at school which led to her refusing to attend. On further exploration of her difficulties at this time, Anna reported that she was verbally bullied by girls at the school and felt that she did not fit in, leading to anxiety and low mood. Unfortunately, the move to the new school exacerbated this situation and the level of bullying she experienced escalated to include physical aggression from other pupils. She left this school at seventeen without qualifications and went on to attend college where she enrolled in a child care course. After the first year of the course, Anna was not allowed to proceed to Year 2, as it was felt that she would be unable to meet the requirements of the course on account of her ID. Anna then took up a voluntary position as a clerk, working two days a week in the hospital administration office where her mother worked. The work involved filing and placing letters in envelopes. Anna was still working there at the time of her referral.

4.3 Assessment

4.3.1 CBT suitability assessment

A CBT suitability assessment was carried out prior to engaging Anna in a psychological intervention in order to inform the decision as to whether Anna would benefit more from either a ‘simplified’ version of CBT or a ‘complex’ version of CBT. Anna’s performance on this assessment led to a recommendation of individual simplified CBT, where extra support in therapy would be required to facilitate her understanding of the mediational link between behaviours and beliefs with emotions and to identify and understand feelings such as ‘worry’ and feeling ‘frightened’ in a way that would be meaningful to her experience of anxiety.

4.3.2 Diagnostic Interview for Social and Communication Disorders (DISCO)

During the course of Anna’s therapy, her mother attended three assessment sessions with a Senior Psychologist in the service, with whom she completed the Diagnostic Interview for Social and Communication Disorders (DISCO). The results of the assessment suggested that Anna met diagnostic criteria for Childhood Autism in accordance with ICD-10 criteria (code: F84.0). Based on clinical impression, it was also concluded that Anna met the criteria for Autistic Spectrum Disorders suggested by Wing and Gould (1979).

4.3.3 Psychological assessment

Anna’s needs and psychological difficulties were assessed over five sessions. Her presenting problems were then formulated from a cognitive behavioural and psychodynamic perspective. For the purpose of this case study, the cognitive behavioural formulation is presented on its own. Please refer to Appendix A for the psychodynamic formulation of this case.

4.3.3.1 Presenting problems

Anna and her mother felt that the main presenting problem was the aggression between Anna and her siblings, who regularly argued and sometimes became physically aggressive to one another. In order to cope with these difficult interactions, Anna would choose to avoid her siblings by isolating herself in her room as much as possible, which in turn impacted on Anna's quality of life and wellbeing.

Anna had very limited contact with a peer social network apart from two friends whom she text and met up with on an irregular basis. Her mother expressed concerns over Anna's vulnerability to being taken advantage of and her difficulties in navigating social interactions with peers, reporting that she would often misinterpret the intentions of others.

Other than the two mornings she worked a week, Anna lacked routine and structure to her day. She had a limited repertoire of activities and preferred to stay in her room watching television or flipping through magazines when she was not otherwise engaged. She remained very dependent on her mother regarding activities of daily living and still required some assistance and prompting with self-care routines, which was inconsistent with her level of ability.

After not being permitted to proceed with her year at college, Anna reported a decline in mood and self-esteem. For example, Anna reported feeling 'useless' and like the 'black sheep' of her family members, whom were all employed and had clear roles. She described comparing unfavourably with her older sister, who she felt was smarter, prettier and slimmer than her. She remarked that she felt that her mother preferred talking to her sister, as they were able to talk about 'grown up' things together. She also presented with feelings of hopelessness and passive suicidal ideation, in addition to risky behaviour, which involved holding a knife to her chest and pretending to faint.

4.3.3.2 Measures

As part of the assessment of Anna's difficulties a number of standardised measures were administered (please refer to the list, below). Measures were selected based on their acceptability for use with individuals with learning disabilities.

1. Glasgow Depression Scale for people with a Learning Disability (GDS-LD; Cuthill et al, 2003)
2. Beck Anxiety Inventory (BAI; Beck & Steer, 1993)
3. The Maslow Assessment of Needs Scale – Learning Disabilities (MANS-LD)
4. Inventory of Interpersonal Problems – 32 (Barkham, Hardy & Startup, 1996)
5. The Social Comparison Scale – Adapted (Gilbert & Allen 1994; Allen & Gilbert 1995; adapted for individuals with learning disability by Dagnan & Sandhu, 1999)
6. The Stigma Perception Questionnaire (Szivos, 1991; Szivos-Bach, 1993)
7. Adapted Rosenberg Self-Esteem Scale for use with adults with mild Learning Disabilities (Rosenberg, 1965; Beail & Warden, 1996; Beail, 2000).

Anna scored 21 on the GDS-LD, which suggested the presence of depression (cut-off score = 13). On the BAI, she scored 14 which indicated a mild level of anxiety (range 10 – 18). In terms of her anxiety, Anna reported frequent feelings of 'hotness' and 'dizziness' which she found difficult to explain. When having a 'hot' or 'dizzy' spell Anna reported catastrophising cognitions, e.g. 'I will be like this forever' and 'If this continues, my life is over'. Anna did not link these physiological experiences to a psychological state, e.g. anxiety, and remained keen to find a medical explanation.

Anna scored 26 out of 45 on the Stigma Perception Questionnaire, where higher scores are indicative of greater levels of perceived stigma. Her scores on the Adapted Rosenberg Self-Esteem Scale (2/10) indicated low levels of self-esteem, as lower scores correspond to a lower level of self-esteem. On the MANS-LD, Anna scored 32 out of 76, where lower scores are associated with less satisfaction with current quality of life and fewer needs being met.

Her scores on the IIP-32 indicated clinical significance on the overall measure and specifically in the following areas: hard to be supportive, hard to be involved, too aggressive, and too dependent.

The Social Comparison Scale, is composed of a number of analogue response choices, without numerical scores. Anna's responses on this measure are represented below with an 'X'. The measure asks the responder to consider the following statement in respect a range of responses (below): 'When I am with other people, I generally feel…'

1) X	
Worse than other people	Better than other people
2)	X
Better at things	Not as good at things
3)	X
More friendly	Less friendly
4) X	
More shy	Less shy
5)	X
Part of the group	On my own
6)	X
The same	Different

4.4 Formulation

Anna's difficulties became apparent when she did not meet the required competencies for Level 2 of her child care course in college and was not allowed to continue. This impacted negatively on Anna and triggered latent beliefs about not being good enough, feeling ‘useless’ and being a ‘black sheep’. This resulted in an exacerbation of mood which was compounded by the loss of a recently gained social network, structure and a sense of identity and purpose. At this time Anna also turned eighteen, an event which she found quite aversive as she had difficulty seeing herself as an adult and did not feel that she was on the same trajectory as her peers. This was evident in Anna’s difficulty in meeting socially normative milestones, such as issues pertaining to sexuality and accepting responsibility for self-care and activities of daily living. Though Anna had a desire to become more independent, her fears around growing up served to maintain her dependence on her mother. As her mother felt Anna was quite vulnerable she was very protective of Anna and at times colluded with Anna’s tendency towards dependence, despite having her own desires for Anna to accept more responsibility.

Anna’s lifelong experiences of being bullied at school appeared to have had a significant impact on her self-esteem. The rigid nature of her thinking may have also increased her vulnerability to internalising others’ view of her in a very concrete way. When bullied at school, girls called Anna ‘fat, ugly and stupid’ and these are words that Anna continued to use to describe herself when she was feeling low. Additionally, Anna’s difficulties with developmental delay also appeared to have been compounded by her difficulties with social interaction which have served to further marginalise her from her peer group. Anna’s difficulties with her siblings seemed to reflect her difficulties with peers and highlight the impact of social comparison on her self-esteem, where Anna reported feeling ‘useless’ and ‘worthless’ compared to her older sister. These difficult feelings may have played an important role in the conflict between siblings.

Anna had adopted a number of strategies to help her to cope in the short term. These strategies included isolating herself, over-dependence on her mother and avoidance of taking on adult responsibilities and roles. However, these strategies proved unhelpful in the long-term and contributed to vicious cycles, which were impacting negatively on her family relationships and her social development. Latent beliefs about being ‘useless’ were triggered exacerbating her mood and undermining feelings of self-efficacy and self-esteem. Lack of confidence in managing her day to day life and social situations was also leading to increased anxiety and stress; however, due to the fact that Anna had difficulty verbalising feelings and identifying salient thoughts, she tended to experience what she called 'stress' somatically and acutely (e.g. sweating, 'hotness', dizziness, stomach pains, etc.) Anna's lack of understanding of the aetiology of these physiological responses and the nature of their sudden onset increased her distress and tended to lead to an exacerbation of symptoms.

Therapeutic work was informed by a formulation based on Fennell's (1998) cognitive model of low self-esteem. See Figure 2.

4.5 Goals for therapy

In collaboration with Anna, the following goals were identified:

1) To make new friends and widen her peer network
2) To start a new college course
3) To decrease aggression and conflict between herself and her siblings

In order to meet these goals, it was agreed that the focus of therapy would be to:

1) Develop and improve Anna's self-esteem
2) Build confidence and develop Anna's skills to work towards greater independence
3) Learn new ways of managing stress when it is difficult to cope

4.6 Treatment summary

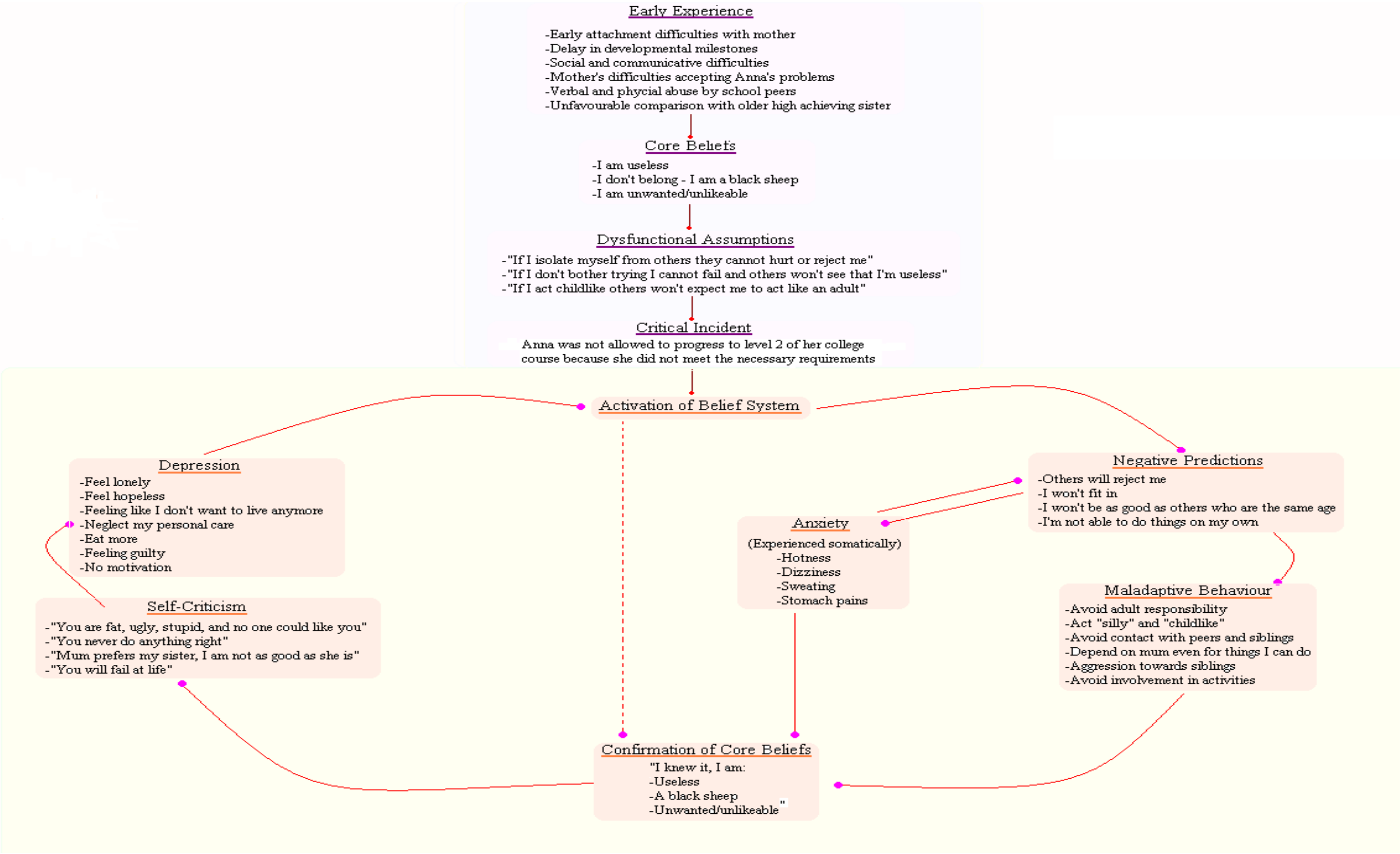
Treatment focused primarily on CBT for self-esteem and was supplemented by work to enhance Anna's sense of self-efficacy, including work on problem solving, and organisational and interpersonal skills. Specific aspects of Anna's treatment plan are described in detail below. In line with recommendations for delivering CBT to individuals with ID (Lynch, 2004) the following adaptations were made: 1) simplified and concrete language was used, 2) Anna's understanding was checked routinely throughout the session, 3) therapy sessions aimed at being as structured as possible using frequent reference to the agenda, 4) real-life situations and personally meaningful examples were used, 5) large formulations were broken down into smaller, simplified formulations, 6) visual aides were used to facilitate understanding and serve as prompts and reminders, and 7) written correspondence was presented in an accessible format using simplified language, pictures and photo symbols

4.6.1 Risk Management

In the initial sessions a risk management plan was collaborated on and more helpful ways of coping were explored. Strategies such as attention switching and focusing on positive topics were described and practiced. Anna was also provided with a list of numbers she could ring outside of office hours if she felt she was likely to engage in risky or self-harming behaviour (e.g. the Samaritans and Emergency Services). A list of helpful coping strategies was generated through collaborative discussion, and these were transferred onto a coping prompt card which included pictures. A key ring with her top preferred coping strategies was also made and provided to Anna so that she would have reminder with her at all times. Risk and coping strategies were reviewed at the beginning of each session throughout the intervention. Coping strategies were later generalised for use in managing ‘stress’ in other contexts and were enhanced with the introduction of relaxation and deep breathing strategies.

4.6.2 Collaborative case conceptualisation

A number of sessions were spent helping Anna come to an understanding of her difficulties via facilitation of her understanding of the link between feelings, thoughts, behaviours and physiological responses. An idiographic interpretation of Anna’s difficulties was generated using a simplified version Fennell’s model of self-esteem was utilised (as seen in Figure 2). The relationships between different variables were presented separately before being presented as the entire model, in order to provide Anna with extra support in understanding different parts of the cycle. Psychoeducation around the link between physiological experiences, cognitions and emotional distress was also provided, specifically focusing on Anna’s experience of ‘hotness’ and dizziness in the context of stress and catastrophic cognitions.



Early Experience

-Early attachment difficulties with mother
-Delay in developmental milestones
-Social and communicative difficulties
-Mother's difficulties accepting Anna's problems
-Verbal and phycial abuse by school peers
-Unfavourable comparison with older high achieving sister

Core Beliefs

-I am useless
-I don't belong - I am a black sheep
-I am unwanted/unlikeable

Dysfunctional Assumptions

-"If I isolate myself from others they cannot hurt or reject me"
-"If I don't bother trying I cannot fail and others won't see that I'm useless"
-"If I act childlike others won't expect me to act like an adult"

Critical Incident

Anna was not allowed to progress to level 2 of her college course because she did not meet the necessary requirements

Activation of Belief System

Depression

-Feel lonely
-Feel hopeless
-Feeling like I don't want to live anymore
-Neglect my personal care
-Eat more
-Feeling guilty
-No motivation

Self-Criticism

-"You are fat, ugly, stupid, and no one could like you"
-"You never do anything right"
-"Mum prefers my sister, I am not as good as she is"
-"You will fail at life"

Negative Predictions

-Others will reject me
-I won't fit in
-I won't be as good as others who are the same age
-I'm not able to do things on my own

Anxiety

(Experienced somatically)
-Hotness
-Dizziness
-Sweating
-Stomach pains

Maladaptive Behaviour

-Avoid adult responsibility
-Act "silly" and "childlike"
-Avoid contact with peers and siblings
-Depend on mum even for things I can do
-Aggression towards siblings
-Avoid involvement in activities

Confirmation of Core Beliefs

"I knew it, I am:
-Useless
-A black sheep
-Unwanted/unlikeable"

Figure 2. Collaborative Case Formulation

4.6.3 Developing structure and routine

Sessions also focused on helping Anna to develop structure and routine and assisting her in activity planning with a view to helping her to manage her anxiety and to improve her mood and feelings of self-efficacy. Anna presented with anxiety around being ‘too busy’ which would make her feel ‘stressed’, and therefore found it difficult to consider the addition of new activities. We used a weekly diary to determine the percentage of Anna’s time which was ‘free’, with the results suggesting that Anna was ‘busy’ for only a small proportion of her week. Anna’s ambivalence around being busy and having time to do ‘nothing’ was also explored. In the end, Anna felt that being busy meant that you had a role and had important things to do, and she felt like this was something she would like to integrate into her life.

4.6.4 Problem solving

Issues and problems arising for Anna over the course of therapy were utilised as foci for problem solving work. For example, Anna commenced a new job at a hairdressers midway through therapy and presented with a number of concerns regarding scheduling her time and travelling to the salon. Ongoing conflict with her siblings was also prioritised for problem solving work. In both areas, interpersonal effectiveness skills were also integrated, for example considering another person’s perspective, seeking clarification by asking questions when necessary, managing conflict and being assertive.

4.6.5 Thought and belief challenging

Anna’s unhelpful and rigid beliefs around becoming an adult were challenged using Socratic questioning and guided discovery in order to consider other possible ways of viewing the situation. More flexible thinking was fostered around transitioning into adulthood, and gradually, rather than suddenly taking on more responsibilities. Using examples of people she knows, we explored the range in difference that exists between people with regard to their achievements and level of responsibilities at a certain age. Because of Anna’s tendency to criticise herself for her lack of achievement, we first spent time making a list of Anna’s achievements and things she could be proud of, before collaborating on a list of goals that would bring Anna closer to a sense of independence and personal development. Of particular importance for

Anna was to ‘try out new things’ and to find a role that made her feel that she was on the same trajectory as her peers and was doing something ‘useful’ with her life.

4.6.6 Strengthening more positive and realistic views

In addition to focusing on Anna’s achievements, we also made a list of Anna’s positive personal qualities. Throughout therapy, we enhanced this list by making a log of positive achievements and qualities that continued to arise over the course of therapy. Anna highlighted that criticism received from her siblings was a common trigger for feelings of worthlessness, and so we spent time finding evidence against the negative thoughts and beliefs that she experienced as a result. Homework involved reminding herself of her positive achievements and qualities between sessions. Anna was also asked to continue to notice new positive experiences between therapy sessions and to bring these to the next therapy session. Significant achievements such as starting a new job and starting college were reviewed alongside her old negative beliefs (e.g. not fitting in and feeling useless) in order to challenge these beliefs and rescript them based on her new experiences.

4.6.7 Ending

Our last two sessions involved exploring Anna’s feelings around ending therapy, reviewing the work we had completed together and thinking about how Anna could use what she had learned in therapy in the future. Anna was encouraged to keep her therapy file and sheets so that she could review them at times when she needed to remind herself of the skills she has developed and the tools that she has found most effective in helping her to cope.

4.7 Outcomes

Anna’s post-intervention measures indicated improvement across all measures. Please see Table 1 for a summary of the scores. She was no longer in the clinical range for depression, anxiety or on the total score on the IIP-32. Subscales of on the IIP-32, however, indicated that she still felt she was ‘too aggressive’ and found it ‘difficult to be supportive’ to a significant degree (See Table 2). She showed notable improvements on measures of quality of life, perceived stigma and self-esteem. These outcomes will receive further comment in the Discussion.

Table 1

Summary of Pre- and Post-Intervention Scores

Measure	**Pre-Intervention**	**Post-Intervention**
GDS-LD	21/40	5/40
BAI	14/63	5/63
MANS-LD	32/76	61/76
Stigma Perception Questionnaire	26/45	43/45
Adapted Rosenberg Self-Esteem Scale	2/10	9/10

Table 2

Summary of IIP-32 Pre- and Post- Intervention Scores

Scale/Subscale	**Pre-Intervention Mean**	**Post- Intervention Mean**	**Direction of change**
Hard to be assertive	2.5	1	↓
Hard to be sociable	2.25	1	↓
Hard to be supportive	3*	3.25*	↑
Hard to be involved	2.5*	0.75	↓
Too aggressive	4*	3*	↓
Too open	1.75	2.25	↑
Too caring	1.75	2.25	↑
Too dependant	3.25*	0	↓
Full IIP-32	2.63*	1.69	↓

*Clinically significant (Kellett et al, 2005)

Shifts in Anna’s responses on the Social Comparison Scale are represented below, with ‘**B**’ representing her response pre-intervention and ‘**A**’ representing her response post-intervention. Anna’s responses indicate notable improvements across all aspects of social comparison.

1) **B**-----------------------------------→ **A**

Worse than other people Better than other people

2) **A** ←-------------------------------------**B**

Better at things Not as good at things

3) **A** ←---**B**

More friendly Less friendly

4) **B** ---→ **A**

More shy Less shy

5) **A** ←---**B**

Part of the group On my own

6) **A** ←--**B**

The same Different

4.8 Discussion

This single case study provides support to the existing evidence base for the effectiveness of CBT interventions for people with ID. The current piece of work employed recommendations suggested in the literature for the adaptation of assessment and intervention to consider the specific needs of a person with ID. This adapted approach has been effective in engaging the client in therapy, promoting improved understanding and facilitating change.

Anna showed improvement across all measures and was in the normal range for anxiety and depression. Self-esteem, the main target of the intervention, improved notably and at the end of therapy was rated at 9 out of 10.

In terms of her other goals, she began to take steps towards becoming more independent, including travelling independently, organising her own timetable, and beginning to take over household chores. By the end of therapy she had started a new college course and was working one day a week in a hair salon, employment which fit better with her personal interests. She stated that she felt she was closer to becoming an adult and was less anxious about this, as she was going to take ‘baby steps’ rather than expect to happen all at once. In terms of managing aggression and distress, Anna developed more helpful coping strategies which she was keen to continue using following therapy.

Incidents of aggression and conflict decreased over the course of therapy; however, conflict remained an ongoing issue between the siblings and Anna continued to score in the significant range for being ‘too aggressive’ on the IIP-32 (self report). On exploration of the ongoing issues with her brother and sister, Anna felt that they remained very critical and unkind to her, thus making getting along with them more difficult. Physical aggression had ceased by the end of therapy but arguments remained frequent. In terms of what she felt might help the situation, Anna believed that it would be easier if they did not live in the same house.

Anna’s scores on the Stigma Perception and Social Comparison Questionnaires showed a marked decrease. As the literature suggests, it is possible that changes in these processes may have contributed to a decrease in overall depression scores and improved self-esteem (Sivas-Bach, 1993; Swallow & Kuiper, 1998; Dagnan & Sandhu, 1999).

Other factors outside the therapeutic intervention must also be considered. During the course of therapy Anna was given a diagnosis of Childhood Autism. Though Anna did not want to explore this diagnosis in therapy, it was received positively by her mother who welcomed an explanation of Anna’s difficulties after many years of not knowing. The implications of this for the family can only be speculated upon, but it is possible that it may have led to greater acceptance of Anna’s difficulties, peculiarities and odd behaviour, which may have improved the dynamic of their relationship. Additionally, towards the end of therapy Anna was offered a college place and though she had begun to show improvements prior to this, this event served to bolster her confidence and hope for the future.

Feedback from Anna

At the end of therapy, Anna reported feeling like her life was ‘back on track’. In terms of her achievements, she stated ‘I’m proud of me’ and ‘I know I can do a good job’. On exploration of what personal qualities she feels has brought her through this, she stated ‘that I never give up’. She was looking forward to completing her college course and felt excited about making new friends on her course.

4.9 Reflections

One aspect of this work that I found important to consider was Anna’s understanding of the concept of confidentiality. Risk issues arose early during the assessment phase of our work and as a result it was necessary to involve Anna’s mother and to document the events as Serious and Untoward Incidents (SUI) under trust policy. This required that I break confidentiality. Though the limits of confidentiality were outlined prior to our work, Anna found it difficult to understand this when the time arose. At this time I was concerned that breaking confidentiality would result in a therapeutic rupture and make it difficult to engage Anna in therapy. In order to manage this, I spent a lot of time in session explaining to her the reasons that managing this risk was important and used more concrete examples of when confidentiality may need to be overridden. It was subsequently decided that confidentiality would be discussed at the beginning of each session as a reminder. Fortunately, in this case Anna eventually came to an understanding of the limits of confidentiality and the therapeutic relationship did not appear to be negatively affected. However, this experience highlighted the importance of taking time to explain more complex concepts such as confidentiality in the context of an intellectual disability.

References

Allen, S. & Gilbert, P. (1995). A social comparison scale: Psychometric properties and relationship to psychopathology. *Personality and Individual Differences*, *19*, 293–299.

Barkham, M., Hardy, G. & Startup, M. (1996). The IIP-32: A short version of the Inventory of Interpersonal Problems. *British Journal of Clinical Psychology, 35 (1),* 21 – 35.

Beail, N. (2000). An evaluation of outpatient psychodynamic psychotherapy for adults with intellectual disabilities. *Journal of Intellectual Disability Research, 44,* 204.

Beail, N. & Warden, S. (1996). Evaluation of a Psychodynamic Psychotherapy Service for Adults with Intellectual Disabilities: Rationale, Design and Preliminary Outcome Data. *Journal of Applied Research in Intellectual Disabilities, 9(3),* 223 – 228.

Beck, A.T., Steer, R.A., Beck, J.S. & Newman, C.F. (1993). Hopelessness, Depression, Suicidal Ideation, and Clinical Diagnosis of Depression. *Suicide and Life-Threatening Behavior, 23(2),* 139 – 145.

Beck, A.T. (1987). Cognitive models of depression. *Journal of Cognitive Psychotherapy; An International Quarterly*, *1*, 5–37.

Beck, A.T., Emery, G. & Greenberg, R. (1985). *Anxiety Disorders and Phobias: A Cognitive Perspective*. New York: Basic Books.

Beck, A.T. Freeman, A. & Davis, D.D. (1990). *Cognitive Therapy of Personality Disorders*. New York: Guildford.

Benson, B.A. (1994). Anger management training: a self-control programme for persons with mild mental retardation. In N. Bouras (Ed.), *Mental health in mental retardation: Recent advances and practices* (pp. 224–232). Cambridge: Cambridge University Press.

Benson, B.A. & Ivins, J. (1992). Anger, depression and self-concept in adults with mental retardation. *Journal of Intellectual Disability Research*, *36*, 169–175.

Black, L., Cullen, C. & Novaco, R.W. (1997). Anger assessment for people with mild learning disabilities in secure settings. In B. Stenfert Kroese, D. Dagnan, & K. Loumidis (Eds), *Cognitive–behaviour therapy for people with learning disabilities* (pp. 33–52). London: Routledge.

Black, L., & Novaco, R.W. (1993). Treatment of anger with a developmentally handicapped man. In R.A. Wells & V.J. Giannetti (Eds), *Casebook of the brief psychotherapies* (pp. 143–158). New York: Plenum.

Borthwick-Duffy, S.A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology*, *62(1)*, 17-27.

Champion, L.A. & Power, M.J. (1995). Social and cognitive approaches to depression: Towards a new synthesis. *British Journal of Clinical Psychology, 34(4),* 485-503.

Crocker, J. & Park, L.E. (2004). The Costly Pursuit of Self-Esteem. *Psychological Bulletin, 130(3),* 392 – 414.

Cuthill, FM, Espie, CA, and Cooper, SA (2003). Development and psychometric properties of the Glasgow Depression Scale for people with a Learning Disability: Individual and carer supplement versions. *The British Journal of Psychiatry, 182,* 347 – 353.

Dagnan, D. & Chadwick, P. (1997). Cognitive–behavior therapy for people with learning disabilities: assessment and intervention. In B. Stenfert Kroese, D. Dagnan & K. Loumidis (Eds), *Cognitive–behavior therapy for people with learning disabilities* (pp. 110–123). London: Routledge.

Dagnan, D., & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research*, *43*(5), 372–379.

Dagnan D. *&* Waring M. *(2004).* Linking stigma to psychological distress: a social-cognitive model of the experience of people with learning disabilities. *Clinical Psychology and Psychotherapy* ***11,*** 247–254.

Dagnan D., Chadwick P. *&* Proudlove J. *(*2000) Towards an assessment of suitability of people with mental retardation for cognitive therapy. *Cognitive Therapy and Research,* **24***,* 627–636.

Fennell, M.J.V. (1998). Cognitive Therapy In the Treatment of Low Self-Esteem. *Advances in psychiatric treatment, 4,* 296 – 304.

Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, *7*, 117–140.

Gilbert P. & Allen S. (1994) Assertiveness, submissive behaviour and social comparison. *British Journal of Clinical Psychology*, *33*, 295-306.

Haddock, G., Lobban, F., Hatton, C. & Carson, R. (2004). Cognitive-behaviour therapy for people with psychosis and mild intellectual disability: a case series. *Clinical Psychology & Psychotherapy, 11(4),* 282 – 298.

Hastings, R.P., Hatton, C., Taylor, J.L. & Maddison, C. (2004). Life events and psychiatric symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 48(1),* 42 – 46.

Joyce, T., Globe, A., and Moody, Clare. (2006). Assessment of the Component Skills for Cognitive Therapy in Adults with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities, 19(1),* 17 – 23.

Kirkland, J. (2005). Cognitive-behaviour formulation for three men with learning disabilities who experience psychosis: how do we make it make sense? *British Journal of Learning Disabilities, 33(4),* 160 – 165.

Kroese, B., Dagnan, D. & Loumidis, K. (Eds). (1997). *Cognitive–behaviour therapy for people with learning disabilities.* London: Routledge.

Lindsay, W. (1999). Cognitive therapy. *The Psychologist*, *12*, 238–241.

Lindsay, W., Howells, L., & Pitcaithly, P. (1993). Cognitive therapy for depression with individuals with intellectual disabilities. *British Journal of Medical Psychology*, *66*, 135–141.

Lindsay, W., Neilson, C., & Lawrenson, H. (1997). Cognitive–behaviour therapy for anxiety in people with learning disabilities. In B. Stenfert Kroese, D. Dagnan, & K. Loumidis (Eds), *Cognitive-behaviour therapy for people with learning disabilities* (pp. 124–140). London: Routledge.

Linville, P.W. (1987). Self-complexity as a cognitive buffer against stress-related illness and depression. *Journal of Personality and Social Psychology*, *52*, 663–676.

Lunsky, Y. (2003). Depressive symptoms in intellectual disability: does gender play a role? *Journal of Intellectual Disability Research, 6,* 417 – 427.

Matson, J. & Sevin, J.A. (1994). Theories of dual diagnosis in mental retardation. *Journal of Consulting and Clinical Psychology, 62(1),* 6 – 16.

Meins, W. (1993). Prevalence and risk factors for depressive disorders in adults with intellectual disability. *Journal of Intellectual and Developmental Disability, 18(3),* 147 – 156.

Meltzer, H., Gill, B. & Petticrew. M. (1995). OPCS Surveys of Psychiatric Morbidity in Great Britain. Report I: The Prevalence of Psychiatric Morbidity among Adults Aged 16-64. *Living in a Private Household, in Great Britain.* London: HMSO.

Nezu, C.M., Nezu, A.M., Rothenburg, J.L., DelliCarpini, L. & Groag, I. (1995). Depression in adults with mild mental retardation: are cognitive variables involved? *Cognitive Therapy and Research*, *19*, 227–239.

Oatley, K. & Johnson-Laird, P.N. (1987). Towards a cognitive theory of emotions. *Cognition and Emotion*, *1*, 29–50.

Reed J. *&* Clements J. *(*1989*).* Assessing the understanding of emotional states in a population of adolescents and young adults with mental handicaps. *Journal of Mental Deficiency Research,* **33***,* 229–233.

Reiss, S., & Benson, B. (1985). Psychosocial correlates of depression in mentally retarded adults: I. Minimal social support and stigmatisation. *American Journal of Mental Retardation*, *89*, 331–337.

Richards, M., Maughan, B., Hardy, R., Hall, I. & Wadworth, M. (2001). Long-term affective disorder in people with mild learning disability. *British Journal of Psychiatry, 179,* 523 – 527.

Rosenberg, M. (1965). Society and the adolescent self-image. Princeton, NJ: Princeton University Press.

Sams, K., Collins, S. & Reynolds, S. (2006). Cognitive Therapy Abilities in People with Learning Disabilities. *Journal of Applied Research in Intellectual Disabilities, 19(1),* 25 – 33.

Swallow, S.W., & Kuiper, N.A. (1988). Social comparison and negative self-evaluations: an application to depression. *Clinical Psychology Review*, *8*, 55–76.

Szivos, S.E. (1991). Social comparisons with siblings made by adolescents with a learning difficulty, *Journal of Community and Applied Social Psychology, 1,* 201- 212.

Szivos-Bach, S.E. (1993). Social comparisons, stigma and mainstreaming: the self-esteem of young adults with a mild mental handicap. *Mental Handicap Research*, *6*(3), 217–236.

Taylor, S.E. & Brown, J. (1988). Illusion and well-being: Some social psychological contributions to a theory of mental health. *Psychological Bulletin*, *103*, 193–210.

Voelker, S. L., Carter, R. A., Sprague, D. J., Gdowski, C. L., & Lachar, D. (1989). Developmental trends in memory and metamemory in children with attention deficit disorder. *Journal of Pediatric Psychology, 14*, 75-88.

Wing, L. & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9(1),* 11 – 29.

Appendix

Psychodynamic Formulation

Malan's (1979) triangles of conflict (ToC) and person (ToP) provide a way of thinking about a person's development and how it impacts on their psychological presentation. The approach initially focuses on the triangle of conflict which the person is supported to understand in terms of their own anxieties in the context of relationships in the present and the defence mechanisms they employ to cope with these anxieties. Such an approach is useful to consider even when therapy is based on other therapeutic models, such as CBT, because it promotes awareness of how past experiences and relationships influence present conflicts and difficulties in addition to acknowledging the role of defence mechanisms, transference and countertransference, all of which are played out in the therapeutic relationship.

At the time of assessment Anna was progressing through to early adulthood and she was increasingly confronted with situations that required independence and an adult appropriate response. From a psychodynamic perspective, she could be seen as experiencing anxiety regarding her ability to adequately succeed in an adult role. Linked to this anxiety were defence behaviours. For example, Anna chose to shy away from others who have certain expectations of her and from peers who highlight where she should be at in terms of achievements and development. For example, most of her time at home was spent alone in her room. She could also become angry or aggressive towards those who directly provoked this anxiety. These anxieties and defences were linked to her recent relationships with others, which are represented in the triangle of the person. For example, for Anna such anxieties and defences were evident in her relationships with her siblings whom she preferred to avoid. When avoidance was not possible interactions would commonly result in anger and aggression towards the siblings before eventually retreating again to her room. Such intense reactions warranted reflection on why such situations were so anxiety provoking and distressing. In this regard it was important to acknowledge Anna's hidden feelings which were characterised in essence by feelings of being devalued and useless as a result of being someone with learning disability. According to this model, hidden feelings are shaped by experiences and relationships in early life. For Anna, it was apparent that early attachment was characterised by anxiety from her primary caregiver, her mother, who was struggling to understand and accept Anna’s emerging difficulties in addition to finding it difficult to form a strong attachment with a child who did not engage in the expected attachment-seeking behaviours. Additionally, as Anna proceeded through development, her mother’s worry about her development, her guilt around not knowing how to best support her, and her sense of being burdened by Anna’s difference evoked and sustained feelings in Anna of not being normal and being a disappointment.