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Psychosis: Recognising the Needs of Carers and Service Users

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Portfolio submitted in fulfilment of the requirements for the
Professional Doctorate in Psychology (DPsych)
Department of Psychology
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Introduction to The Portfolio

Psychosis is often portrayed in the media as a formidable illness synonymous with danger: it is '*madness*'. The stigma is inordinate, which can reduce the likelihood of a relative/carer or the individual with psychosis seeking any form of help. The outcome: two isolated people, ashamed to share their secret for fear of the possible reaction. The isolation as well as the shame and fear seem only to exacerbate the tumultuous, unpredictable and often scary nature of psychosis. In this portfolio, I endeavour to demonstrate my growth and development as both a practitioner and researcher whilst demonstrating an immense passion for improving service provision for people affected by psychosis and their carers in an evidence based, compassionate manner.

The portfolio consists of three sections.

Section A presents the empirical research 'The Development & Pilot of a Remote Telephone Intervention for Carers of Individuals with Psychosis: TICIP study.

Section B presents the case study, 'Psychosis and Low Self-Esteem': a clinical piece of work.

Section C is an article submitted to the journal 'Psychosis', which disseminates the research findings of Section A.

Acknowledgements

R.B.

You touched my heart more than you could ever have imagined. You gave me strength to finish when I had none. Your strength, courage and determination never failed to amaze me. You found beauty and moments of happiness despite being plagued by the most horrific voices. Thank you for trusting me. Thank you for sharing cream soda and cake. I will forever see it and be reminded of you. May you rest in peace.

Firstly, I would like to thank Professor Farida Fortune, for quite literally keeping me alive! Her determination, dedication and care (aside from her unbelievable brain) have enabled me to do this. Thank you. I have a wonderful medical team and am indebted to the NHS.

I would like to thank my supervisor, Dr. Jessica Jones Nielsen for the kindness that she has shown me. Her belief in me has enabled me to cross the finish line.

I would also like to thank my parents for believing in me and supporting me on this journey. Especially my mum who brought me up to treat every human being with dignity, respect and compassion; to ask questions and attempt to work towards a more inclusive, humane world. My mum taught me to strive for my dreams and made them possible. To my dad, who has encouraged me, believed in me and expressed such pride in me all the way. To Gray, whose quiet wisdom and thoroughness helped me to 'pull through'. I thank my sisters, Bo and Maya, for their love. To Ben's parents and my dear friend Debs, who rooted for, and championed me all the way. Professor Robin Banerjee's belief and support in key moments of crisis enabled me to continue with this research. His warm words of wisdom and compassionate understanding of what it means to have an incurable illness was phenomenal "We measure everything [at home] in dog walking nowadays. If you get the dogs out the house, to the park et cetera; it's a pretty good day".

I am truly thankful to my partner Ben, who has been by my side every step of the way. He has put up with terrible moods, high levels of stress and often lacked a partner in the true sense. He has made crossing the finishing line a reality.

Above all, I would like to thank my son Joseph, who is the real reason I began to study. Being a young mother, I felt I had something to prove to the world and to myself. I wanted to do something my son would be proud of. Joseph attended my undergraduate classes, helped me with my postgraduate studies, attended seminars I taught, and has been with me every day of this Doctorate. His unfaltering support, his gifts, his notes of encouragement and his study plans have meant everything to me. His special chocolate delivery contraptions have been award winning! This thesis is primarily dedicated to him. He has been very patient. I am forever grateful for the journey I began with Joseph some 14 years ago and overjoyed that through this he has developed such a passion for learning and the mind. Joseph, your curiosity has been an inspiration.

Finally, I would like to thank all the carers and service users that I have had contact with. I hope in time we can develop services that better meet their needs.

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SECTION A: DOCTORAL RESEARCH

The development & pilot study of a remote telephone intervention for carers of individuals with psychosis: TICIP study

Candidate: Khanya Price-Evans
Supervisor: Dr. Jessica Jones Nielsen

Abstract

Abstract

Background:

Carers play a pivotal role in the provision of care to individuals with psychosis improving service user recovery, which also saves the NHS millions of pounds. Carers nevertheless often suffer degradation to their quality of life and may experience anxiety, stress, depression, post-traumatic stress and burnout. And yet there are few carer specific interventions and little targeted support to meet carers needs.

Aims:

To develop and pilot a guided self-help telephone intervention for carers (TICIP) to target their wellbeing: specifically, to decrease anxiety, depression and stress and increase quality of life.

Method:

A small pilot study ($n=16$) was conducted as a waitlist control outcome study. Participants ($n = 16$) were randomised; to either receive the intervention immediately ($n = 7$) or act as the control in the waitlist control group ($n = 9$). The groups were crossed over following the intervention.

Results:

Results indicated that the TICIP had a significant effect, reducing anxiety, stress and depression and increasing quality of life. Although results were overwhelmingly positive, the intervention is still in its development phase and results need to be interpreted with caution. However, there is potential for further research, particularly with regard to ‘accessibility’, which could substantiate the initial results and greatly extend the usefulness of the study.

Chapter 1: INTRODUCTION

1.1 Psychosis

1.1.1 A brief history

The mainstream classification of psychosis was initially borne out of the work of Emil Kraepelin who, in the early 19th century, was the first to classify it as a distinct form of mental illness. He outlined psychosis as having a pattern of symptoms resulting in significant disability (Kraepelin, 1896). He coined the term *dementia praecox* and believed that it followed a deteriorating course, which incurred significant lifelong disability. This Kraepelinian view dominated psychiatric care for over a century and was epitomised in the original psychiatric institutions. With the advent of antipsychotic medication in the 1950's a shift occurred in the treatment of individuals with psychotic symptoms which favoured a community-based approach (Scull, 1977; Rogers & Pilgram, 2001). However, the necessary financial structures were not in place to support this, and the old views of many health professionals, who perceived only the disabling life-long effects of the condition, resulted in a bleak prognosis (Bentall, 2009). In the 1980's, however, research began to indicate that individuals with severe psychosis were able to make a partial or even full recovery provided they received the correct treatment (Harding et al., 1987; Ciompi, 1980). This research paved the way for the shift in the conceptualisation of psychosis from one of life long disability and suffering to one based on a recovery model.

1.1.2 Definition, Symptoms, Prevalence and Incidence

Psychotic disorders are both serious and distressing mental health conditions that are used to describe 'a type of problem in which the patient appears to be, at least to some degree, out of touch with reality' (Morrison, Renton, French & Bentall, 2008, p.4). The expression of these disorders are defined by "abnormalities in one or more of the following five domains: delusions, hallucinations, disorganised thinking, grossly disorganised speech, or abnormal motor behaviour (including catatonia), and negative symptoms" (DSM-5 p.87) and fall within the DSM-5 classification of

‘Schizophrenia and Other Psychotic Disorders’. They can be further categorized into non-affective (schizophrenia), affective (bipolar disorder with psychotic symptoms, or major depressive disorder with psychotic symptoms) and substance induced psychotic disorders (Kirkbride et al., 2012). There are elevated levels of psychiatric comorbidity in psychosis: for example, psychosis is often accompanied by significant emotional dysfunction with symptoms including anxiety, depression and traumatic stress (Freeman & Garety, 2003; Keks & Blashki, 2006; Krabbendam & van Os, 2005), with high rates of suicide and substance misuse (Hartz et al., 2014). Furthermore, research indicates that although some service users are aware of what is happening, many lack insight (Keks & Blashki, 2006) and often present at emergency departments with aggressive and suicidal behaviours (Payne et al., 2006). Many of the common changes evident in psychosis, such as deterioration in social functioning, cognition and affect, are indicative of a fluctuating prognosis, with the result that the provision of care may include episodes of remission and relapse during recovery (Cooke, 2014). All the psychotic disorders are related to social disability, significant personal distress and the fundamental need for care (Kirkbride, 2012). Empirical evidence suggests that the aetiology of psychotic disorders is related to both genetic and environmental risk factors (Howes & Murray, 2014; van Os, Rutten & Poulton, 2008) though separation of these factors remains difficult, with certain factors falling within both genetic and environmental categories. There appears to be a general consensus in the literature that the average age of onset for psychosis is mid-to-late twenties, though it is later for women than for men, and slightly earlier for the non-affective disorders (Kirkbride et al., 2012). In general, psychotic disorders affect more men than woman (an estimated three men are affected for every two women; McGrath, 2004). The prognosis is distinctly variable with the most severe outcomes in those with a non-affective disorder (Kirkbride, 2012). The comprehensive Aetiology and Ethnicity in Schizophrenia and Other Psychoses (AESOP) multicentre study (Fearon et al., 2006; Kirkbride et al., 2006) provides data (from three UK cities: Nottingham, London and Bristol). Specifically, it found that: 1) males had higher incidence rates than females, 2) black minority groups (including first and second-generation migrants) had higher incidence rates compared with ‘white British’ groups; and 3) incidence rates differed significantly between the cities, with the highest rates in London. Recent research provides substantial

evidence on the links between environmental factors such as social fragmentation, social capital, ethnic density, individual social experience over a lifetime (e.g. childhood abuse and deprivation, adult social disadvantage, racial discrimination and or substance misuse) and the onset of psychotic disorders (Moore et al., 2007; Morgan et al., 2007; Veling et al., 2008). Psychosis is one of the most disabling and debilitating mental health conditions with high incidents of co-morbidity and premature mortality (McGrath et al., 2014). Furthermore, evidence suggests that the mortality gap is increasing (Saha et al., 2007; Beary et al., 2012). Mortality rates and general physical health outcomes are significantly worse for people with psychosis than in the general population, with recent research indicating that individuals with psychosis die 15-20 years earlier (Moore, Shiers, Daly, Mitchell & Gaughran, 2015). The side effects of antipsychotic medication and unhealthy lifestyle further increase the physical health risks, with a significantly higher proportion of individuals diagnosed with psychosis being prone to cardiovascular disease in comparison to the general population (Hert, et al., 2011). This suggests that many individuals with psychotic disorders are not yet reaping the benefits of improved services (Saha et al., 2007).

1.2 Caregiving in Psychosis

Carers of people with psychosis are commonly family members; (Lauber, Eichenberger, Luginbuhl, Kellar, & Rossler, 2003), although there are some discrepancies over how carers are defined. The Carers Trust define carers as follows: “A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support” (not specifically for mental health; Carers Trust UK www.carerstrust.org). The Equality Act (2010) proposes that “carers are people who care, unpaid, for others who are elderly or disabled” (The Equality Act, 2010). For further clarity, Kuipers (2010) view has been adopted here, which, predicates that carers of individual’s with psychiatric problems are not generally carers by choice (Kuipers, 2001). Furthermore, they are faced with extra responsibilities that relate to the high dependency of the individual being cared for (Kuipers, & Bebbington, 2005).

Over the past fifty years, the institutionalised treatment of service users with psychosis has been substituted with a community-orientated service in which

families and relatives have played a far more significant role (Chen, 2011). The Department of Health (Department of Health 1999a) estimate that about 50 per cent of service users with severe and chronic mental health needs reside with family or friends; which increases significantly with psychosis (Lauber, et al., 2003). Informal caregiving has many documented benefits [for the individual with psychosis] such as reducing both the requirement for and length of inpatient admissions (Norman et al., 2005) as well as helping the service user to receive the requisite treatment at all the different stages of the illness (Bergner et al., 2008). Furthermore, informal caregiving appears to increase self-reported quality of life in service users (Stowkowy, Addington, Liu, Hollowell & Addington, 2012), and positive physical health outcomes (Stowkowy et al., 2012), whilst in first episode psychosis service users it appears to reduce mortality rates (Revier et al., 2015). However, despite the numerous benefits to service users, providing informal care is often a somewhat negative experience for the carer (Boydell et al., 2014; Dyck, Short & Valentno, 1999; Flyckt et al., 2013).

The idea of the ‘burden of care’ was first defined by Platt (1985) as “the presence of problems, difficulties or negative events that influence the life of a family member when taking care of the client” (p. 113). Despite the positive effect that carers have on service user outcomes (Bergner et al., 2008; Norman et al., 2005) there is extensive evidence that details the negative impact that the caregiving role may have on the carer (Boydell et al., 2014; Dyck, Short & Valentno, 1999; Flyckt et al., 2013), causing high levels of emotional and physical distress (Patterson et al., 2005). The World Health Organisation estimates that the burden psychosis places on family and community is exceeded only by quadriplegia and dementia (World Health Organisation, 2001). Carers face significant financial burdens as a direct result of their role (Csoboth, Witt, Villa & O’Gorman, 2015) with many spending the equivalent of full-time working hours, providing unpaid care (Flyckt et al., 2013). It is unsurprising therefore that over 50 per cent of carers report financial difficulties (de Silva & de Silva, 2001). Providing care in psychosis is evidentially stressful and places a significant burden on the carer (Boydell et al., 2014; Flyckt et al., 2013). Depression and emotional dysfunction are reported in approximately 40 per cent of carers (Dyck, Short & Valentno, 1999; Kuipers & Raune, 2000), This increases in the initial stages of illness and with in-patient admission and is exacerbated further if

the service user is detained (Addington, Coldham, Jones, Ko, & Addington, 2003; Boydell et al., 2014). Burnout and exhaustion in carers is reported to be comparable to that of paid psychiatric staff (Angermeyer, Bull, Bernert, Dietrich & Kopf, 2006). Even in the early stages of the illness carers report feeling burdened (Onwumere et al., 2008a). Challenging behaviours such as violence (Onwumere, Hunter, & Kuipers, 2014), or delusional beliefs (Onwumere et al., 2008a) are just some of the challenges that carers face (Onwumere, Grice, & Kuipers, 2016). The sense of loss and guilt experienced by the carer has been found to be comparable to when physical bereavement occurs (Patterson, Birchwood & Cochrane, 2005) as illustrated in the following excerpt:

“... and the boy we know is lost to us. Like a missing child the pain never dies but haunts us with hopes that some day we will find him again” (Bingham, 1991, cited in Kuipers, Leff, and Lam, 2002, p. v).

Not only do carers have the service users' mental health to cope with, but they also have to contend with the stigma attached to mental illness (Sanbroke & Harris, 2003; Addington et al., 2003; Barker, Lavender & Morant, 2001). Carers are also often isolated and have poor social support (Magliano, Fiorelli, Malangone, De Rosa, & Maj, 2006). Such social isolation is directly linked to the exacerbation of carers' distress and burden (Magliano, et al., 2002). Research has consistently indicated that the onset of psychosis is a life changing health event that is often traumatic and can be catastrophic for both the sufferer and the carer (Tanskanen et al., 2011). The risk of the carer developing clinical levels of anxiety, depression, stress and trauma is well documented (Fadden, Bebbington & Kuipers, 1987; Savage & Baily, 2004; Tennakoon et al., 2000). Although common reactions, left untreated could lead to a degradation in quality of life with poor physical and psychological health (WHOQOL Group, 1999). Recent research further indicates that carers may have trouble recognising the sufferers' initial symptoms as psychosis (Tanskanen et al., 2011). This in turn may lead to further treatment delays, resulting in increased levels of guilt and frustration (Tanskanen et al., 2011), as well as causal attributions linked to service user relapse (Dyke et al., 1999). Furthermore, where the carer viewed the sufferers' symptoms as 'controllable' their caring style was often

perceived as hostile [by the service user] and resulted in higher sufferer relapse rates (Barrowclough et al., 1999).

1.3 Family Interventions

Family interventions were developed based on the rationale that interpersonal stress could increase psychotic symptomatology, resulting in frequent and premature relapse (Haddock, 2011). Specifically, referred to as Expressed Emotion (EE); research indicated that psychosis sufferers living within family units that displayed high levels of EE, had significantly higher relapse rates than those residing in low EE families (Bebbington & Kuipers, 1994). Furthermore, research indicated that decreasing EE within the family decreased patient relapse rates (Butzlaff & Hooley, 1998, 2012). An high EE environment however, did not appear to be the result of deliberately hostile and critical carers (family members) but appeared to be related to the great amount of stress associated with providing care for an individual with a psychotic illness (Haddock, 2011; Barrowclough & Hooley, 2003). A combination of an increasing understanding of the experience of carers, the difference in patient relapse rates between high and low EE family environments, and, the consanguinity between patient outcomes and family functioning, resulted in the initial impetus for the development of family interventions (Onwumere et al., 2016). Originally Family Intervention for Psychosis (FIPs) were developed with the primary aim of decreasing EE within the family (Budd & Hughes, 1997). However, greater emphasis also began to be placed on service user recovery, which was as a direct reflection of the implementation of the recovery model within services. Thus, more traditional family interventions were adapted to incorporate cognitive behavioural and systemic therapy techniques with the primary goal of decreasing distress and improving the well-being of the family unit (Addington, et al., 2003; Kuipers et al., 2010).

Evidence of effective psychosocial interventions for schizophrenia became apparent in the late 1980's (Leff et al., 1985). However, despite the evidence, the interventions were rarely implemented (Anderson & Adams, 1996). There were multiple reasons related to the ineffectual implementation of evidence-based treatments (O'Carroll, Rayner & Young, 2004) one of which was a lack of skills within the treatment team (Brooker et al., 1994). Based on earlier research by Leff

and colleagues (1985) the development of training courses (The Thorn Initiative) for nurses in the deliverance of psychosocial interventions for families began at The Institute of Psychiatry and The University of Manchester (Kuipers, Leff, & Lam, 2002). The initiative chiefly aimed to train community psychiatric nurses to deliver psychosocial interventions through the completion of a very well supervised diploma course, thus increasing access to evidence-based family treatment (Kuipers, Leff, & Lam, 2002). The treatment programme that was developed was based on a family work guide that incorporated tailored psycho-education, positive communication and problem-solving approaches with emotional and stress management. Uniquely, a significant section of the programme was delivered in the carers own homes (Kuipers et al., 2002). The Thorne Initiative continued to develop training courses and demonstrated that: 1) student skills and knowledge increased and 2) service user outcomes were significantly improved (Lancashire et al., 1997). Despite the positive outcome, implementation of family interventions remained low (Fadden, 1997). This led Burbach and Stanbridge (2008) to develop the Family Interventions (Research, Skills, & Theory) in Psychosis course (known as FIRST) – the primary aim of which was to establish a family intervention service in Somerset, UK (Burbach & Stanridge, 2008). The authors proposed a two-pronged strategy in an attempt to address implementation difficulties. Initially, FIRST aimed to train multidisciplinary staff teams and secondly, to integrate cognitive behavior therapy for psychosis (CBTp) with systemic therapy, skills and theory (Burbach & Stanbridge, 2008; 2006). Flexibility in the approach was a crucial factor and later allowed for the treatment of families affected by first episode psychosis (Burbach & Stanbridge, 2008). The primary aim of the course was to address difficulties in service delivery, which was tackled by *in-situ* team training to enable the development and establishment of the broadest skills set (Burbach & Stanbridge, 2008). Evaluations of the FIRST course were very positive and encouraging, indicating that staff that had completed the training worked with a greater amount of families and reported little difficulty (Bailey et al., 2003). Furthermore, a study that compared five different family psychosocial interventions found that teams that completed the FIRST course had significantly less difficulty in implementing FIPs (Brooker & Brabban, 2004). Although FIPs had diversified in techniques of delivery they continued to conform to the stress-vulnerability model for the development and maintenance of psychosis

(Barroclough & Tarrier, 1992; Falloon, Boyd & McGill, 1984; Kuipers, Leff & Lam, 2002) and to maintain a cognitive-behavioural therapeutic underpinning (Pharoah et al., 2006). FIPs attempt to improve the interpersonal environment and often follow a similar structure (see Pharoah et al., 2006; for a detailed description). FIP's are open to both family and carers and can be delivered to individual families or groups of families (McFarlane et al., 1995). FIPs remain the best evidence-based treatment option for carers of individuals with psychosis (Lobban, et al., 2013), with a significant body of research demonstrating their efficacy (Bird et al., 2010; Onwumere, Bebbington & Kuipers, 2011). A recent Chochrane review concluded that family interventions could: 1) reduce frequency of service user relapse, 2) reduce hospital admission and 3) increase medication adherence (Pharoah, Mari & Streiner, 2006). Most of the research, however, has focused largely on FIPs (Szmukler et al., 2003) as a means to decrease relapse rates and reduce inpatient admissions, decrease EE within the family, and to increase the social functioning of the patient (Pharoah et al., 2006). Patient outcomes have been the primary focus (Onwumere, et al., 2016) with carer outcomes as secondary (Szmukler et al., 2003; & Birchwood, et., 2004). Although the research is limited with regard to carers in comparison to patients, it does suggest that FIPs may increase the quality of life of the carer, decrease carer burden and increase positivity about the role of caregiver (Berglund, Vahlne, & Edman, 2003; Lobban et al., 2013) Specific research indicates that anxiety and depression can be reduced through learning better coping skills (Bourgeois et al., 1997); and that effective behavioural management skills can also alleviate some of the pressure placed on the carer whilst enhancing their well-being through increasing pleasant activities (Stevens & Burgio, 2000).

1.4 New Interventions

The UK government have placed great emphasis on supporting carers (Department of Health, 2011) and the National Institute for Health and Care Excellence (NICE) recommend FIPs in their guidelines (NICE 2009). Yet, despite the evidence base, the implementation of FIPs within services is poor (Lobban et al., 2013). There are a multitude of reasons that implementation has been slow, such as the high work-load already placed on staff, a lack of confidence, difficulties related to the engagement of the carers, and an individualised model of care (Fadden, 2006).

In line with policy, strategies such as supported self-management tools, which aim to increase access to interventions, and potentially also carers knowledge and skills (Department of Health, 2005) have been developed (Lobban et al., 2013). However, although there have been advances for physical health conditions, there has been little development within mental health (Lobban et al., 2013). The Relatives' Education And Coping Toolkit (REACT) (Lobban et al., 2013) was the first supported self-management intervention for carers of recent-onset psychosis. The toolkit was developed to cover all the main evidence-based elements of FIPs (Lobban et al., 2013). In comparison to previous research (Barrowclough et al., 1999; Szmukler et al., 2003) carers appeared keen to participate despite showing significant levels of distress and participation remained high at follow up (Lobban et al., 2013). Results from the feasibility study were positive and indicative that supported self-management to reduce distress was a viable possibility for carers of people with recent-onset psychosis (Lobban et al., 2013). The REACT trial did not collect any service user data and therefore did not require service user consent; the authors believe this was an important element of REACT as it allowed (possibly the most in need) carers who would not have previously been able to access FIPs (due to a lack of consent) access (Lobban et al., 2013). With increasing financial demands on healthcare the role of carers is also increasingly important (Broese van Groenou & De Boer, 2016) and the need for the development of innovative and appropriate interventions is paramount. The Schizophrenia Commission (2012) recommended that "...Clinical Commissioning Groups and local authorities commission an appropriate range of services to support the needs of carers of people with schizophrenia and psychosis including information and advice..." (p.63) as their needs are still not being adequately met.

1.4.1 What Do We Know?

Carer burden and the ability of the carer to cope are linked to service user recovery (Kuipers, Onwumere, & Bebbington, 2010). The majority of interventions focus on the service user (Yesufu-Udechuku et al., 2015) and access to FIPs are reliant on local training initiatives (Kuipers, 2010). Although research indicates that psychosocial interventions have a positive effect on both the carer and service user's recovery (Kuipers, Onwumere, & Bebbington, 2010) implementation remains poor

(Insel, 2009). Furthermore, carers can be denied access to current interventions if the service user declines (Kuipers, 2010). Carers suffer from poor physical health in comparison to non-carers (Schulz & Sherwood, (2008) and research consistently links poor mental health and caring (Pinquart, Sörensen, 2003). Recent research demonstrated that carers are twice as likely to meet the clinical thresholds for psychiatric symptoms than non-carers (Smith et al., 2014). Kuipers et al., (2010) suggest that “it is now time to consider theory-based interventions focused on improving carer outcomes” (Kuipers et al., 2010, p.259). A systematic review of the literature concluded that “substantial improvements in critical outcomes shown in a number of quite varied studies can (at least in part) be taken as evidence of an underlying need that carers have for help, not just as caregivers but as individuals” (Yesufu-Udechuku et al., 2015, p. 273). The impetus for providing interventions that meet the carers own needs has been recognised and is reflected in the most recent and updated NICE guidelines (NICE, 2014); [they] recommend that services “offer carers of people with psychosis or schizophrenia an assessment (provided by mental health services) of their own needs and discuss with them their strengths and views. This would include developing a care plan to address any identified needs. A copy would be given to both the carer and their GP, who would ensure it was reviewed annually’. Wider research suggests that primary care will be required to play an important role in meeting carers own needs as the majority of carers feel their GP is the most influential professional with regard to improving their lives (Henwood, 1998, cited in Onwumere, Shiers, & Chew-Graham, 2016).

1.5 Research Aims and Study Hypotheses arising from Literature Review

The aim of the research was to develop and evaluate (pilot) a remote guided self-help telephone intervention for carers of individuals with psychosis. The research focused on carer outcomes, both specific (anxiety, stress and depression) and global (quality of life). It was hypothesised that participants that completed the TICIP intervention would benefit from (i) a reduction in anxiety, depression and stress as measured by the Depression, Anxiety, and Stress Scale (DASS: Lovibond & Lovibond, 1995) and (ii) an improvement in their quality of life as measured by the World Health Organisation Quality of Life Brief Questionnaire (WHOQoLBREF, 1999).

Chapter 2: THE INTERVENTION

2.1 Developing the Intervention

2.1.1 Theoretical Basis

Research has demonstrated that the appraisal the carer makes of their situation and their resources for coping is of greater importance than the actual severity of the problem itself (Scazufca & Kuipers, 1996). Specifically, researchers note that all carers are vulnerable to potential stresses but, it is the carers appraisal of the situation and how they attempt to manage it that accords well-being to the service users (Kuipers, Onwumere & Bebbington, 2010). This concept forms the basis for the Cognitive Model of Caregiving in Psychosis (Kuipers, Onwumere & Bebbington, 2010) and indicates that the carers own appraisals should be the target of future interventions (p.259). The authors classify the style of caregiving provided by the carer into three different relationship types all based on the carers previous relationship with the service user. These are positive, emotionally overinvolved, and critical and hostile relationships which they posit can be used to guide and tailor interventions based on the characteristics of the relationship (Kuipers, Onwumere & Bebbington, 2010). Other research indicates that theory driven interventions can help to target specific behaviours (Reinhard, Given, Petlick & Bemis 2007; Houts et al., 2010). Specifically, interventions that increase the carers' confidence and competence have a direct effect on the care they provide which indirectly affects their levels of distress (Reinhard et al, 2007).

The cognitive-behaviour therapy (CBT) model developed by Beck (1967) formed the theoretical basis for the TICIP. CBT is an evidence-based, problem-focused psychological intervention developed for the treatment of anxiety and mood disorders (Butler, Fennell, Robson & Gelder, 1991). Successful treatment of anxiety disorders has paved the way for new CBT developments to treat a variety of conditions, including psychosis (Byrne, Birchwood, Trower & Meaden, 2006; Fowler, Garety & Kuipers, 1998) eating disorders (Fairburn & Cooper, 1989) and substance abuse (Woody et al., 1983). Extensive research has provided evidence for these models of disorder specific treatment (Clark, 2004) and disorder specific protocols and treatment (Wells, 1997). Cognitive Therapy (CT) (Beck, 1967) was originally developed for use in the treatment of depression. In CT the facilitation of

change occurs through a process of Socratic questioning whereby the therapist questions the beliefs of the patient and guides them to towards their own conclusions.

Behaviour Therapy (BT) focuses on observable learned behaviours. BT or behaviour modification would then aim to help the client change ‘unhelpful’ behaviours through the processes of both classical and operant conditioning (Bennet-Levy, Butler, Fennell, Hackmann, Mueller & Westbrook, 2004). CBT provides the client with both the cognitive and behavioural aspects of both therapies; the basic premise, that thoughts, behaviours, emotions and physiology are all part of an interactive system. CBT addresses this interactive system and helps individuals: 1) intercept their automatic thoughts that, according to Beck and Greenberg (1974) can be visual as well as verbal; and 2) tap into their underlying beliefs.

Psycho-education is an evidence-based intervention that combines psychological and educational interventions with the primary aim of behavioural change. Psycho-education is a holistic approach (Dixon, 1999; Lukens & McFarlane, 2004) that incorporates both cognitive and behavioural elements and maps well onto the CBT structure. The intervention that forms the basis of this thesis was specifically designed to incorporate psycho-education. It employs this approach to help to alleviate some of the carers anxiety and stress through developing a more comprehensive understanding of psychosis and learning better coping strategies.

2.1.2 Treatment of Anxiety in Carers

The treatment of anxiety disorders with CBT is well documented (see Clark & Beck, 1988; Heimberg, 2002). Anxiety is a normal response to threat that is depicted in four response systems within the CBT framework: the physiological, cognitive, behavioural and emotional response systems (Westbrook, Kennerley & Kirk, 2007). The anxiety response is largely an automatic response to threat or the anticipation of threat and only becomes problematic when the normal response occurs in either the absence of threat or is extremely exaggerated (Westbrook, Kennerley & Kirk, 2007). A central part of therapy [for anxiety disorders] is psycho-educational work to help the patient normalise their anxiety and understand that it is an amplified normative response (Westbrook, Kennerley & Kirk, 2007). It is widely accepted that anxiety is maintained through cognitive and behavioural processes (Beck, 1967) characterized by dysfunctional beliefs that can have specific situational

triggers or occur as the result of a misinterpretation of bodily sensation(s) (Westbrook, Kennerley & Kirk, 2007). The efficacy of CBT for the treatment of anxiety disorders has been well established (Clark & Beck, 1988; Heimberg, 2002).

2.1.3 Treatment of Depression in Carers

The behavioural model of depression focuses on the *relationship* between the individual and the environment (Zettle, 2007) and has further developed into a model of behavioural activation. Through a variety of techniques, the therapeutic process emphasises rewarding predictable response behaviours to result in an increased behaviour-reward contingency (Martell, Addis, & Jacobson, 2001). There are many cognitive models of depression. A salient model developed by Beck and colleagues (Beck, Rush, Shaw, & Emery, 1987) posited that depressive symptoms are caused and maintained by biased and/or distorted thinking. Thus, an individual suffering from depression will hold a negative view of self, experience and future (Beck & Greenberg, 1974). A wide array of behavioural techniques - for example, self-reward, visualisation, behavioural activation, and mindfulness - can be successfully combined with cognitive elements such as identifying cognitive distortions, challenging cognitive distortions, and self-instruction/control.

2.1.4 Complex Interventions

The process from development through to implementation of a complex intervention usually consists of many phases (see Fig 1) - though research shows that the process is not necessarily linear or cyclical (Campbell et al., 2007) but rather appears to ebb and flow between the different phases before moving towards the phase of implementation. A central assumption is that prior to the implementation phase reasonable certainty in the worthwhile effect of the intervention should be gained.

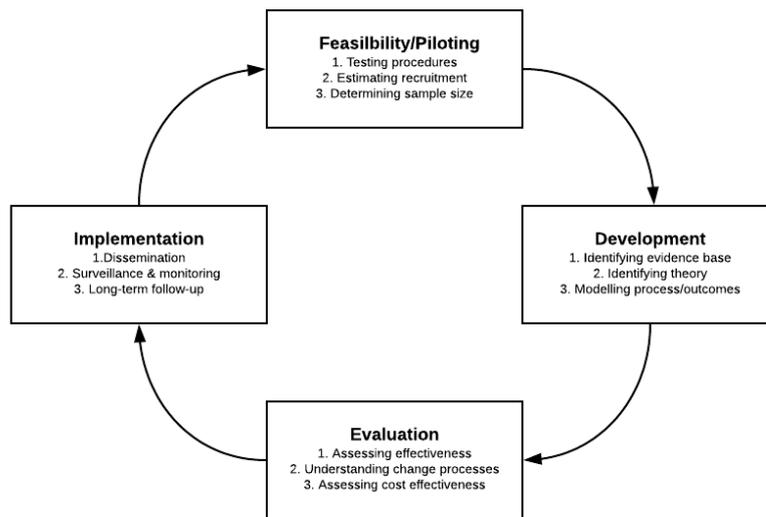


FIGURE 1: KEY ELEMENTS OF THE DEVELOPMENT AND EVALUATION OF A COMPLEX INTERVENTION (CAMPBELL ET AL., 2007).

2.1.5 The Intervention

The development of the Telephone Intervention for Psychosis Carers (TICIP; Appendix A) was informed by: 1) a systematic review of the literature related to caregiving in psychosis; in particular, research that had examined carers outcomes as the primary outcomes, and 2) clinical and personal expertise of the researcher and associated colleagues. The TICIP was developed in the United Kingdom by Khanya Price-Evans (2014) to form part of her doctoral thesis.

The TICIP was developed as a brief telephone intervention for carers to work remotely and collaboratively with a mental health practitioner trained in delivering the intervention.

The TICIP consists of three discrete but interconnected [succinct] modules (38 x A5 pages in total) that are ideally completed over a six-week period but allow for flexibility depending on the carers situation. The TICIP although originally designed to be completed in sequential order can be completed as individual units. Each module has been designed as a stand-alone unit to enable this.

The TICIP commences with a brief introduction to the intervention, followed by an introduction to carer burden.

Module One: Anxiety, Stress and Depression

Module one commences with psycho-education about anxiety, stress and depression during which the carer is encouraged to complete particular exercises to make the information as relevant to their own situation as possible. A brief introduction to CBT with emphasis on the Five Aspects (Padesky & Mooney, 1990) follows. Again, the carer is guided through some examples in the manual before being guided to work through their own personalised example. Throughout this module, information about alternative thoughts and reactions is presented and considered. The need for this will vary based on the carers needs. This first module then focuses on ways to reduce some of the difficulties experienced by the carer. Attention is drawn to the carers own coping resources and they are provided with psycho-education about goal setting, prioritising and learning the significance of and how to say 'no'. Again, the material is all complimented by spaces to explore and write up their own relevant example. Information is presented about the importance of staying healthy as a carer (taken from standardised NHS guidance) and how this relates to the Five Aspects (Padesky & Mooney, 1990). This first module concludes with information about the importance of recognising daily achievements- no matter how small. Again this is explored through a guided example.

Module Two: Dealing with Challenging Behaviour

Module two provides information on the positive and negative symptoms of psychosis and explores new ideas and tools to increase their repertoire of responses to these challenges. This includes basic information and signposting as appropriate. Again, the carer is encouraged to select a behaviour that they find very challenging and to work through this example, so that the information is personalised and relates to their situation.

Module Three: The Balancing Act

Module three aims to link all the information, combining it with each participant's specific personal examples to maintain personal relevance. The focus is on connecting and integrating the information in order to be able to put the ideas into practice in the future. The module concludes with developing a personal plan. In the

final session of the intervention basic mental health contact details and blank worksheets are provided.

Chapter 3: METHOD

3.1 Rationale for analysis

Quantitative methodologies enable new interventions to be benchmarked against existing interventions. A major aim of this research was to develop an intervention that would have real world validity and the possibility of future application within the National Health Service (NHS). The specific research questions were best analysed by a quantitative methodology due to the specificity of the methods (Aliaga & Gunderson, 2000) and to add to the existing evidence base.

3.2 Design

3.2.1 Statement of Ethics

Ethical approval was granted by City, University of London, Department of Psychology Ethics Committee, (Appendix B). Although there was no foreseeable risk of physical harm to participants there were possible psychological risks such as increased distress. The researcher was fully trained in relation to managing these difficulties and able to terminate sessions when appropriate or provide the relevant debrief information immediately. An extensive debrief session followed at the end of the research study and provide a further opportunity for carers to raise and discuss any residual concerns (Appendix C). Carers were reminded that participation was voluntary and that they could withdraw at any time without explanation. Carers were informed that confidentiality would only be broken if there were serious concerns that involved a risk to the carers or others in which case the relevant emergency service would be contacted. All participants were provided with standard mental health helpline contacts. An experienced clinician and academic, Dr Jessica Jones Nielsen (City, University of London, 2018) supervised the research (Appendix B).

The study was designed as a randomised waitlist control pilot study. The specific design was chosen as it is a good way of assessing whether an intervention works in a clinical or public health setting (Desveaux et al., 2016). Participants were randomised into an immediate treatment group (ITG) and a waitlist control group (WCG). The ITG received the TICIP intervention immediately and the WCG did not

receive any intervention. Following the ITG completing (6 weeks) the WGC crossed over to receive the TICIP intervention (see Fig 2).

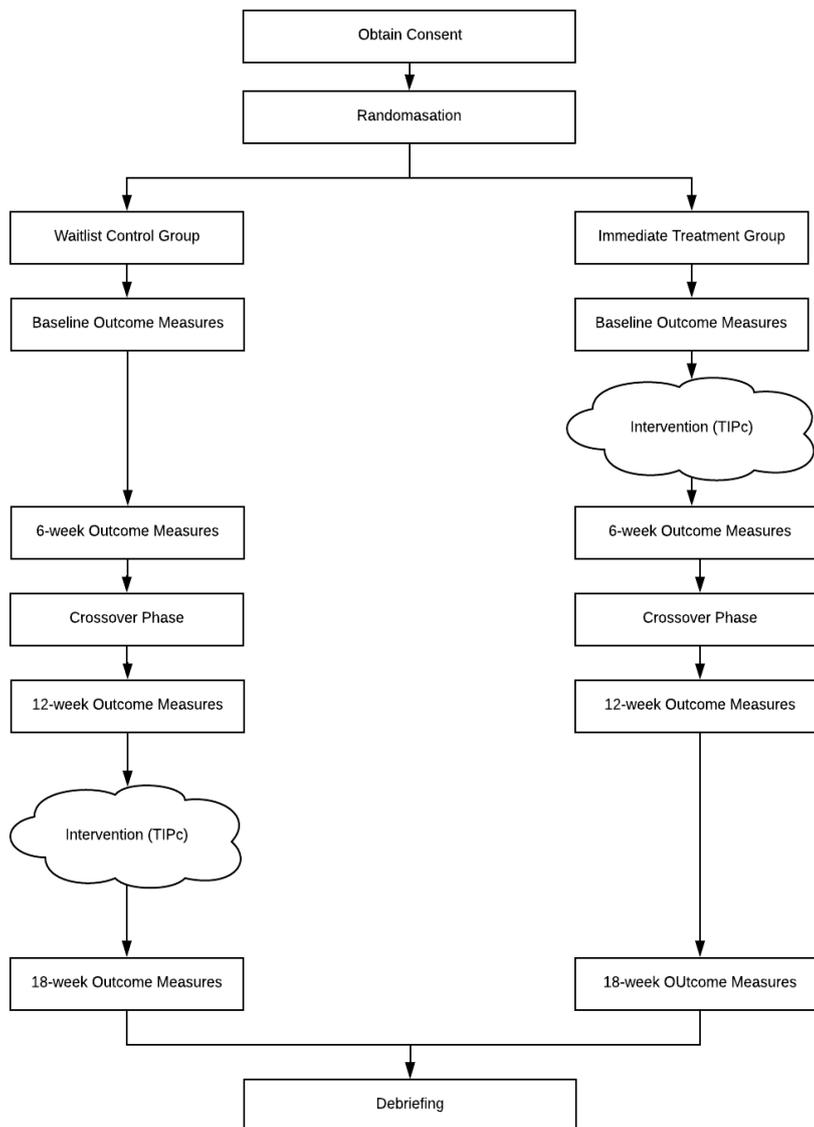


FIGURE 2: DIAGRAM TO ILLUSTRATE PARTICIPANTS STEPS IN THE TWO PATHWAYS (ITG VERSUS WCG).

Sample

3.2.2 Participant Eligibility

Participants were considered eligible for the study if they: (a) classified them self as a carer, through providing unpaid care to a relative or friend diagnosed with a psychotic illness, (b) were able to communicate sufficiently in English (both verbal

and written), (c) provided care within the United Kingdom, and (d) were over 18 years of age. For the purpose of this research carers were defined as follows: Residents of the United Kingdom (UK) providing unpaid care to a loved one/ friend/ family member but not as a paid employee (this does not include receiving a carers allowance or any social support).

3.2.3 Recruitment of Participants

Participants were recruited through advertisements (Appendix D) posted in local pharmacies, community centres, churches and via Carers Trust UK. The researcher contacted the establishments and provided them with a brief synopsis of the study and permission to post the adverts on their notice boards. The advert contained brief information about the study and included a contact telephone number and email for the researcher. If participants were interested in finding out more about the research or signing up, they were able to contact the researcher by telephone or email. The researcher would then post out an information leaflet (Appendix E), consent form (Appendix F) and prepaid addressed envelope. Participants were free to contact the researcher for further information or simply return the consent form (Appendix F) providing full written consent if they felt they had received adequate information and were keen to participate.

3.3 Clinical Outcome Measures

All the clinical outcome measures were standardised and had acceptable psychometric properties.

3.3.1 Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995).

The Depression Anxiety Stress Scale (DASS; Appendix G) is a 42-item self-report measure of depression, anxiety, and stress developed by Lovibond and Lovibond (1995). The DASS, which is used in a diverse range of settings, has been demonstrated to have very good reliability and validity, with demographic variables having little effect on the scores (Crawford & Henry, 2003). Specifically, α for the depression, anxiety and stress subscales were .91, .84 and .90 respectively (Lovibond & Lovibond, 1995). Brown, Chorpita, Korotitsch, and Barlow (1997) replicated these findings with a large clinical sample. The Depression Anxiety Stress Scale (DASS)

was developed for people aged 17 or older but has since been demonstrated as appropriate for younger age groups as well (McDowell, 2006). The DASS evaluates the severity of the core symptoms of depression, anxiety and stress (or tension) (Lovibond & Lovibond, 1995). Symptoms of hopelessness, dysphoria, devaluation of life, self-deprecation, lack of interest or involvement, anhedonia and inertia are all assessed by the depression subscale. Symptoms of autonomic arousal, skeletal and musculature effects, situational anxiety, and the subjective experience of anxious affect are assessed by the anxiety subscale. Finally, the stress subscale assesses symptoms of nervous arousal, getting easily upset/agitated, overreacting, having difficulty in relaxing, and impatience and irritability. The DASS provides a broad assessment of symptoms of psychological distress and has been extensively validated across a range of socioeconomic groups, and clinical and non-clinical populations, as well as in a variety of languages and cultural groups. The DASS continues to be recommended by researchers for its application in clinical assessments to identify emotional disturbance (MacDowell, 2006).

3.3.2 The World Health Organization - Quality of Life Brief (WHOQoL-BREF; WHOQOL Group, 1999).

The World Health Organization - Quality of Life Brief (WHOQOL-BREF) (APPENDIX H) is a 26-item self-report measure developed by The World Health Organisation (WHO) as a tool for use in clinical trials to assess physical, psychological health, social and environmental factors without impacting too greatly on the respondent's time (WHOQOL Group, 1999). The WHOQOL-BREF was developed with international collaboration to provide a cross-cultural measure of quality of life (Power, Bullinger, Harper & The WHOQoL Group, 1999). The WHOQOL-BREF is a well-validated measure that has performed well in extensive epidemiological studies (Skevington, Lotfy, & O'Connell; 2004) and has good psychometric properties with α ranging from .65 to .93 across the four domains assessed (Power et al., 1999). It has been validated across 23 countries with a very large sample ($n = 11,830$).

3.4 Procedure

3.4.1 Allocation/Randomisation

Participants were randomised into two groups (ITG versus WCG) with the aid of Research Randomizer (Urbaniak & Plous, 2013). This is a randomisation programme designed specifically for psychological and medical research purposes.

3.4.2 Quality Assurance

Two cognitive behavioural therapists - accredited by the British Association of Behavioural and Cognitive Psychotherapy (BABCP) trained in the administration of both the measures and the intervention - collected the data and provided the telephone sessions. Training included practice telephone sessions with the researcher, family, and friends. These sessions included data collection and working through the TICIP. The two clinicians completing the telephone sessions had weekly group supervision to discuss any difficulties that arose. The clinicians were able to contact the researcher for individual support on any aspect of the intervention, if required.

3.4.3 Session delivery outline of the TICIP

The TICIP intervention consisted of three modules, delivered over six weeks. Each module was completed over two sessions. The 50-minute sessions would (ideally) be delivered weekly, allowing enough time for the carer to assimilate the information and tools that they had learned whilst providing an opportunity to realise the new skills. It would require the clinicians to work flexibly at times that were convenient to the carer (including evenings and weekends).

The breakdown of the specific modules was delivered as follows: Following a welcoming process (5 minutes) the module was introduced, and the psycho-educational component presented and worked through. The carer was guided through the interventions' examples and then encouraged to explore their own relevant circumstantial examples. This protocol was repeated for all of the subsequent sessions. The delivery schedule of the TICIP shown in Table 1.

| Session | Module | Content |
|---------|--------|---|
| 1 | One | Introduction to the idea of 'caregiver burden' and introduction to anxiety, stress, and depression. |
| 2 | One | Review of the previous week and then move on to CBT and The Five-Aspects Model (Padesky, 1986). |
| 3 | Two | Review of the previous week including any difficulties or issues to be raised and discussed prior to moving on to the second modules of the intervention (TICIP). |
| 4 | Two | Review of the previous week, including any difficulties or issues raised and discussed. Review challenging behaviours and alternative ways of responding. |
| 5 | Three | Review of the previous week, including any difficulties issues raised and discussed, prior to the introduction of the final module. |
| 6 | Three | The final session briefly reviews the whole course, identifying and summarising the salient points (made relevant by using the carer's own material) and to debrief the carer/participant adhering to the correct procedure (Appendix B). |

TABLE 1: SESSION DELIVERY SCHEDULE

3.4.4 Data Collection

All data was de-identified immediately and coded numerically (i.e. 01, 02, 03) respectively on all materials/measures. All identifying material would be destroyed securely after publication. The self-report measures DASS and WHOQoLBREF were precompiled into an assessment pack and mailed out to participants. Participants had the choice to complete the measures in their own time and return them to the researcher in a prepaid envelope or to complete them with a researcher. This method enabled the researcher to prompt participants at the start of sessions, which, aimed to decrease the extent of missing data.

All participants provided the following personal data: gender, age, marital status, who is in the family, area of residence, employment status (if participants answered 'unemployed' they were then asked whether this was directly related to their caring role), their relationship with the individual with psychosis, and time spent with the individual with psychosis. Participants also provided the following patient information: diagnosis, time since diagnosis and current patient circumstance (e.g. inpatient/outpatient/first episode/longer term; Appendix I).

All participants completed outcome assessment measures at four time points (T1: pre, T2: post, T3, T4). Both the ITG and the WCG completed baseline outcome assessments (T1: pre). The immediate treatment group then completed the TICIP with a researcher for six weeks. During this time period the waitlist control group received no direct input from the researcher. At six weeks, both groups completed

outcome assessments (T2: post). Both the waitlist control group and the immediate treatment group were then crossed over. The waitlist control group then received the intervention (TICIP). There was a six-week washout phase. Following this, both groups completed outcome assessments (T3) at 12 weeks following the start date. For the immediate treatment group, the T3 outcomes acted as follow up data providing information on how well the effects of the intervention lasted. For the waitlist control group T3 data simply acted as a repeat baseline measure. The waitlist control group received the TICIP for six weeks whilst the immediate treatment group had no direct contact with the researcher. At 18-weeks both groups completed the same outcome assessments (T4). For the waitlist control T4 provided the post intervention data and for the immediate treatment group T4 provided data on the lasting effect of the intervention.

3.4.5 Sample Size: Pilot Study

There is contradictory information within the literature in relation to sample sizes for both pilot and feasibility studies (Billingham, Whitehead, & Julious, 2013). For example, a sample size of 12 per group is recommended as a rough guide by Julious (2005) whereas Browne (1995) recommends a minimum of 30 participants. In a comprehensive review of the literature Billingham, Whitehead and Julious (2013) conclude that for both feasibility and pilot studies a sample size justification is required, but that a formal calculation may not be necessary. In line with these recommendations the study aimed to recruit in excess of 12 participants, aware that by adopting a crossover design the n would be doubled.

3.4.6 Data Analysis

Analyses were conducted on an intention-to-treat basis; thus, missing data would not invalidate analyses. Analyses were performed on a MacBook laptop using SPSS for OSX (Version 24). The study utilised a 2 x 2 Mixed ANOVA analysis. Specifically, the independent variables (IV's) were 1: Condition with two levels (Intervention versus Control) x 2: Time with two levels (Time: Pre versus Post). The dependent variables (DV's) were the participant's scores on the Depression, Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995) and The World Health Organisation Quality of Life Brief version (WHOQoLBREF; WHO, 1998) at two

time periods (pre versus post). This would allow for the analysis of the intervention and all interactions. A series of One-Way ANOVAs were then used to assess the means on each DV across all four-time points (T1- pre, T2- post for ITG, T3- pre WCG, 12-week follow-up ITG, T4- post for WCG, 18-week follow-up ITG. It would also allow for replication of the initial findings and add further information about how long the effect of the intervention may last. Based on Jacobson, Follette, and Revenstorf's (1984) assumption that clinically significant change relates to an individual returning to a normative level of functioning following the clinical intervention, Jacobson and Traux (1991) suggest the following operationalisation which was therefore applied to the data: '*a) The level of functioning subsequent to therapy should fall outside the range of the dysfunctional population... b) The level of functioning subsequent to therapy should fall within the range of the functional or normal population... c) The level of functioning subsequent to therapy places the client closer to the mean of the functional population than it does to the mean of the dysfunctional population*' (Jacobson & Traux, 1991, p. 13).

Chapter 4: RESULTS

4.1 Participants: Recruitment, Retention and Characteristics

A total of 23 carers responded to the adverts (a total of 65.21% female versus a total of 34.78% male) (Fig. 3). However, when the researcher made initial contact with them, 5 declined once receiving further details (1 carer thought it was not relevant, 1 did not have time, and 3 did not provide a reason). 1 carer was excluded due to age (they were under the age 18), and 1 was not contactable. Therefore, a total of 16 carers were randomised with an age range 31-76 years (Mean = 48.8, SD = 12.51). The 16 carers consisted of 8 females and 8 males. However, it is worth noting that the carers that were excluded were female (mothers) indicating an overall greater response rate from females, which resulted in 30.4% female dropout. The sample consisted of brothers ($n = 3$), fathers ($n = 4$), step-fathers ($n = 1$), mothers ($n = 4$), grandmothers ($n = 1$), sisters ($n = 2$), and an aunt ($n = 1$). There were 6 carers not in work (retired: $n = 1$; total unemployed $n = 5$; unemployed as a result of caring $n = 3$). All carers resided in Sussex, United Kingdom. The most common patient diagnosis was psychosis ($n = 10$), schizophrenia ($n = 4$), and bipolar disorder ($n = 2$). Most relatives lived with the individual with psychosis ($n = 14$), and the remaining ones lived in either their own accommodation ($n = 1$) or local hostel ($n = 1$). The majority of individuals with psychosis were outpatients ($n = 13$), the remaining being inpatient ($n = 2$), and first-episode ($n = 1$).

4.1.1 Telephone Sessions

All participants allocated to the ITG group were initially offered 6 weekly 50-minute sessions with the clinician. Sessions were offered 6 days per week from 7am to 8pm during the week and 10am-4pm on Saturdays. Participants were given the option to book all 6 sessions at the start, or on a weekly basis. Sessions were normally provided on the carers mobile telephone, however, this remained flexible and could be changed at short notice. The TICIP intervention was designed to provide accessible, flexible, guided self-help, however, carers requests for reasonable support were usually met, provided it was within the allocated time and did not clash with the clinicians' other sessions (a clashing time was only requested once). 76% of carers preferred either evening or weekend sessions. Due to the time of the sessions

the clinicians were often at home whilst the sessions were conducted. Clinicians were required to have a separate quiet room and delivered the sessions on mobile phones provided to them by the researcher.

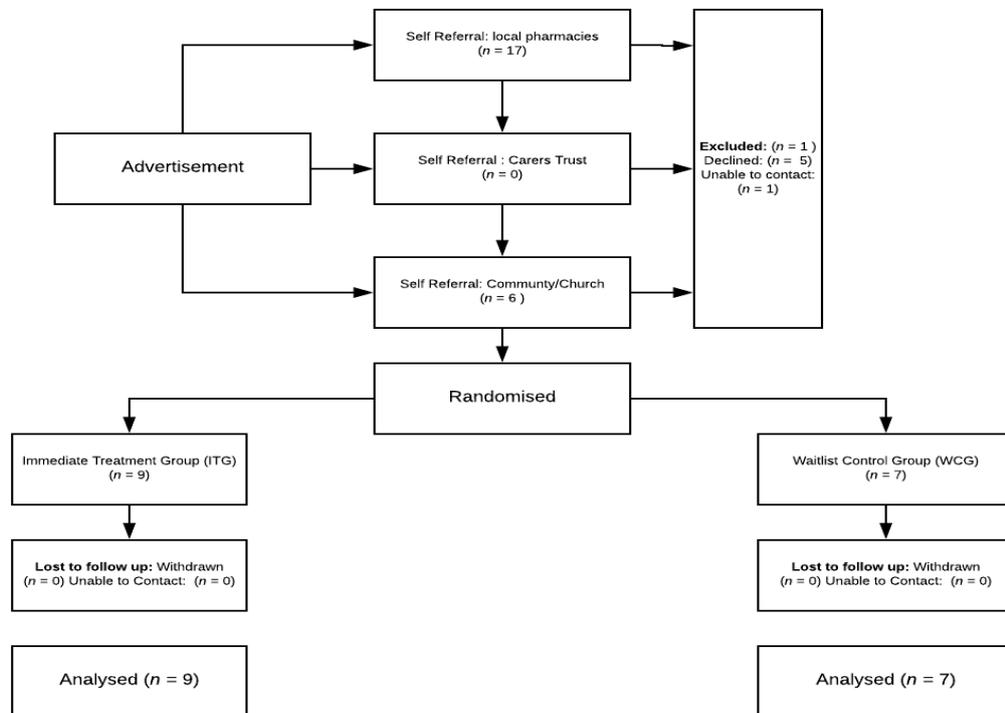


FIGURE 3: CONSORT DIAGRAM SHOWING FLOW OF PARTICIPANTS THROUGH STUDY

4.2 Main Outcomes

4.2.1 Depression, Anxiety and Stress

Baseline scores for depression, anxiety and stress (as measured by DASS) are shown in Table 2. Both the ITG and the WCG scores were within the significantly severe category for depression and anxiety (see Fig. 4 & Fig. 5) and the severe category for stress. At time point 2 (post intervention for the ITG) the mean scores had reduced to moderate for depression, anxiety and stress (see Table 2). This is in comparison to the WCG which showed no change. There was a significant main effect of time (T1 pre vs T2 Post) $F(1,14) = 28.54, p < .001$ and a significant interaction between time and condition, $F(1,14) = 30.85, p < .001$ for depression. There was a significant main effect of time (T1 pre vs T2 Post) $F(1,14) = 23.58, p < .001$ and a significant interaction between time and condition, $F(1,14) = 16.67, p < .001$ for anxiety. There was a significant main effect of time (T1 pre vs T2 Post) $F(1,14) = 16.67, p < .001$ and a significant interaction between time and condition, $F(1,14) = 16.67, p < .001$ for stress.

.001 for anxiety and stress respectively $F(1,14) = 21.963, p < .001, F(1,14) = 12.839, p < .005$. Following the participants crossing over the results were replicated at T3 (pre TICIP for WCG) and T4 (post TICIP for WCG). Furthermore, at T3 (12-week follow up for ITG) and T4 (18-week follow up for ITG) the effect remained significant $F(1,8) = 8.45, p < .05$. There was also a significant effect on carers self-reported anxiety, stress and depression scores across all four time points respectively $F(3,24) = 17.354, p < .001, F(3,18) = 14.711, p < .001$ and $F(3,24) = 25.700, p < .001$ (Fig. 6).

| Measure | Time 1: baseline (pre) Mean (s.d.) | Time 2: 6 wks. (post) Mean (s.d.) | Time 3: 12 wks. Mean (s.d.) | Time 4: 18 wks. Mean (s.d.) |
|-------------------------|------------------------------------|-----------------------------------|-----------------------------|-----------------------------|
| Depression: ITG | 28.4 (8.99) | 13.78 (9.74) | 14.44 (10.18) | 18.89 (9.4) |
| Depression: WCG | 29.57 (5.79) | 26.0 (6.66) | 28.4 (7.06) | 16.86 (2.91) |
| Anxiety: ITG | 23.3 (8.95) | 10.11 (6.75) | 12.00 (7.46) | 16.11 (8.92) |
| Anxiety: WCG | 27.14 (6.14) | 26.0 (5.03) | 28.2 (7.27) | 16.0 (5.71) |
| Stress: ITG | 30.11 (5.66) | 18.33 (6.94) | 20.7 (7.54) | 23.78 (6.45) |
| Stress: WCG | 30.43 (7.97) | 28.43 (7.01) | 29.71 (4.49) | 18.43 (5.15) |
| | | | | |
| <i>Extremely severe</i> | <i>Severe</i> | <i>Moderate</i> | <i>Mild</i> | <i>Normal</i> |
| | | | | |
| Measure | Time 1: baseline (pre) Mean (s.d.) | Time 2: 6 wks. (post) Mean (s.d.) | Time 3: 12 wks. Mean (s.d.) | Time 4: 18 wks. Mean (s.d.) |
| QoL: Phys: ITG | 19.22 (3.92) | 25.44 (3.84) | 23.33 (4.66) | 23.33 (3.5) |
| QoL: Phys: WCG | 18.43 (4.82) | 19.71 (4.30) | 19.43 (4.82) | 23.86 (2.41) |
| QoL: Psych: ITG | 15.11 (3.1) | 19.56 (4.69) | 10.11 (3.14) | 17.44 (3.94) |
| QoL: Psych: WCG | 16.43 (6.39) | 16.49 (4.67) | 7.43 (3.86) | 19.29 (1.79) |
| QoL Soc: ITG | 6.22 (2.81) | 10.11 (3.14) | 9.89 (2.84) | 8.67 (3.04) |
| QoL Soc: WCG | 5.43 (1.98) | 7.43 (3.86) | 7.71 (3.81) | 10.71 (1.79) |
| QoL: Enviro: ITG | 22.78 (7.20) | 28.67 (6.38) | 26.56 (6.48) | 24.33 (7.76) |
| QoL Enviro: WCG | 22.71 (7.27) | 23.71 (7.63) | 22.71 (6.55) | 27.43 (4.65) |

TABLE 2: MEAN SCORES FOR DASS AND WHOQoL-BREF ACROSS ALL TIME POINTS FOR BOTH THE ITG AND WCG GROUP.

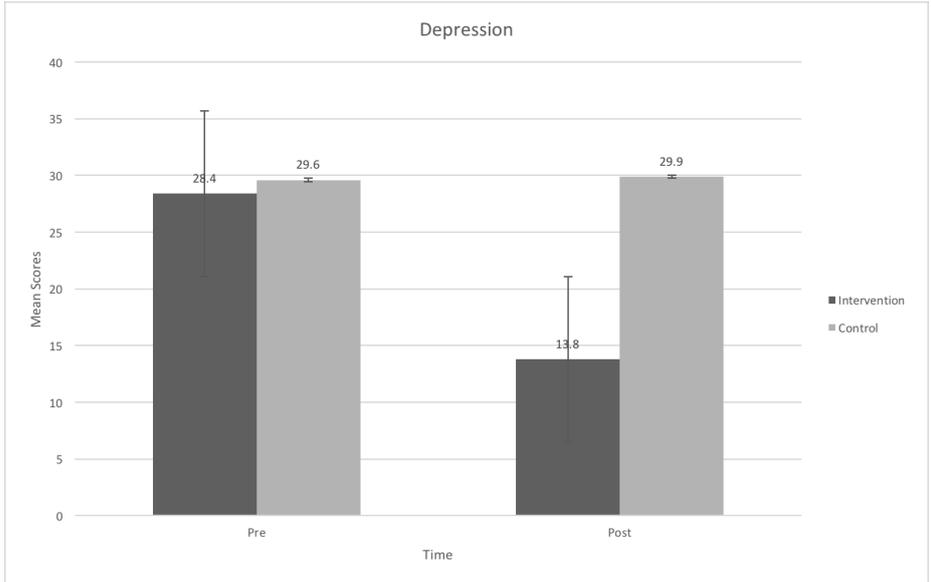


FIGURE 4: GRAPH TO SHOW MEAN DEPRESSION SCORES BETWEEN T1 AND T2.

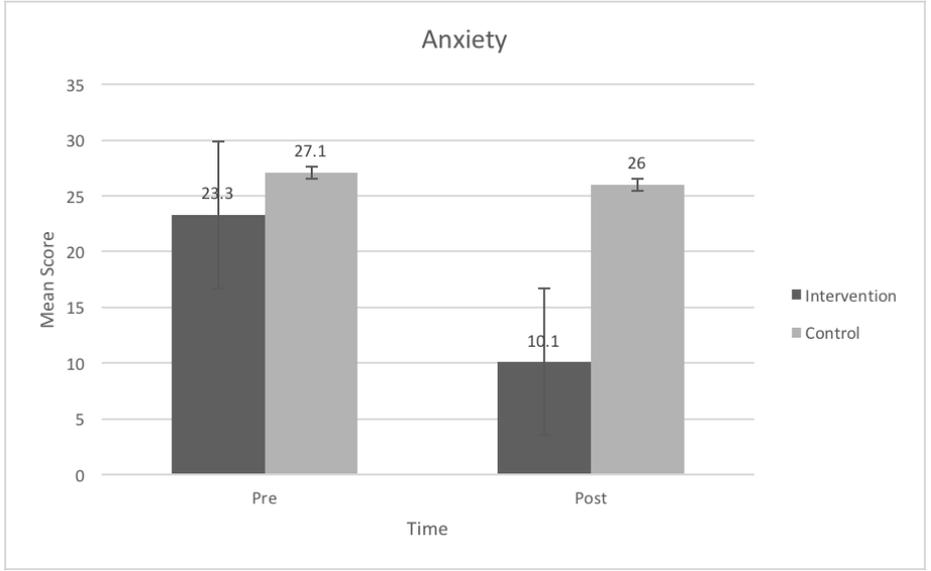


FIGURE 5: GRAPH TO SHOW MEAN ANXIETY SCORES BETWEEN T1 AND T2.

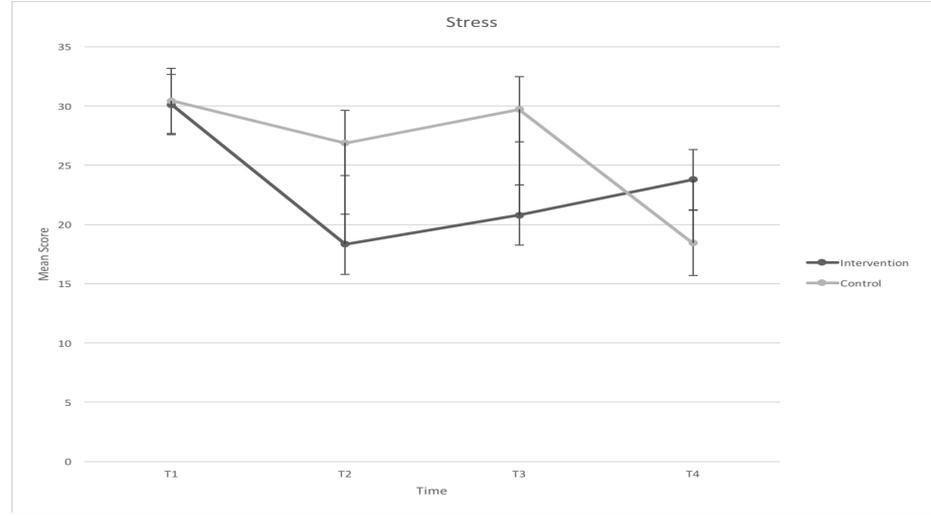


FIGURE 6: GRAPH TO SHOW THE MEAN STRESS SCORES ACROSS FOUR TIME POINTS

4.3 Quality of Life

4.3.1 Physical, Psychological, Social and Environmental Domains

Baseline scores for the physical, psychological, social and environmental domains of the WHOQoL-BREF are shown in Table 2. For the physical domain there was a significant improvement at T1 (pre for ITG) versus T2 (post for ITG) in quality of life $F(1,14) = 23.020, p < .001$ and a significant interaction between time and condition, $F(1,14) = 9.952, p < .05$ (Fig. 7). There were also significant effects for the psychological domain $F(1,14) = 6.287, p < .05$ and a significant interaction between time and condition, $F(1,14) = 8.133, p < .05$. There was a significant effect for the environmental domain $F(1,14) = 21.640, p < .001$ and a significant interaction between time and condition, $F(1,14) = 10.899, p < .005$. However for the social domain there was a significant increase in the stress for both the ITG and the WCG with a non significant interaction between time and condition, $F(1,14) = .943, p = .348$ $F(1,14) = 17.528, p < .001$. A comparison of scores across all four time points indicate a significant effect of the intervention across all domains in the WHOQoLBREF. Specifically, physical, social and environmental domains; with F's respectively $(3, 18) = 8.031, 9.398$ and 10.27 significant at $p < .001$. Finally, there was also a significant effect of the intervention in the psychological domain across all four time points $F(3, 18) = 5.643, p < .005$.

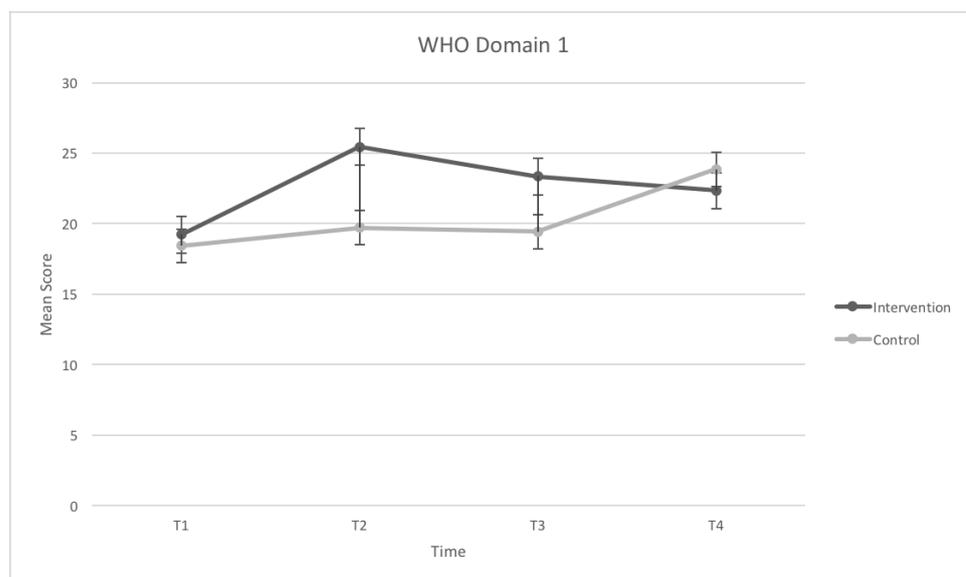


FIGURE 7: GRAPH TO SHOW THE MEAN SCORES FOR THE PHYSICAL DOMAIN OF THE WHOQoLBREF ACROSS FOUR TIMES POINTS

Chapter 5: DISCUSSION

Preliminary evidence from this small pilot study indicates that a remote telephone intervention for carers of individuals with psychosis (TICIP) may decrease mood disturbances and increase quality of life. Given that the study was small, the findings need to be interpreted tentatively and cannot be generalised. Nevertheless, within this small study, the anxiety, stress and depression of carers decreased following the intervention. This was maintained at the 12- and 18-week follow up for anxiety and depression. The ITG group, on the other hand, showed an increase in stress at follow up, though this remained significantly less than at baseline. This increase could be related to participation in the intervention, indicating that carers may need extra support or adjustments to the intervention for it not to increase their stress levels.

Despite a significant reduction in mood disturbances, all carers remained within the clinical range following the intervention. One possible way of interpreting the data would be to adopt similar methods to the NHS Increasing Access to Psychological Therapy (IAPT; Clarke 2011) service. NHS IAPT services record the outcome scores however, the individual does not necessarily need to score within the 'normal' range to demonstrate improvement. Depending on the level of severity at baseline, they aim rather to achieve a 'reliable improvement' (Clarke 2011). It is possible that due to the severity of the baseline scores (DASS) in this study, carers would require a longer intervention for their scores to fall outside of the clinical range.

Quality of life also improved significantly though it showed subtle variation across the different time periods. At this stage it is not possible to attribute the improvement of mood and quality of life to the intervention alone, however, there is consistent evidence that this kind of intervention is effective in both dementia and eating disorders (Goddard et al., 2011; Wilz, Schinköthe, & Soellner, 2011). There were other confounding variables such as the carers 'involvement' with the study that may have had an effect and need to be accounted for. Not only are psychosis carers more isolated than similarly matched non-carers (Hayes, et al., 2015), they are the most isolated subgroup of carers in comparison to carers in all other psychiatric disorders (Magliano et al., 2005). As a result of such severe isolation it is possible to speculate that the regular weekly telephone sessions per se may have had a

significant effect on the carers mood, though his needs further investigation. Research has shown that the telephone provides a very stress free and comfortable setting (Salfi, Ploeg, & Black, 2005) and that large numbers of carers would like to participate in telephone-based interventions (Ploeg, Biehler, Willison, Hitchison, & Blythe, 2001). The majority of research comes from literature and research evaluating interventions for carers in dementia (Wilz, Schinköthe, & Soellner, 2011) or general respite care (Ploeg, et al., 2001) but it is plausible that they could apply in psychosis. It is possible therefore, that the low rates of attrition are partly attributed to this. Carers that participated in the recent trial of a supported self-management programme (REACT), which was delivered online, provided qualitative data indicating a preference for telephone support and a printed document (Lobban et al., 2013). However, despite these encouraging aspects recruitment remained difficult and slow. This is similar to other research findings (Smukler, et al, 2003), although there is also contradictory evidence in the literature, with some research reporting easy and good recruitment (Barrowclogh et al., 1999; Lobban et al., 2013; Treasure et al., 2001).

5.1 Limitations of this Study

This was intended as a pilot study, not a large-scale study. The aim of the research was to develop and evaluate the TICIP designed by the researcher. Although the research focused on both specific and global outcomes, data on certain key outcomes such as ‘caregiver burden’ were not collected. Although this would have slightly broadened and expanded the aims, given the subject area, it would have been valuable. Furthermore, no qualitative data was collected which would prohibit a thorough evaluation of the intervention. Campbell et al., (2007) carefully outline the phases in the process from development to implementation of a complex intervention (Fig.1) as development, evaluation, implementation, and feasibility/pilot study, noting that the process is not linear and may move between the phases. This study moved between the development and evaluation phase, but requires further research, such as the assessment of acceptability, to enable a more consequential evaluation. ‘Acceptability’ for the purpose of this study is defined as how well an intervention will be received by, as well as meet the needs of the target population (Green & Kreuter, 1999; Steckler & Linnan, 2002). Acceptability should therefore have been

assessed during the development phase with the use of focus groups and interviews to better inform the development and structure of the intervention. During later stages of the development phase the same methods could also be applied to assess, for example, the acceptability of materials, content, presentation and format of the intervention (Freimuth & Mettger, 1990), all of which are crucial to the development and comprehensive evaluation of a complex intervention (Ayala & Elder, 2013). Assessment of acceptability is therefore an important complement to developmental research such as pilot studies (Gottlieb, 2006). To enable a comprehensive evaluation of the TICIP intervention (one of the aims of the research), an assessment of acceptability was necessary. To do more than design the TICIP and run a small pilot study, it was somewhat premature to begin testing the intervention prior to assessing acceptability. Given the limitations this represents for comprehensive evaluation, the researcher proposes returning to the development phase to assess and formulate a more comprehensive understanding of the intervention's acceptability.

A further methodological issue relates to the recruitment pathway. This could have benefitted from being broader to include a range of mental health charities such as Sane, MIND, and Rethink. It would also have been helpful to adopt a national recruitment strategy, which could have given rise to a more diverse and therefore representative sample. Furthermore, 'intervention fidelity' was not assessed. This is an essential component of assessing the viability and effectiveness of such interventions. A measure of fidelity would have provided information about the potential moderation of outcomes. Furthermore, there is research suggesting that studies that assess fidelity thoroughly have a statistically better chance of succeeding (Carroll, Patterson, Wood, Booth, Rick, & Balain, 2007).

This study was conducted as an open trial. It could therefore be concluded that the lack of researcher blindness may have resulted in bias (Robertson & Kesselheim, 2016). Thus, although the study does appear to have had a significant effect on mood disturbance and quality of life, the lack of sufficient methodological rigour has resulted in it being difficult to conclude whether this was a result of the intervention.

The study was designed as self-referral (with self-classification as a carer) for the primary reason of accessibility. However, this could have resulted in a lack of

consistency in terms of classification as ‘individual difference’ of the participants was not accounted for.

Service user outcomes were deliberately not assessed, as one of the main reasons for the TICIP was to develop a carer only intervention that was accessible to carers without service user consent. It is possible to hypothesise based on the cognitive model of caregiving in psychosis (Kuipers, Onwumere, & Bebbington, 2010) that service user outcomes would improve as a result of improved carer outcomes. This would, however, need further research and consideration. It may also detract somewhat from the purpose of the TICIP, excluding the most at need carers who are not able to access current services due to a lack of service user consent. Further data relating to 1) ethnicity, 2) the number of years spent caring, and 3) the number of individuals with psychosis (or other chronic mental health conditions) that are being cared for / are in the household, would also add further real world validity.

5.2 Clinical Implications

Interventions for carers are often dependant on service user consent which can lead to the carer being denied access to an intervention (Kuipers, 2010). The purpose of the TICIP was to avoid this; increasing carers access to necessary psychological support (interventions) without the needs for service user involvement.

The TICIP was developed as a guided self-help intervention so that it does not require the involvement of a qualified therapist. This should make it much easier to recruit individuals from a wide range of ethnic/cultural backgrounds and train them in the TICIP, in order to increase and widen accessibility further. Such expansion of access to carers only interventions is essential (NICE, 2014; Kazdin & Blasé, 2011), in which the linking of this intervention to primary care may prove a valuable strategy (Onwumere, Shiers, & Chew-Graham, 2016).

Given that the TICIP does not require a trained therapist, there may also be novel methods to increase implementation. This could include linking the TICIP to doctoral clinical psychology training programme requirements, which would be welcome in the current financial climate.

5.3 Future Research

Despite methodological flaws the TICIP did appear to reduce mood disturbances and increase quality of life in carers of individuals with psychosis, although this needs to be interpreted with caution. Recent research supports the experience of this research study in indicating that a paper document and telephone combine as the preferred method for carers to participate in interventions (Lobban et al., 2013). To take forward this much needed work, it would therefore be appropriate 1) to rigorously assess the acceptability of the intervention and make the requisite changes, 2) to account for the current flaws in the pilot study and adjust the methodology to include the collection of both qualitative and quantitative data and 3) to explore ways of widening the dissemination options (e.g training clinical doctoral trainees). With regard to future research: if, once the methodological flaws are corrected, and the TICIP still provides significant results, it would then be put to a larger trial. There is also the possibility of scaling out the approach in this TICIP intervention, by adapting it for carers of individuals with other mental health difficulties.

5.4 Conclusion

The benefits of FIPs for carers of individuals with psychosis are well documented, yet despite this only a very small percentage of eligible carers are a) being offered it and b) even less are receiving it (Haddock et al., 2014). There are a range of new approaches that have been reviewed extensively elsewhere (Kuipers, 2010; Onwumere et al., 2011; Onwumere et al., 2016). These include the break-up of full FIP treatment manuals/plans into brief stand-alone interventions, which do not need to be delivered by therapists (Cohen et al., 2008).

Within the growing understanding of the needs of carers, the TICIP was not designed to take the place of FIPs but to be used as an adjunct to the FIPs with carers that desperately need some form of support. This research study has also attempted to highlight the need for and value of carer only interventions: the TICIP was designed in response to this situation, and in factors outlined above, the initial data appears very promising as a basis for much needed interventions and for further research.

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Appendices

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Appendix I: Demographics/Patient Information Questions

Appendix A: Intervention Material

A guided self-help programme for those caring for a loved one with a psychotic illness.

We know that caring for someone with a psychotic illness can be very demanding and exhausting, often leaving you with no time for anything, let alone yourself. This can lead to anxiety, stress, low mood and often feelings of guilt. Just to say here, these feelings are a hundred percent normal, but it is easy to feel guilty for having them. Some people also experience stigma either directly towards them or around their loved one, which of course only adds to the strain of everyday life. This programme has been developed specifically for people that are caring for someone with a psychotic illness, to fit in with a demanding schedule and be as flexible as possible. One of the many things we know is that carers are often not able to attend groups so this programme is coming to you! No fancy equipment or overwhelming technology to grapple with, just a telephone and your time. This programme will give you a toolbox to help you look after yourself (something that is mostly forgotten) and lead to an overall better and healthier quality of life. The programme will involve three modules in total.

Carer Burden

Psychosis is a term used when a person appears to have lost touch (to some degree) with reality. This can occur in a variety of mental illnesses such as bipolar disorder (when mood is the main problem), schizophrenia, or from substance misuse. Every person will have their own unique picture of symptoms and experiences. However, there are some common types of experiences that occur, such as: hallucinations, delusions, confused and or disturbed thoughts and often people have a lack of insight, (a lack of insight means that they don't really recognise they are unwell). I will not go into detail about all the symptoms here, as there is more information later on. What I will focus on though, is how you, the carer, are also affected by your loved ones' diagnosis. There is lots of research about aggression and violence and how intimidated and vulnerable many carers feel. Carers put up with an awful lot from verbal aggression to physical threats, with some carers having their lives threatened. On top of this, carers often feel isolated and 'left out' of their loved one's care. These difficulties aside, research has found that carers actually struggle most with the negative symptoms of depression and low mood e.g. lack of motivation. Regardless of what you find most difficult to cope with, the aim of this is to help you look after yourself!

Module One

Anxiety, Stress & Depression

To get a little more specific we'll focus on anxiety, depression and stress and how these would be defined by a health professional. This may help you to label some of your feelings and experiences. Rest assured, the emotions you are feeling are completely normal, whatever they may be.

Anxiety

Anxiety is completely normal and is our bodies response to a specific or perceived threat. Adrenalin surges into the blood and prepares our bodies for action we could run, we could fight, or we could freeze- often talked about as the fight, flight, freeze response. If the threat is real then this system is amazing, quite probably lifesaving. However, due to the way our brains are wired, our body responds to threat in exactly the same way whether the threat is real or imagined. To add to this, when we feel unsafe, we continuously scan our environment for any possible threat. This means we are hyper-alert to anything that could pose a threat to us. When we are feeling anxious it is often because we feel under more pressure than we can cope with (in the jargon you may see this written as minimising our perceived ability to cope). Now, although the body's response is normal and a pretty good one at that (when you need it!) when you don't it can be horrible and at worst debilitating.

Too much anxiety affects us physically, it affects our thoughts, moods, and behaviours. The problems caused by anxiety are often a result of unhelpful thoughts (more in a minute) and behaviours; such as: avoidance (staying away from public places), preoccupation (thinking about something over and over again), and association (starting to think about everything together in relation to what is making you anxious). You may have noticed that you end up going around in circles- this is often referred to as a vicious cycle (we'll return to the cycles again later).

The Physical Side of Anxiety

As I mentioned a moment ago, our bodies will automatically respond to threat whether real or imagined. The body's response includes a combination of:

- Increased heart rate (this takes blood to where we need it most, remember the fight, flight, freeze response).
- You may breathe faster (this takes oxygen to areas that need it most- think about running away from a lion in Africa!). Tight chest, chest pain, feelings of choking, dizzy, and blurred vision.
- Your whole digestive system slows (as it's not a necessity when escaping from that lion!) Nausea, dry mouth and a sensation of 'churning' or 'butterflies' in your tummy.
- Muscle tension: Aches and pains from mild to severe and shakiness.

- Sweating (to cool down the hard working, tense muscles).
- Alertness (we become extremely alert to any possible dangers, scanning our environment continuously). We are noticing everything and anything, which is likely to increase our anxiety.

Are some of these sounding familiar? I thought so. Now these physiological reactions are super smart. From an evolutionary point of view, when we were cave men needing to escape a lion on the African Plains they were fabulous! However, nowadays when they occur in response to a small or even imagined threat, they can be pretty dire. The symptoms caused by the reactions above are listed in purple. As a result of experiencing some or all of these physical sensations we may do certain things to compensate (safety behaviours) or avoid doing particular things (avoidance). Examples include: avoiding certain places and / or people; avoiding going out the house; only going out the house with someone else; going out at particular times; managing to go out but using a number of 'strategies' to cope with the situation (that in reality are not very helpful but, feel like they are at the time! There our minds go again, playing tricks on us!) These strategies that are unhelpful in the longer-term include things like: having an escape plan, twiddling your hair, avoiding eye contact, smoking or consuming alcohol.

Our mind is now super alert and scanning for any possible threat. It also tends to play yet another trick. Our brains minimise our ability to cope whilst at the same time enhancing and exaggerating the threat. Great when you're in the jungle but less so when you need to leave the house or catch a bus!

Stress

So, having looked at anxiety in a little further detail we turn to stress. Stress is a word all too often used, but what does it really mean? Are stress and anxiety the same? Stress is basically your brain responding to a demand made on it. Stress can be short-term and / or long-term and can be both positive and negative. Obviously, the positive aspects of stress probably aren't interfering with your life, so we'll take a look at some of the negative aspects of stress.

We all (that's all of us, animals included) have what we call a stress response; we looked at this in the Anxiety Section, so we won't go into it again here (see Adrenalin Response above). Suffice it to say that the chemicals and hormones that are released by your body are preparing it for fight, flight or freeze. If you're experiencing these sensations in the short-term, they may not be having a terrible effect on your health; either physical or mental. However, when the stress response is constant, it can cause problems. Now, specifically for you as a carer, there are probably many stressors (triggers) that are always there (constant/chronic) and possibly others that occur for shorter bursts that add to your everyday stress. There are three types of stress commonly talked about: 1) Stress related to family life, caring, working, finances... you get the idea; 2) Stress that occurs as a direct result of something such as a divorce and 3) traumatic stress that is caused by something major like a natural disaster, or major accident. (Just to add here, there are a great many people caring for loved ones with psychosis who have felt that their lives have been endangered at some

point or faced very challenging behaviours, which could well have been a very traumatic experience). Whichever particular stressors or combination of stressors you have, our bodies react in a similar manner, though everyone's own symptom picture varies from one person to the next. Stress can manifest in physical ways such as headaches, digestive problems and/or sleep related difficulties. However, stress can also manifest as irritability and anger, depression, and/or anxiety disorders. Furthermore, long-term stressors weaken our immune systems, making us altogether more prone to infections such as colds, increase our blood pressure and our chance of developing diabetes and heart disease. As you can see, stress may be a little word, but it has an enormous effect on us. In a few moments we'll start to look at ways that YOU can reduce these difficulties.

For now, have a think about how all of this may affect you. It can be helpful to write, draw arrows (or whatever you find useful) on the diagram below.

Depression

Finally, we'll take a brief look at depression, as it can be hard to distinguish your feelings when your circumstances are very difficult. Firstly, depression is different from feelings sad, though it is very common and interferes with your daily life, making life difficult for yourself and other loved ones. As a carer, the impact of depression can be even greater for you and your loved ones. So, how did we get there? Well, there is probably a combination of different factors, such as psychological, environmental, genetic and biological ones, although psychological and environmental factors may play the greatest part for you as a carer. Remember earlier we talked about anxiety, well anxiety and depression can often occur together. Recall that feelings anxious may lead to you avoiding certain things, which then in turn may lead to isolation. Throw in the feelings of guilt, uncertainty and financial strain, mix it up and out comes depression!

There are a wide variety of symptoms and each person will experience depression differently. The common symptoms are losing interest in things that you had once enjoyed, fatigue, feelings of hopelessness, guilt and worthlessness. You may also be restless and irritable, find concentrating difficult and have problems with your sleep (too much or not enough!) Suicidal thoughts are common, as are physical symptoms such as aches and pains and sometimes even digestive problems. Without trying to rub it in, I think you get the idea.

Depression has an awful effect on you and makes your life and your role as a carer impossible. When carers are struggling, sometimes they are able to care for their loved one. However, every last bit of strength goes into this and your own needs get forgotten, quite probably not even given a second thought. Does that sound familiar? Unfortunately, as a carer you tend to neglect yourself. However, I hope that I've at least started to illustrate that the effects of neglecting yourself are awful and will make caring almost, if not altogether, impossible. I can't stress enough how important taking care of yourself is. So now we'll look at things that you can do to take care of yourself and hopefully decrease the symptoms of stress, anxiety, and depression as well as increase your quality of life. It doesn't matter one bit if you don't have a diagnosis, or only have a few symptoms; looking after yourself now can still improve your quality of life!

Cognitive Behaviour Therapy

Cognitive Behaviour Therapy (CBT) refers to how we **THINK** about things (including ourselves, other people and the world). It also refers to the things we **DO** when stressed which may have an impact on our thoughts and feelings. CBT focuses on difficulties in the here and now (not your past) and it finds ways to change how we think and how we respond. In doing so, we increase our sense of wellbeing, and reduce some of the negative symptoms that you may experience. CBT techniques can help you break a problem down into smaller parts. This allows you to deal with it bit by bit without being completely overwhelmed.

CBT divides everything up into five parts; these are: 1) the situation, trigger, event or problem; 2) thoughts; 3) emotions/ feelings; 4) physical sensations, and; 5) behaviour's (actions we take). All of these parts interact with each other, which explains how a situation (trigger, event, or problem) can have such an effect on how we are both physically (remember back to the Adrenalin Response) and emotionally (think back to depression).

The diagram below shows how this works across all of the Five Aspects (Padesky, 1986).

The idea is that in CBT, if you challenge a negative thought and come up with a more balanced alternative then this makes us feel better; our thoughts affect how we feel. Lets take a look at an example.

I had an interview (**SITUATION**) which triggered lots of unhelpful **THOUGHTS** such as: I'll make a fool of myself; What if I forget what to say? These thoughts make me feel anxious (**EMOTION**) so I read through my preparation notes for the hundredth time (**BEHAVIOUR**) whilst noticing that my heart is pounding (**PHYSICAL**). This feeds back into more **THOUGHTS** such as, they will judge me for being so nervous. All the different parts feed back into each other making the anxiety worse. You will see this set out on the next page.

In order to break this viscous cycle, we will try to challenge the unhelpful thoughts by presenting more balanced alternatives. We also look at modifying some of the unhelpful behaviours, and in doing so, we hopefully lower the emotional and physical distress.

Situation

This little section is all about: where, who with, when and how information.

Thoughts & Images

What went through my mind at that time? What upset, angered, and/or worried me?

Body / Physical sensations

This section is all about your body and how it reacts? What physical reaction(s) did you have? In what part of the body did you feel them?

Moods / Emotions

How did this make me feel emotionally? Can you name the emotion or the mood you experienced?

Behaviours

This bit is all about what you did- the way you behaved. Were these reactions automatic?

Here's another example: **before** challenging the unhelpful thoughts:

Situation

This little section is all about: where, with, who with, when and how information.

With my son rushing to an appointment when someone I knew ignored me when I waved

Thoughts & Images

What went through my mind at that time? What upset, angered, and or worried me?

I thought how rude she was to ignore me. I then started to worry that maybe I'd done something to offend her and she was deliberately ignoring me.

Body / Physical sensations

This section is all about your body and how it reacts? What physical reaction(s) did you have? What part of the body did you feel them?

At first my heart started to beat faster and harder and my head felt hotter! Then I felt a tight sick feeling in my tummy, it churned.

Moods / Emotions

How did this make me feel emotionally? Can you name the emotion or the mood you experienced?

Angry, embarrassed, anxious,

Behaviours

This bit is all about what you did- the way you behaved. Were these reactions automatic?

I got really annoyed and stopped what I was doing as I wanted to go and say something to her. But then, I just quickly walked away as fast as possible in case I had offended her. I ducked into the nearest shop to make sure I wouldn't pass her again and decided to avoid walking past her house again.

Here's another example: **after** challenging the unhelpful thoughts:

Okay, so now let's go through the same example altering just one aspect at a time. So keeping the situation the same let's try and challenge our **thoughts**- what would the alternative be to your original thoughts? The balanced thoughts are in pink.

Situation

This little section is all about: where, who with, when and how information.

With my own son rushing to an appointment when someone I knew ignored me when I waved.

Thoughts & Images

What went through my mind at that time? What upset, angered, and or worried me?

Unhelpful Thoughts: I've offended her

Balanced Thought: She could be in a rush

Can you think of any other unhelpful thoughts and more balanced alternatives?

Unhelpful Thoughts:

Balanced Thought:

Unhelpful Thoughts:

Balanced Thought:

Body / Physical sensations

This section is all about your body and how it reacts? What physical reaction(s) did you have? What part of the body did you feel them?

Heart Rate, Sweaty, Hot

Moods / Emotions

How did this make me feel emotionally? Can you name the emotion or the mood you experienced?

Angry, embarrassed, anxious,

Behaviours

This bit is all about what you did- the way you behaved. Were these reactions automatic?

Duck into shop (AVOIDANCE)

Okay, using the same example, let's go through the same situation and this time we'll change our **behaviours**. Again, the idea in CBT is if we modify some of our unhelpful behaviours and introduce more constructive ones, then we feel better in the long run.

Situation

This little section is all about: where, with, who with, when and how information.

With my son rushing to an appointment when someone I knew ignored me when I waved

Thoughts & Images

What went through my mind at that time? What upset, angered, and or worried me?

I've offended her

Body / Physical sensations

This section is all about your body and how it reacts? What physical reaction(s) did you have? What part of the body did you feel them?

Increased heart rate, Very hot

Moods / Emotions

How did this make me feel emotionally? Can you name the emotion or the mood you experienced?

Embarrassed, Angry, Anxious

Behaviours

This bit is all about what you did- the way you behaved. Were these reactions automatic?

Unhelpful behaviour: Duck into a shop (AVOIDANCE)

Modified behaviour: Approach and say hello

In the space below try and think of some other unhelpful behaviours and then how you could modify them.

Unhelpful:

Modified:

Unhelpful:

Modified:

Unhelpful:

Modified:

There's a blank template for you on the next page. Let's try and have a go with an example that is relevant to you before we move on.

Using the above example, we can see that if our thoughts are more rational and balanced, as well as our behaviours more constructive then the difficult emotions and physical sensations reduce; we feel less anxious or angry, with less palpitations and no longer feel hot.

Let's look at some other things we can do. Now these are not all instant fixes but the more you do them the more they help. Remember after your telephone session it will be your turn to try some of these!

Situation

This little section is all about: where, with, who with, when and how information.

Thoughts & Images

What went through my mind at that time? What upset, angered, and or worried me?

Body / Physical sensations

This section is all about your body and how it reacts? What physical reaction(s) did you have? What part of the body did you feel them?

Moods / Emotions

How did this make me feel emotionally? Can you name the emotion or the mood you experienced?

Behaviours

This bit is all about what you did- the way you behaved. Were these reactions automatic?

Ways to reduce difficulties- drawing on your own inner resources.

Well, anxiety and stress increasingly build up the longer they are left unchecked. The tools that we're going to look at should help whether you are stressed, anxious or depressed, but it's important to remember that if your mood drops or you begin to feel suicidal that you contact your GP. There are also a variety of organisations that you can call if you are in crisis. I'll pop these in at the end so don't worry.

A first step is to start paying attention to yourself. This will help you to name some things that may trigger feelings before they overwhelm you. How do you feel? Ask yourself questions along the way, sometimes even keeping notes or a diary. This can feel like a strange thing to do but with practice, it can help alert you to the triggers and symptoms before they build up and you erupt like a volcano! Making time to check in with yourself is a vitally important part of selfcare. People have different methods for checking in so it's important to find the one that works for you. Different tools do the same job, so it's about finding the tool that is right for you.

So let's start adding tools!

Checking In:

It's really important that you ask yourself how you're doing every day. This will help you to notice your body's stress response and eventually (using other tools) put a hurdle in front of stress! People find many different ways to check-in with themselves. I particularly like my two-minute duvet day. By this I mean I lie in bed for two minutes (normally first thing in the morning), I pull the duvet up to make it quiet and private and I just lie there for two minutes asking myself how I feel. There's no right or wrong answer and it may seem quite weird at first but having a quick and easy way to check in means that you won't forget yourself.

Try lying in bed for 2 minutes with the duvet over you & ask yourself how you feel...

Goals

Another really important thing to do is to set yourself goals. Now, this may sound really silly. Setting a goal (writing it down) seems to help people to keep to it. It may be that your goal for the week is to give yourself a two-minute duvet day every day or to eat an extra piece of fruit every day. Goals should be achievable (so not climbing Mt Everest!) and specific. Note I said eat an extra piece of fruit everyday rather than just eat more fruit. For some reason (we won't go into the science bit here, don't worry) this makes it easier for us to do! Set yourself goals for the day, the week and the month at the most but don't go further than that- it helps to keep it in reach.

So, set yourself a variety of goals to work towards. You need to break up the 'getting there' bit into lots of bite sized pieces (preferably Terry's chocolate orange pieces!).

My TODAY Goal:

What I need to do to achieve this?

My goal for this week:

What I need to do to achieve this?

My goal for this month:

What I need to do to achieve this?

Prioritising & saying NO!

Something else that's really important and prevents us from feeling overwhelmed by everything is to make a list of things that you have to do. Then put them in priority order. It may be that some things can wait (tidying the lounge) but others (attending a hospital appointment with your loved one) are fixed and must be done. It's hard to do when there is heaps going on and sometimes we prefer not to think at all (avoidance). In the long run this only makes things worse. I have a daily list of things and a long-term list of things. I try and sort the things out as they come into my mind or when I get asked to do them. This helps with the next bit: saying NO.

When we are caring for someone else it's so easy to forget about yourself and your needs, thus no is often a very unfamiliar word. However, you need to try and use it. Saying no when you are at your limit can be the difference between feeling as though you are coping and feeling completely overwhelmed. And thinking back to those cycles we looked at earlier - one thing has a real effect on another.

Try and get into the habit of completing these and updating them regularly. Here's an example, there are blank ones at the back.

TODAYS LIST (DATE)

LONG TERM LIST

If it helps you, it's okay to number the items, but you don't need to!

Staying healthy

Another thing that helps with anxiety, stress and depression is exercise. Now I'm not going to bang on and on about the sciencey bit but here is just a little: exercise causes your brain to produce endorphins, the 'feel good' chemical. Endorphins have been shown to reduce pain (physically and psychologically) and help to alleviate symptoms of stress, depression and anxiety. Now, this could be walking, or anything that you can realistically fit in. It's much better to do 10 minutes of exercise everyday (back to the sciencey bit- as this means those chemicals are being pumped into our bodies regularly) rather than an hour every week. So, try and think of ways to incorporate some activity into your day- you could even walk up and down your stairs!!! We'll look a little more at ways to fit this in shortly.

I'm also including the NHS recommended healthy eating guidelines as what we eat and drink can make a big difference to how we feel, think and behave- remember back to the Five Aspects (Padedsky, 1986) we looked at earlier. Remember just making a few changes can make a big difference! Caffeine and alcohol can also exacerbate symptoms of anxiety and low mood.

So, try to eat:

- plenty of fruit and vegetables
- plenty of bread, rice, potatoes, pasta and other starchy foods - choose wholegrain varieties whenever you can
- some milk and dairy foods
- some meat, fish, eggs, beans and other non-dairy sources of protein
- just a small amount of foods and drinks high in fat and/or sugar

Daily Achievements

Finally, the last thing that I'm going to suggest you do is every night take two minutes to think about what you have achieved during the day. When things are really tough, and we feel overwhelmed by life, our brains often forget all the things we have actually done. It's really important to remind yourself of everything you've achieved that day; however small, it's an achievement!

Here's an example of an activity to do (again blanks at the back). Try and do this daily or at least make a written note of them. Try and fill in as many stars as you can every day

Module Two

Dealing with challenging behaviour

Okay, so we're moving on to the next bit which is more about practical things that may help you to deal with some of the difficult and challenging aspects of a loved ones' behaviour. In this section we'll look at how we can cope better in ourselves, by building and increasing our resilience to certain challenges (sometimes there are specific behaviours such as self harm and sometimes it's the day-to-day things). The things in this section aren't necessarily an exhaustive list but are the things that I've most commonly been asked by carers or that carers have said they find really difficult. There are many other challenges that you may face that require more specific help and support, such as if a loved one is stealing from you or using illicit drugs. However, although this won't solve all these challenges, it may give you the strength to seek further support that you may need and are entitled to whilst looking after your general well-being. For each behaviour, we'll have a look at some helpful and unhelpful responses. Again, it's important to reiterate the significance of looking after yourself, as if you are feeling slightly less overwhelmed, we tend to think more clearly and can avoid automatic emotion led reactions which may cause an argument.

Staying in bed/low mood/isolation

It can be very hard when somebody is in their room and doesn't want to come out. As a carer we automatically try and help and encourage the person to come out. There are different reasons why someone may stay in their room. Sometimes the medication they are on can make them feel pretty groggy and sleepy. Also, sometimes being unwell makes you need more sleep- just like if you have a physical health problem. There could be things related to their mental health too, low mood and possibly strange thoughts. If you've tried a few times and they remain in their room, it may be better to leave them there for a while. Although it's really hard, it can be the best option. You could take this moment to do something nice for yourself. Now, if this has taken you by surprise, it may be that you go and sit and have a cup of tea, check-in with yourself or do some exercise (remember that exercise helps to make you feel better!) If this is a more regular occurrence, you could maybe start to factor this into your day and allow yourself 'me time'. You need to be explicit about this, explaining that you are going to the park, for coffee, to visit a friend and that you will be back again in 30 minutes. Looking after yourself is probably the best thing we can demonstrate to someone. Taking a short break away from the situation can alleviate some stress and tension that, if allowed to grow could result in an argument.

Lack of motivation

Hmmmmmm. Now this is another tricky one and can be pretty hard to tease out from the above. It can be a very useful tool to ascertain how a loved one is doing. Often someone who appears to have little or no motivation may be struggling more-so than they are able to say. They may be struggling because the world outside the door for example, feels a very scary place. They may feel hopeless, confused, have delusional beliefs, or a mix of everything. Therefore, if we continue to encourage them to go out, it can lead to anger and frustration,

which is often how someone who is scared will behave. At the same time, you're just wearing yourself down. You could make a few different suggestions, but if they are all turned down, give yourself a break. A very useful tip is to make very specific suggestions, as these are often easier for the sufferer to comprehend. For example, opposed to suggesting they get some fresh air you could suggest that you both go to have a look at X or go and feed the ducks.

When someone is unwell and you're under pressure it's very easy to become frustrated at their inactivity. However, whenever possible, ignore the negative things they do (or don't do) and rather praise them when they do something positive. Here's the science bit again-when we praise someone, it releases dopamine in their brain which actually starts to make them feel better. Dopamine is a neurotransmitter that has an effect on many different things, such as rewards and motivation. Therefore, being able to praise someone, even for achieving something very small, will start to help them feel better. Now, this also works for you! Remember when we looked at the section on thinking about your achievements at the end of every day!

Another useful thing to do is try and have a daily routine. This can be planned out and displayed on an activity planner (included at the back). Once you have a regular pattern, for example cleaning, you could start to ask them to help you. Again, keep it very specific, such as, "could you clean the kitchen sink", or "could you pop the vegetables in the cupboard".

When our mood is low it tends to affect our appetite. Now in depression it can make you lose your appetite or overeat. However, medication for psychosis actually increases people's appetite, which is often why weight related issues become a problem. One handy thing to do is to have as little treat/snack food in the house as possible. Your loved one may tend to gravitate towards eating snacks on their own rather than meals, so if you can prepare healthy snacks it could be a real help.

Living with delusional beliefs

In psychosis, people can often suffer from what we call delusions or delusional beliefs and these beliefs may cause strange behaviour(s). It is very tricky to be around someone who has a very firmly held belief (that you know is deluded). One of the best things to do is to acknowledge how scary/difficult it is for them but also suggest that this may be related to the psychosis (or mental health). What you don't want to do is go along with their delusion because it will make it even harder for them to distinguish what is real or not. It is very important to acknowledge their distress, but it is equally important to state that you think the cause of their belief is psychosis related without colluding with their delusions. However, you also need to try and avoid arguments and confrontations by challenging these directly. A good option is to sidestep the actual belief with a distraction. Sometimes this can be changing the subject, putting on a particular DVD or CD or doing a particular activity. It can be very tricky, as sometimes the conversations themselves may not make any sense. It's important to calmly let them know this and assure them you will come back to discuss it again later. Delusional beliefs are a reality to the person. They can often be paranoid and cause enormous amounts of anxiety; you would be terrified if you thought the government were sending someone to assassinate you. Again, try and reassure them that you can see why

they are so anxious but gradually start to suggest the role of their psychosis.

As I mentioned above, if you or other family members are at the centre of paranoid delusional beliefs, I would recommend talking to your GP for further advice and guidance. It may be that a partner or friend needs to provide the reassurances and start to introduce the possibility that the beliefs are related to psychosis.

Aggressive and or violent behaviour

Research shows that it is very rare (even when psychosis is severe) that someone is aggressive or violent to others. Normally, they pose a greater risk to themselves.

However, sometimes, especially if you have become part of their delusional belief(s), people may become very suspicious and this could lead to increased anxiety and aggressive behaviours.

The recommended advice is to take any threat seriously:

- Ask the person firmly and calmly to stop
- Do not argue
- Move away from surrounding area
- Leave the house if needs be
- Call police (999).

Now, obviously you will not necessarily have to go through all these stages. However, it's important that you feel able to follow them should you need to. Sometimes people are too worried to call the police but if the person is behaving in an aggressive way because of their mental health, then they will not be treated like a criminal. Police stations have little areas that are places of safety (Section 136 suites) where the individual will wait and have further psychiatric input. If things don't escalate to this degree it is very important that you do inform the team responsible for your loved one's care or your GP, as they may need to adjust the care they are providing. Remember you are helping and supporting your loved one by doing this as they will get the help and support they need.

Self-harm

A very common fear when a loved one is self-harming is to worry that they want to end their life. This is not always the case. Many people self-harm as a coping tool. As a carer, you may self-harm as a coping tool.

What is self-harm? (The information here has been published with permission from 'mind'. If you would like to have a look at any of the 'mind' resources yourself, you can find them at www.mind.or.uk).

The Viscous cycle of self-harm

Self-harm is when you hurt yourself as a way of dealing with very difficult feelings, old memories, or overwhelming situations and experiences. The ways you hurt yourself can be physical, such as cutting yourself. They can also be less obvious, such as putting yourself in risky situations, or not looking after your own physical or emotional needs.

Ways of self-harming can include:

- cutting yourself
- poisoning yourself
- over-eating or under-eating
- burning your skin
- 1. inserting objects into your body
- 2. hitting yourself or walls
- overdosing
- exercising excessively
- scratching and hair pulling.

After self-harming, you might feel better and more able to cope for a while. However, self-harm can bring up very difficult feelings and could make you feel worse.

If you self-harm, you may feel embarrassed or ashamed about it. You might be worried that other people will judge you or pressurise you to stop if you tell them about it. This may mean that you keep your self-harming a secret. This is a very common reaction, although not everyone does this.

Why do people harm themselves?

There are no fixed rules about why people self-harm. For some people, this can be linked to specific experiences, and be a way of dealing with something that is happening now, or that happened in the past. For others, it is less clear. If you don't understand the reasons for your self-harm, it's important to remind yourself that this is OK, and you don't need to know this in order to ask for help.

Any difficult experience can cause someone to self-harm. Common causes include:

- pressures at school or work
- bullying
- money worries
- sexual, physical or emotional abuse

- bereavement
- confusion about your sexuality
- breakdown of relationships
- an illness or health problem
- difficult feelings, such as depression, anxiety, anger or numbness, experienced as part of a mental health problem.

Some people have also described self-harm as a way to:

- express something that is hard to put into words
- make experiences, thoughts or feelings that feel invisible into something visible
- change emotional pain into physical pain
- reduce overwhelming emotional feelings or thoughts
- have a sense of being in control
- escape traumatic memories
- stop feeling numb or disconnected
- create a reason to physically care for yourself
- express suicidal feelings and thoughts without taking your own life
- communicate to other people that you are experiencing severe distress.

What can friends and family do to help?

This section is for friends and family who want to support someone they know who self-harms.

Be supportive

There are lots of things that you can do to make a difference to someone you know who self-harms. Your attitude and how you relate to them is one of the key things that can help them feel supported.

Things that you can to help include:

- Let your friend or family member know that you are there, if and when they are ready to talk. It is common for people to worry that they will be judged for their self-harm or that they will be a burden on others, so it's important to let them know you are there for them if they want
- Show concern for their injuries, but at the same time, relate to them as a whole person rather than just someone who self-harms.
- Offer them a chance to talk about how they are feelings. Try to understand and

empathise with what they are saying even when it is hard to hear.

- Try to understand that they may be scared of stopping self-harm if they use it as a way of coping. If they are finding it hard to stop, try to help them find other ways of coping and to seek help if they need it.
- Let them be in control of decisions about support and any plans to reduce or stop their self-harm.
- Emphasise other parts of their life where they are doing well, and the good qualities that they have.

Have an honest conversation about staying safe

It is common to feel scared about the possibility of someone you care about seriously hurting themselves or even committing suicide. While it is understandable to have these fears, it is useful to remember that self-harm doesn't necessarily mean that someone wants to end their life.

There are, however, a small number of people who do go on to take their own lives, either intentionally or accidentally. It's therefore important to have an honest conversation with your friend or family member about staying safe – for example, being aware when things are getting too much and knowing when to seek help.

What can friends and family do to help?

Take care of yourself

Finding out that someone you love and care about is self-harming can be a very shocking and upsetting experience. And supporting someone who is self-harming can be a long process with many ups and downs. It's important to take care of yourself – this will help you to be able to stay involved for longer and avoid becoming unwell yourself.

You might find these suggestions could help:

- Try to have clear boundaries about how much and what sort of support you can offer.
- Find out what other support is available, so you are not the only source of support.
- Get support for your own feelings Lots of organisations offer information and support to people who are concerned about someone else's self-harm, or you may find it helpful to try a talking treatment if you are finding things difficult.

Threats of suicide

If your loved one has made or appears to be making an attempt on their life you need to get help. Always treat it seriously. Contact: Police or ambulance on 999. It's very important that you tell your loved one that you are calling for help and always be consistent. This can be very hard if your loved one has made numerous suicide attempts. A very common reaction is that people around them start to feel that they are being manipulated which can cause feelings of frustration, anger and guilt often all mixed up together. Wherever possible try and avoid arguing as this just makes the situation worse, and try to remain consistent. You

need to get help but, remember you are not responsible for their behaviour. Whatever you do, don't agree to any bargains or deals and or keeping of secrets. This puts you in a very difficult position and is not good for your loved one. They need help urgently and not receiving it will only exacerbate the problems. They really do need professional help. Despite this sometimes due to your loved one having a lack of insight or due to their delusional beliefs they may try very hard to bargain with you in an attempt to stop you calling for help. Stand firm, stand strong. It's not easy but you've got this far!

There have been a variety of things mentioned throughout this module. Hopefully some will be of use to you. It's really important to try and practice these things so they become more familiar. Although it can be very scary, it is for your own wellbeing and also for your loved one (even if they don't see it right now).

So let's choose a suggestion to focus on for the coming week whilst still keeping up with last week's activities.

Choose a behaviour that you are finding most challenging to cope with and using some of the ideas listed above, think about how you could manage it differently.

Module Three

The balancing act

You've reached the final section of the programme. Congratulations on doing so well! I hope so far you've found some of the tools and advice both interesting and helpful. I guess for me, what I wanted to leave you with by the end of this programme is a kind of plan. A plan for yourself for the near future that incorporates some of the tools we've looked at over the past few weeks and ways you can make them part of daily life. Believe me, the more you practice them the easier they become and the more use you will find them! I also wanted to encourage you to think about a crisis plan. There are a few reasons for that. As we know from the first section, when we are frightened our adrenalin response kicks in. This often results in our minds going blank. Yep, it's that all too familiar feeling where you have absolutely no idea what to do or where to turn. Having a crisis plan that you've prepared means you can follow it step by step if your mind goes blank and you will have all the information and telephone numbers you may need right there, altogether. Another reason is that if you've thought about various different scenarios and are prepared for them you will find it easier to cope with should it occur.

At the end of the manual there is plan with all the details you should need. Take some time to fill it out. Whilst preparing the following here are some things to think about.

Things that have really helped or I have enjoyed doing the most

It sounds really obvious, but it really can help to take a minute and think about the things that you have done that work for you. It may be for example that you've found having a daily schedule is really helpful for both you and your loved one. It may be that there is a particular CD or herbal tea that you find really enjoyable or relaxing. Again, making a note of these can prompt you to act accordingly when you are too busy to think straight! So, let's think about the future and how we may start to put this altogether.

Have a think and make some notes for the following questions:

What things have I found helpful when I've been anxious, depressed or stressed?

What are my own inner strengths? How can I nurture these?

What support do I have, and could I delegate some tasks?

The good bits about caring!

What can I do if I become completely overwhelmed?

It is also worth having a think about what you can do if you feel completely overwhelmed. You could also be in crisis and need support. Importantly think about what your triggers are... Then you can move on to have a think about how you could respond to these triggers in a way that is both kind and helpful to you rather than unhelpful.

My Triggers:

How I can respond to these triggers:

I'd like to leave you with something that I use often for myself and with patients. Again, you can find a blank one of these at the back.

Think about and try to visualise a tiny little sunflower seed. Now, in order for that seed to grow and survive you need to nurture it. In order for the seed to flourish you will also need to nourish it and give it time. Now imagine you are that seed. What do you need? How will you make sure you flower year after year? (I've included some examples: Watching films, Going swimming and seeing friends).

Lastly...

.. I hope that you have found some of this useful and I thank you for allowing me to share in the challenges and difficulties you have faced.

Contact Numbers:

I'd like to also take a moment to point out a few contact numbers that you may find useful in your journey.

Carers Trust: A useful resource for information for carers on rights and benefits. 0844 8004361 (Mon-Fri 9-5) www.carers.org

Mind: a mental health information service. 0300 123 3393 or mind.org.uk

NHS Carers Direct: 0808 8020202

Samaritans: A mental health support line 08457 909090 (24 hours).

The 'Mind' info line will be able to put you in touch with specific support or services available in your area.

Extra Notes:

PLANNING (for and preventing CRISIS)

My plan for noticing my triggers: What I will do when I notice them?

My Plan for what to do when everything is starting to get too much:

Things to do:

People to Contact:

My Plan for what to do if I am in a complete panic/crisis:

Things to do:

People to Contact:

Contact Numbers:

Appendix B: Ethics



Psychology Research Ethics Committee
School of Arts and Social Sciences
City University London
London EC1R 0JD

15th October 2015

Dear Khanya Price-Evans

Reference: PSYETH (R/F) 15/16 251

Project title: Caring for a loved one with psychosis: A preliminary evaluation of the feasibility of a novel telephone-based intervention to reduce anxiety, stress, and depression, and increase quality of life in carers.

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

- (a) Recruit a new category of participants
- (b) Change, or add to, the research method employed
- (c) Collect additional types of data
- (d) Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee (██████████), in the event of any of the following:

- (a) Adverse events
- (b) Breaches of confidentiality
- (c) Safeguarding issues relating to children and vulnerable adults
- (d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Hayley Glasford
Student Administrator
Email: ██████████

Katy Tapper
Chair
Email: ██████████

Appendix C: De-brief Information

Caring for a loved one with psychosis: A preliminary evaluation of the feasibility of a novel telephone-based intervention to reduce anxiety, stress, and depression, and increase quality of life in carers.

Thank you for taking part in this research study. Your help and support are vitally important in developing better ways of supporting carers. Having completed the intervention, I would like to take a little more time to explain the research rationale. Firstly, research has shown that some people are more susceptible to developing anxiety; stress and or depression, which mean some people, are 'at risk'. Part of the research was looking to see whether we could identify people 'at risk' using new, simple to administer questionnaires.

Secondly, to be able to investigate whether the intervention has been any better than existing treatments at reducing distress and increasing quality of life it needs to be compared in an unbiased way to existing treatments. That is why you were not informed which group you had been in (until completion).

It is well documented that caring for someone that is suffering from psychosis can be really stressful, traumatic and anxiety provoking; at such a challenging time it can be easy to forget about yourself. Due to the huge demands and both the personal and financial burden that caring places on you I have been developing an intervention that will support you and other carers like you without demanding too much time and with great flexibility. Hopefully, if the research has been successful this intervention will be adapted to have a mobile phone application to make it even more accessible and flexible.

Although the intervention is designed to reduce symptoms of anxiety, depression, and stress making any change no matter how small and positive in the longer term often brings short-term discomfort (negative consequences). Therefore, it is possible that your levels of distress increased initially during the research. This is quite normal however, if you feel that you are becoming increasingly distressed or if your mood drops it is a good idea to seek professional advice/ support. You can always contact your GP, however, there are also a variety of organisations that may be of help. I have included the numbers below. However, if at any point you find yourself feeling very low and do not feel able to keep yourself safe it is important that you attend your local Accident and Emergency department.

Carers Trust: A useful resource for information for carers on rights and benefits. 0844 8004361 (Mon-Fri 9-5) www.carers.org

Mind: a mental health information service. 0300 123 3393 or mind.org.uk

The mind info line will be able to put you in touch with specific support or services available in your area.

NHS Carers Direct: 0808 8020202

Samaritans: A mental health support line 08457 909090 (24 hours).

I hope you found the study interesting and would be happy to discuss the interim results of the study with you. If you would like any further information or to talk to me in relation to the study you can contact me by telephone on [REDACTED] or email: [REDACTED] Alternatively, please contact Dr. Jessica Jones Nielsen on [REDACTED] or by email: [REDACTED]

I would like to take this opportunity to thank you again for your participation in the research study. I will be collating the data and results shortly and hope to have them ready for December 2015. If you would like an update on the findings, please do let me know.

Khanya

Appendix D: Advert

PARTICIPANTS NEEDED FOR RESEARCH

Department of Psychology, City University, London.

Are you caring for a loved one with Psychosis?

Caring for someone suffering from psychosis (no matter what their diagnosis) can be incredibly hard and very stressful. Research has found that anxiety, depression and stress are all common symptoms experienced by carers. As part of my Doctoral research I am trying to develop ways of supporting carers through this difficult time. I am investigating whether a new telephone-based intervention could help to reduce some of the symptoms of anxiety, depression and stress so often experienced; and also increase your quality of life.

I need your help.

Would you be interested in participating in this new telephone-based intervention? You don't need to be struggling or have been told you have anxiety, stress or depression. You just need to be caring for a loved one with psychosis. The whole intervention is telephone-based (the researcher will call you) so there are no financial costs of this, or for transport. There are also no group attendances required. The researcher will provide everything you need. Communication will all be by telephone and post. Everything will be anonymous. If you would like some more information before you make your decision or if you are interested in participating, please get in touch with me by telephone or email. You can contact me by telephone on: [REDACTED] or email: [REDACTED]

I look forward to hearing from you and thank you for taking the time to read this.

Khanya

This study has been reviewed by, and received ethics clearance through the Research Ethics Committee, City University London PSYETH (R/F) 15/16 251

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on 020 7040 3040 or via email: Anna.Ramberg.1@city.ac.uk

Appendix E: Participant Information Sheet

Caring for a loved one with psychosis: A preliminary evaluation of the feasibility of a novel telephone-based intervention to reduce anxiety, stress, and depression, and increase quality of life in carers.

I would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please get in touch and ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Anxiety, depression and stress are all very common symptoms for people caring for someone with a psychotic illness. I am investigating whether a new telephone-based intervention could reduce some of these symptoms and increase quality of life. With your agreement, you will be randomly assigned to a group. This is to enable the new intervention to be adequately and fairly tested. You will complete some questionnaires at home and return them to the researcher in pre-paid envelopes on agreed occasions. Both groups will complete the same questionnaires and intervention just in a different order.

Why have I been invited?

In order to participate in this research study there are a few requirements that I need you to meet:

- Classify yourself as a carer, not through employment but through providing unpaid care to a relative or friend.
- Able to communicate in English both verbal and written.
- Providing care within the United Kingdom
- Be over 18 years of age (ethical reasons). Y

- If you are unsure of any of these or would like to discuss them in further detail, please contact me. I have tried to keep this intervention as accessible as possible so if you are unsure whether you meet the criteria just ask.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate in part or the entire project. You can withdraw at any stage of the project without being penalised or disadvantaged in any way.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

- Firstly, you will be randomly allocated to one of three groups; a computer programme does this. You will not be told which group you are in until after the study as we need the study to be fair and unbiased.
- You may have a number of phone sessions with a researcher to complete the intervention being developed, complete a control task or complete a control + task. The exact requirements will vary according to the group you are randomly assigned to. However, everything will be made clear by the researcher once you have been randomised to a group.
- You will complete 3 questionnaires on the day you start the programme, 2 on the day you finish the programme and 2 questionnaires 3 weeks later. You will complete all questionnaires on paper at home and return them to the researcher in prepaid envelopes.
- The intervention will last 6 weeks (you will be contacted by phone weekly at a time convenient to you) for 6 weeks.
- The study will run for 14 weeks in total after which you will be required to fill in the same questionnaires again.

What are the possible disadvantages and risks of taking part?

You will not be at a risk of harm or disadvantaged in any foreseeable manner through participating. However, you will be talking about things that could cause you some form of distress. Initially when you start an intervention like this, feelings such as anxiety or low mood may increase. This is perfectly normal, and they tend to decrease again in time. You are free to withdraw without reason at any time however, it may be worth thinking about or talking to the researcher about how you could manage difficulties should they occur.

What are the possible benefits of taking part?

This intervention is designed to reduce symptoms of anxiety, stress and depression. These symptoms affect how we think, feel and behave. The intervention will hopefully change some of these and increase your quality of life.

What will happen when the research study stops?

You will keep the booklet that accompanies the intervention, which includes a variety of worksheets and suggested activities.

Will my taking part in the study be kept confidential?

- Your name is automatically assigned a code so that it will never be attached to the information collected. The information is completely confidential.
- Restrictions on confidentiality: should the researcher become aware that an individual poses a risk to the safety of themselves or another then I would have an ethical obligation to report this information.
- All records will be kept in line with the British Psychological Society Code of ethics- they will be retained and stored for 5 years in a locked filing cabinet only accessible to the researcher and supervisor prior to be destroyed.

What will happen to the results of the research study?

The results of this study will form a big component of my doctoral thesis. The intervention and its results will be submitted for publication (again, you are guaranteed anonymity). It is hoped that with further funding this intervention could be available to all those caring for a loved one with psychosis. After the results have

been analysed if you would like to receive an information sheet detailing the findings you can do so by ticking the box on the consent form.

What will happen if I don't want to carry on with the study?

You can withdraw at any stage of the project without being penalised or disadvantaged in any way.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Caring for a loved one with psychosis: the development and preliminary evaluation of a remote intervention.

You could also write to the Secretary at:

Anna Ramberg

Secretary to Senate Research Ethics Committee

Research Office, E214

City University London

Northampton Square

London

EC1V 0HB

Email: 

City, University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study, you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City University London Research Ethics Committee PSYETH (R/F) 15/16 251

Further information and contact details

If you would like any further information or to talk to me in relation to the study you can contact me by telephone on [REDACTED] or email: [REDACTED]
[REDACTED]

Alternatively, please contact Dr. Jessica Jones Nielsen on [REDACTED] or by email: [REDACTED]

Thank you for taking the time to read this information sheet.

Appendix F: Participant Consent Form

Caring for a loved one with psychosis: A preliminary evaluation of the feasibility of a novel telephone-based intervention to reduce anxiety, stress, and depression, and increase quality of life in carers.

Ethics approval code: PSYETH (R/F) 15/16 251

Please initial box

| | | |
|----|--|--|
| 1. | <p>I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.</p> <p>I understand I will be assigned randomly to one of two groups. I will not be informed of this until after I have finished or withdrawn from the research. I understand that the reason for this is to help keep the research study unbiased.</p> <p>I understand that the programme will require me to have weekly telephone contacts with the researcher for a period of 6 weeks. You will be informed of dates as soon as you are allocated, and a suitable time will be arranged.</p> <p>I understand that I will complete a variety of questionnaires for the researcher and return them in the prepaid envelope prior to starting the study, during the study and after the study at agreed time points. Again, all returned to the researcher in the prepaid envelopes provided.</p> <p>I understand that if I pose a risk to myself or others the research has an ethical obligation to report to the required professionals/service (police, emergency services).</p> | |
| 2. | <p>This information will be held and processed for the following purpose(s):</p> <p>The information will be held and processed to evaluate a newly developed intervention and determine whether the intervention has any significant effect on the participant's mood and quality of life.</p> <p>Information will also be used to ascertain if a simple questionnaire is able to highlight whether certain individuals are more susceptible to the intervention.</p> <p>I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.</p> | |
| 3. | I understand that my participation is voluntary, that I can choose not | |

Appendix G: Depression, anxiety and stress scale (DASS; Lovibond & Lovibond, 2005).

| | | | | | |
|---|---|-------|---|---|---|
| Name: | | Date: | | | |
| Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you <i>over the past week</i> . There are no right or wrong answers. Do not spend too much time on any statement. | | | | | |
| The rating scale is as follows: | | | | | |
| 0 Did not apply to me at all | | | | | |
| 1 Applied to me to some degree, or some of the time | | | | | |
| 2 Applied to me to a considerable degree, or a good part of time | | | | | |
| 3 Applied to me very much, or most of the time | | | | | |
| 1 | I found myself getting upset by quite trivial things | 0 | 1 | 2 | 3 |
| 2 | I was aware of dryness of my mouth | 0 | 1 | 2 | 3 |
| 3 | I couldn't seem to experience any positive feeling at all | 0 | 1 | 2 | 3 |
| 4 | I experienced breathing difficulty (e.g, excessively rapid breathing, breathlessness in the absence of physical exertion) | 0 | 1 | 2 | 3 |
| 5 | I just couldn't seem to get going | 0 | 1 | 2 | 3 |
| 6 | I tended to over-react to situations | 0 | 1 | 2 | 3 |
| 7 | I had a feeling of shakiness (e.g, legs going to give way) | 0 | 1 | 2 | 3 |
| 8 | I found it difficult to relax | 0 | 1 | 2 | 3 |
| 9 | I found myself in situations that made me so anxious I was most relieved when they ended | 0 | 1 | 2 | 3 |
| 10 | I felt that I had nothing to look forward to | 0 | 1 | 2 | 3 |
| 11 | I found myself getting upset rather easily | 0 | 1 | 2 | 3 |
| 12 | I felt that I was using a lot of nervous energy | 0 | 1 | 2 | 3 |
| 13 | I felt sad and depressed | 0 | 1 | 2 | 3 |
| 14 | I found myself getting impatient when I was delayed in any way (eg, lifts, traffic lights, being kept waiting) | 0 | 1 | 2 | 3 |
| 15 | I had a feeling of faintness | 0 | 1 | 2 | 3 |
| 16 | I felt that I had lost interest in just about everything | 0 | 1 | 2 | 3 |
| 17 | I felt I wasn't worth much as a person | 0 | 1 | 2 | 3 |
| 18 | I felt that I was rather touchy | 0 | 1 | 2 | 3 |
| 19 | I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion | 0 | 1 | 2 | 3 |
| 20 | I felt scared without any good reason | 0 | 1 | 2 | 3 |
| 21 | I felt that life wasn't worthwhile | 0 | 1 | 2 | 3 |

Please turn the page ↩

Reminder of rating scale:

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

| | | | | | |
|----|--|---|---|---|---|
| 22 | I found it hard to wind down | 0 | 1 | 2 | 3 |
| 23 | I had difficulty in swallowing | 0 | 1 | 2 | 3 |
| 24 | I couldn't seem to get any enjoyment out of the things I did | 0 | 1 | 2 | 3 |
| 25 | I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat) | 0 | 1 | 2 | 3 |
| 26 | I felt down-hearted and blue | 0 | 1 | 2 | 3 |
| 27 | I found that I was very irritable | 0 | 1 | 2 | 3 |
| 28 | I felt I was close to panic | 0 | 1 | 2 | 3 |
| 29 | I found it hard to calm down after something upset me | 0 | 1 | 2 | 3 |
| 30 | I feared that I would be "thrown" by some trivial but unfamiliar task | 0 | 1 | 2 | 3 |
| 31 | I was unable to become enthusiastic about anything | 0 | 1 | 2 | 3 |
| 32 | I found it difficult to tolerate interruptions to what I was doing | 0 | 1 | 2 | 3 |
| 33 | I was in a state of nervous tension | 0 | 1 | 2 | 3 |
| 34 | I felt I was pretty worthless | 0 | 1 | 2 | 3 |
| 35 | I was intolerant of anything that kept me from getting on with what I was doing | 0 | 1 | 2 | 3 |
| 36 | I felt terrified | 0 | 1 | 2 | 3 |
| 37 | I could see nothing in the future to be hopeful about | 0 | 1 | 2 | 3 |
| 38 | I felt that life was meaningless | 0 | 1 | 2 | 3 |
| 39 | I found myself getting agitated | 0 | 1 | 2 | 3 |
| 40 | I was worried about situations in which I might panic and make a fool of myself | 0 | 1 | 2 | 3 |
| 41 | I experienced trembling (eg, in the hands) | 0 | 1 | 2 | 3 |
| 42 | I found it difficult to work up the initiative to do things | 0 | 1 | 2 | 3 |

Appendix H: WHOQoL-BREF About You

Before you begin we would like to ask you to answer a few general questions about yourself by circling the correct answer or by filing in the space provided.

1. What is your gender? Male / Female / Other
2. What is your date of birth?
3. What is the highest education qualification that you received?
4. What is your marital status? Single, Married, Living as Married, Separated, Divorced, Widowed
5. Are you currently ill?
6. If something is wrong with your health, what do you think it is?

Illness/problem

Instructions

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about what response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life, in the last two-week period. For example, thinking about the last two weeks, a relevant question might be:

Do you get the kind of support from others that you need? 1 2 3 4 5

You would circle number 1 if you feel you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings and circle the number on the scale that gives the best answer for you for each question.

1. How would you rate your quality of life? **1 2 3 4 5**

2. How satisfied are you with your health? **1 2 3 4 5**

The following questions ask about **how much** you have experienced certain things in the last two weeks.

3. To what extent do you feel that physical pain prevents you from doing what you need to do? **1 2 3 4 5**

4. How much do you need any medical treatment to function in your daily life?

1 2 3 4 5

5. How much do you enjoy life? **1 2 3 4 5**

6. To what extent do you feel your life to be meaningful? **1 2 3 4 5**

7. How well are you able to concentrate? **1 2 3 4 5**

8. How safe do you feel in your daily life? **1 2 3 4 5**

9. How healthy is your physical environment? **1 2 3 4 5**

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

10. Do you have enough energy for everyday life? **1 2 3 4 5**

11. Are you able to accept your bodily appearance? **1 2 3 4 5**

12. Have you enough money to meet your needs? **1 2 3 4 5**

13. How available to you is the information that you need in your day-to-day life? 1
2 3 4 5

14. To what extent do you have the opportunity for leisure activities? ^[L]_[SEP]1 2 3 4 5

15. How well are you able to get around? 1 2 3 4 5

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

16. How satisfied are you with your sleep? 1 2 3 4 5

17. How satisfied are you with your ability to perform your daily living activities?
1 2 3 4 5

18. How satisfied are you with your capacity for work? 1 2 3 4 5

19. How satisfied are you with yourself? 1 2 3 4 5

20. How satisfied are you with your personal relationships? 1 2 3 4 5

21. How satisfied are you with your sex life? 1 2 3 4 5

22. How satisfied are you with the support you get from your friends? 1 2 3 4 5

23. How satisfied are you with your access to health services? 1 2 3 4 5

24. How satisfied are you with your mode of transportation? 1 2 3 4 5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

25. How often do you have feelings, such as a blue mood, despair, anxiety, or depression?

Negative = 1

Seldom = 2

Quite often = 3

Very often = 4

Always = 5

Appendix I: Participant Information Questionnaire

Demographic Data: Carers

Please answer the following questions:

How old are you?

Please give date of birth and current age: day month year. Age:

Please describe your gender:

Are you married, single or living with a partner?

Please describe the make-up of your family:

.....
.....

Where do you live? (Give name of town and county)

Are you currently employed or unemployed?

If you answered 'unemployed' to the last question - is this because of your role as a carer?
.....

What is your relationship to the person you care for? (Child, spouse, friend?)

How much time do you spend with the person you care for?

What is the diagnosis of the person you care for?.....

How long is it since this diagnosis was given?

What is the current situation of the person you care for? (inpatient/outpatient/first episode/longer term)

SECTION B: CLIENT CASE STUDY

Psychosis and Low self-esteem

Khanya Price-Evans

**The Professional Practice Component of this thesis has been
removed for confidentiality purposes.**

**It can be consulted by Psychology researchers on application at
the Library of City, University of London.**

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SECTION C: PUBLISHABLE PAPER

**The Development & Pilot Study of a Remote Telephone Intervention
for Carers of Individuals with Psychosis: TICIP.**

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Appendix A: Submission Criteria for Psychosis- Taylor & Francis

Formatted according to 'Psychosis' Guidelines. Submitted for publication 13th August 2018.

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- evidence-based treatments including individual, family and group therapies derived from a range of models including psychodynamic, cognitive-behavioural and systemic, and from a range of disciplines including nursing, psychology, social work, psychiatry, occupational therapy, art therapy etc.
- descriptions of psychotherapy and first person accounts of psychosis and of experiences using mental health services
- the integration of psychological and social understandings and treatment approaches into all phases of recovery
- training and knowledge of mental health professionals in psychological and psycho-social interventions in the treatment and prevention of psychosis
- conceptual analysis and ethical considerations related to diagnosis, treatment and rehabilitation issues

Psychosis: Psychological, Social and Integrative Approaches fills an important gap in mental health literature, namely research focused on the psychological treatments of psychosis (e.g. cognitive-behavior therapy, psychodynamic therapy, family therapy etc.) and the psycho-social causes of psychosis (e.g. poverty, drug abuse, child abuse and neglect, distressed families, urban living, discrimination, rape, war combat etc.).

The journal publishes papers on both quantitative research (e.g. rigorously designed outcome studies and epidemiological surveys) and qualitative research (e.g. case studies of therapy, first-person accounts of psychosis and experiences of people with psychosis in the mental health system), as well as papers focusing on conceptual and ethical issues.

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