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Lucy Butler B.Sc. (Hons), M.Sc.

**CAREGIVER WELLBEING IN PSYCHOSIS  
SERVICES**

**Section A:**

**Coping strategies, burden and wellbeing in caregivers of people  
with psychosis: A review of the literature**

Word count: 7,994 (435)

**Section B:**

**ACT with Compassion: Exploring third-wave factors and  
trailing a new group intervention for caregivers of people with  
psychosis.**

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A thesis submitted in partial fulfilment of the requirements of Canterbury Christ  
Church University for the degree of Doctor of Clinical Psychology

May 2016

Salomons  
Canterbury Christ Church University

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## **Summary**

Part A is a systematic literature review exploring the current evidence base regarding coping strategies used by caregivers of people with psychosis. The review endeavours to examine how coping strategies are measured in this population, what types of coping strategies are utilised and how such strategies relate to outcomes. The outcomes of burden, distress and wellbeing are explored, in relation to particular strategies. A summary of the review and limitations of the literature base is followed by potential future research directions and clinical implications.

Part B is an empirical paper, firstly exploring wellbeing in a population of caregivers, and the relationship with the third-wave factors of psychological flexibility and self-compassion, as well as other factors including burden and mindfulness. This is the first study of its kind. A new brief (five session) group intervention was also trialled, combining Acceptance and Commitment Therapy and Compassion-Focused Therapy. The feasibility, acceptability and effectiveness of this intervention was assessed. Methodological issues are considered, as are recommendations for clinical implementation and future research.

## Table of Contents

### SECTION A: Systematic Literature Review

<b>Abstract</b>	11
<b>Introduction</b>	12
Psychosis and related disorders	12
Informal caregivers	13
Impact of caregiving	14
Factors influencing burden of care	14
Caregiver coping	16
Rationale for this review	18
Aims of this review	19
Implications of this review	19
<b>Methodology</b>	20
Search Strategy	20
Search terms	20
Additional search strategy	21
Article selection	21
<b>Results</b>	24
Design characteristics	24
Sampling Adequacy	24
Sampling characteristics	25
Caregivers	25
Service users	26
Comparison studies	26
Ethnicity and cultural breadth	27
Study quality	27
Question one: How are coping strategies elicited and measured in this group of caregivers?	28
Question two: What types of coping strategies are employed?	31
Question three: How do coping strategies relate to outcomes in this population?	34
<b>Discussion</b>	40

Limitations of the current literature base	41
Strengths and limitations of the review	42
Future research directions	43
<b>Conclusion</b>	45
<b>References</b>	47

## SECTION B: Empirical Paper

<b>Abstract</b>	63
<b>Introduction</b>	64
Informal Caregivers of people with psychosis	64
Caregiver burden and related models	64
Existing interventions for caregivers	65
Third-wave approaches for caregivers	67
Compassion-focused therapy as an additional approach	69
Aims and rationale for the current study	70
Research hypotheses	71
<b>Methodology</b>	72
Design	72
Sample size and power calculation	72
Participants	73
Inclusion and exclusion criteria	73
Ethical considerations	74
Procedure: Part One – Baseline analyses	75
Measures	75
Part Two: ACT with Compassion	79
Consultation, development and researcher contribution	79
The ACT with Compassion group intervention	79
Procedure: Part Two – Group intervention	81
Data analysis	82
Missing data	83
<b>Results</b>	84
Part One: Sample demographics	84
Sample clinical characteristics	85
Associations of clinical variables with demographics	87
Hypothesis Testing	88
Primary outcome: Wellbeing	89
Secondary outcomes: Distress and burden	89
Post-hoc tests: Predictors of wellbeing	90
Part Two: Group intervention	90

Sample and participant flow	90
Changes from baseline to post-intervention	91
Hypothesis testing	92
Intervention comparison	94
Feasibility and acceptability	96
Qualitative feedback	97
<b>Discussion</b>	98
Third-wave factors in caregivers of people with psychosis	99
A potential new intervention	100
Limitations	100
Strengths	102
Clinical implications	103
Future research directions	104
<b>Conclusion</b>	105
<b>References</b>	106



## **List of Figures**

Figure 1: PRISMA flow chart	23
Figure 2: Participant recruitment and study completion flow chart	91

## **List of Tables**

1. Systematic review inclusion and exclusion criteria	22
2. Session by session summary of the ACT with Compassion group intervention	80
3. Caregiver demographics	84
4. Baseline clinical characteristics	86
5. Levels of psychological distress in the sample	87
6. Baseline correlations	88
7. Pre- and post-intervention clinical characteristics	92
8. t- and p-values and effect sizes for paired data	93
9. Pre- and post-intervention means for the three conditions	95
10. Between group effect sizes for WEMWBS-8	96
11. Frequencies of group feedback responses	97
12. Frequency of themes in qualitative feedback	98

## Section C: List of Appendices

Appendix A:	Table of Included Studies	115
Appendix B:	Methodology of ACT for Recovery study	123
Appendix C:	Ethics approval letter from Research Ethics Committee	124
Appendix D:	R & D approval letter	125
Appendix E:	Information sheet	126
Appendix F:	Consent form	130
Appendix G:	Acceptance and Action Questionnaire (Version 2)	132
Appendix H:	Self Compassion Scale (Short Form)	133
Appendix I:	Warwick Edinburgh Mental Wellbeing Scale	134
Appendix J:	Compassion (for Others) Scale	135
Appendix K:	Five Facets of Mindfulness Questionnaire	136
Appendix L:	Caregiver Guilt Questionnaire	137
Appendix M:	CORE-10	138
Appendix N:	Experience of Caregiving Inventory	139
Appendix O:	Feedback form	140
Appendix P:	ACT with Compassion group intervention protocol extract	142
Appendix Q:	Group powerpoint slides example	152
Appendix R:	Group worksheet example	156
Appendix S:	Parametric data assumptions	157
Appendix T:	Internal Consistency	157
Appendix U:	SPSS output: Multiple regression	158
Appendix V:	Effect size equations and calculations	159
Appendix W:	SPSS: Baseline means across condition	160
Appendix X:	Qualitative feedback – themes and frequencies	161

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**Major Research Project**

**Section A: Systematic Literature Review**

**Coping strategies, burden and wellbeing in caregivers of  
people with psychosis: A review of the literature**

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SALOMONS

Canterbury Christ Church University

## **Abstract**

### *Introduction*

A variety of research studies have explored the relationship between coping strategies and outcomes in caregivers of people with psychosis. This area is broad and many different measurement tools have been utilised, meaning clarity is difficult.

### *Method*

This systematic review aimed to identify and critique studies examining coping strategies within this population, and how such strategies relate to outcomes including burden, distress and wellbeing. Electronic databases were searched to identify relevant literature. The Strengthening the Reporting of Observational Studies statement was utilised to guide critiquing.

### *Results*

Twenty-four studies were included in the review. The review explored how strategies have been measured and elicited in this population, what strategies are used and how these relate to outcomes.

### *Discussion*

A summary of the review is presented, and it is recognised that much of the existing research is cross-sectional in nature. Recommendations are made for future research; these included the use of more tailored measurement of coping, longitudinal studies in order to explore causation, and exploration of the concept of experiential avoidance in this population, due to its potential relationship with coping and wellbeing.

*Key words: caregivers, psychosis, coping strategies, wellbeing, burden, distress*

## **Introduction**

### *Psychosis and related disorders*

Psychosis is a mental health problem that often includes hallucinations (seeing or hearing things that other people cannot see or hear, for example hearing voices), delusions or disordered thinking (including thought blocking, insertion or disorganised thoughts) (NHS Choices, 2014). The International Statistical Classification of Diseases and Related health Problems 10<sup>th</sup> Revision (ICD-10) describes a range of psychotic disorders (F.20-29, World Health Organisation (WHO), 1992). Schizophrenia (F.20) is described as a distressing disorder, and is identified and characterised by longer periods of psychosis ('positive' symptoms), generally lasting at 'least a month or at some point during most of the days' (WHO, 1992, p.78). Negative symptoms are often also present, and typically represent a withdrawal or lack of function, loss of motivation, blunting and 'incongruity of emotional response' (for example, unwilling smiling when feeling sad, WHO, 1993). Additional criteria include evidence of impaired or deteriorating functioning.

Schizophrenia affects approximately four in every thousand people in the UK each year (Kirkbride et al., 2012). People with schizophrenia or other psychotic disorders can recover, and even with residual symptoms or periods of relapse can engage with personally meaningful life goals (Slade, 2009). However, many people need ongoing support and care from mental health professionals and also from their families and loved-ones. In this review the term 'psychosis' will be used to denote the range of psychotic disorders, including schizophrenia.

### *Informal caregivers*

Over the past five decades deinstitutionalisation has led to many people with psychosis<sup>1</sup> being cared for by family or friends in the community, rather than in a hospital setting (Kuipers, 2010). An informal caregiver (or carer) can be defined as “someone who without payment provides help or support to a partner, child, relative, friend or neighbour who could not manage without their help” (Carers Trust, 2012); or alternatively, a person (unpaid) who helps an individual cope with illness or disease (Hileman, Lackey & Hassanien, 1992). Caregivers play an invaluable role in the lives of service users with psychosis, but the detrimental impact that caregiving has upon their own mental wellbeing and physical health is often significant (Kuipers, Onwumere & Bebbington, 2010; Smith et al., 2014). McFarlane and Cook (2007, p.196) conclude that; “family members are as much victims of severe mental disorders as patients themselves”.

Caregivers of people with psychosis often face unique challenges. The person they care for may experience a wide range of unusual and distressing symptoms. Mental health crises, aggression or other risk behaviours, hospitalisation, contact with the police and sectioning under the Mental Health Act (1983) can be traumatic for caregivers as well as clients, as demonstrated by Loughland et al. (2009). Caregivers may also experience added difficulties of social isolation and shame that are very much still attached to such a stigmatised diagnosis in a family member (Kuipers, 2010).

---

<sup>1</sup> Throughout this review, people with a diagnosis of psychosis will be referred to as ‘people with psychosis’.

### *Impact of caregiving on caregivers*

The adverse impact of caregiving (for people with a variety of disorders, including psychosis) has been described as the ‘burden of care’ (Platt, 1985). In their review of the literature concerning caregivers of people with psychosis, Awad and Voruganti (2008) noted that burden is defined by its influence on caregivers in terms of “emotional, psychological, physical and economic impact” (p.151). A substantial base of research has shown that many caregivers of this population experience clinical levels of stress, depression and anxiety, physical ill-health (Brown & Birtwhistle, 1998; Laidlaw, Coverdale, Falloon & Kydd, 2002; Kuipers et al., 2010) and even symptoms of PTSD (Barton & Jackson, 2008). Feelings of shame, guilt, anger and loss have also been documented as common to the caregiver experience (Schene, van Wijngaarden & Koeter, 1998; Patterson, Birchwood & Cochrane, 2005).

Burden of care has been explored via the separate constructs of ‘objective’ and ‘subjective’ burden (Hoenig & Hamilton, 1966). Objective burden is the impact on practical aspects of the caregiver’s life, such as the taking care of household tasks, money spent, or working hours affected, whereas subjective burden is related to the extent to which caregivers perceive themselves to be burdened by their role. Flyckt, Lothman, Jorgensen and Rylander (2011) found that despite long hours and substantial money being spent on caregiving, it was the emotional strain and subjective burden that caused most distress to caregivers of people with psychosis.

### *Factors influencing burden of care*

A substantial body of research has explored factors related to and influencing burden of care in caregivers of this population. Demographic factors, including gender of the caregiver and care recipient, age and ethnicity have been shown to influence levels of burden and distress (Mors, Sorensen & Thirkilden, 1992; Cook, Lefley, Pickett

& Cohler, 1994; Rosenfarb & Aziz, 2006). There is currently no clear consensus regarding how particular symptoms of psychosis relate to perceived burden in caregivers. Provencher and Mueser (1997) found levels of objective and subjective burden differed in relation to the experience of positive and/or negative symptoms in the care recipient, which was supported by Parabiaghi and colleagues (2007).

In terms of psychological processes, caregiver burden and distress have been related to three main concepts of appraisal/attributions, interpersonal responses and coping. Barrowclough and Hooley (2003) surmised that caregivers who appraised psychosis as a more chronic and un-remitting illness experienced higher burden, while Harvey, Burns, Fahy, Manley and Tattan (2001) found caregivers who appraised their loved-ones as having more control over their illness also experienced increased burden and higher levels of distress.

Kuipers and colleagues have extensively explored caregiving in this population and proposed the cognitive model of caregiving in psychosis (Kuipers et al., 2010). This describes the baseline relationship between caregiver and care recipient as paramount, and that this relationship, in combination with how caregivers appraise the illness and the service users' behaviour, predicts a range of caregiver outcomes (in terms of burden) and also impacts how caregivers cope with their role.

The model proposes that caregivers who had an existing positive relationship with the service user are more likely to appraise the service user as not to blame, and thus view them as needing support. They may still be stressed and worried, but may cope in a non-avoidant way, and not isolate themselves. Rather, they may actively seek help and maintain social relationships and their own activities. Conversely, the model suggests that where caregivers previously had an over-involved relationship with the service user, which may indeed have been positive (particularly when the



service user was a child, as these caregivers are usually parents) there are more likely to be difficulties when the service user becomes unwell. Such caregivers may blame themselves for the illness, feel guilty, and thus try to control the situation. This role style can lead to the caregiver coping by taking over many responsibilities for the service user, and thus losing their own activities or social connections, and becoming exhausted. Thirdly, the model describes the caregiving impact where an existing relationship was hostile or critical. In this instance, a caregiver may be more likely to blame the service user, and see them as someone who is lazy or not trying to get better. This type of caregiver may cope in an avoidant manner, and thus may feel depressed, stressed and angry, and may lose hope of things helping or improving.

The model proposes that interventions are important for all caregivers in order to reduce burden, and that considering the existing relationship, appraisals and caregiver reactions is imperative in deciding what support to offer, and how to help improve coping styles and relationships. This model will be considered later in the review in terms of the findings.

### *Caregiver coping*

How a problem is appraised is pertinent to how one then decides to cope with it. The stress-coping model proposes that “coping itself depends on accurate appraisal of situations, on one’s own resources and on how these are marshalled” (Folkman & Lazarus, 1985, in Kuipers et al., 2010, p.260). Coping can be defined as the sum of cognitive and behavioural efforts, which are constantly changing, that aim to handle particular demands, whether internal or external, that are viewed as taxing or demanding (Folkman & Lazarus, 1985). Coping is understood as a process that serves two ends; to eliminate a problem and also to regulate emotions incited by the problem

(Sincero, 2012). Thus coping has often historically been defined as either ‘problem focused’ or ‘emotion focused’ in nature (Folkman & Lazarus, 1988). Coping is a complex concept, and one that has a substantial, yet confused evidence base in terms of how caregivers of people with psychosis cope with their role and the ensuing burden, and indeed how different coping styles and strategies influence and relate to burden and distress within this population.

The coping strategies and styles utilised by caregivers of people with psychosis are of interest because it is possible to learn from adaptive strategies, as well as explore maladaptive strategies and why they continue to be employed, despite not helping. Maladaptive coping strategies are essentially ‘non-coping’. Askey, Holmshaw, Gamble and Gray (2009) found that caregivers themselves wanted professional support around developing effective coping strategies. Many interventions for caregivers, in particular psychoeducation programmes, are ultimately aimed at improving caregiver coping, and thus hope to improve outcomes for care recipients (Lobban et al., 2013). A recent review by Sin and Norman (2013) found that psychoeducation was consistently effective in improving caregivers’ knowledge and coping. Kuipers (2010) argues for the necessity of interventions for caregivers, noting that service users who have the support of family and friends have better outcomes, and also that caregivers deserve help in their own right.

Caregivers suffer more in terms of stress and quality of life when they are unable to cope with the demands placed upon them by their role, particularly during times of crisis (Lauber, Eichenberger, Luginbühl, Keller & Rössler, 2003). Therefore, it is important to understand the coping strategies employed by this population, and how they relate to caregiver distress, burden and wellbeing. Coping strategies have been

explored and defined differently by many researchers, but the evidence base is currently unclear.

### *Rationale for this review*

Grover and colleagues (2015) recent review (published subsequently to the commencement of the work in this thesis) explored coping strategies and caregiver burden in caregivers of people with psychosis. This review concluded that coping strategies are associated with caregiver outcomes, including burden, psychological morbidity and quality of life. The review linked problem-focused coping with better outcomes, and stated that emotion-focused coping is less clear in terms of impact. However, the review was not systematic in nature, nor methodologically sound, as it did not give an account of search strategy, inclusion criteria, the number of studies reviewed or study quality. Regarding chronicity of psychosis, some research has suggested that caregivers of people with early-onset versus established psychosis have higher levels of burden and distress (due to issues such as shock, grief and adjustment (Addington & Burnett, 2004), when compared to caregivers of people with established psychosis (Martens & Addington, 2001). Jansen, Gleeson and Cotton (2015) systematically reviewed the literature exploring distress in caregivers of people with early-onset psychosis only. They concluded that emotion-focused strategies, including avoidant coping, were strongly related to burden and distress in this population.

A systematic review of the literature within the area of established psychosis would therefore provide a rigorous addition to the literature base concerning coping strategies used in this marginalised group of caregivers, and the relationship to burden and distress. The present review will consider findings using systematic methodology and quality judgements, and findings will be compared to the broader, expert review.

### *Aims of this review*

- To provide a systematic review of the literature examining the effectiveness of coping strategies used by caregivers of people with established psychosis in order to consider three key areas:
  1. How are coping strategies elicited and measured in this group of caregivers?
  2. What coping strategies are employed?
  3. How do coping strategies relate to the caregiver outcomes of distress, burden or quality of life?

### *Implications of this review*

- This review will aid a better understanding of successful and unsuccessful coping strategies in caregivers of people with psychosis, and how they potentially relate to caregiver and service user outcomes
- This review should help guide future interventions for caregivers where the aim is to improve coping and wellbeing and reduce burden and distress.

## **Methodology**

### *Search strategy*

A systematic search of the literature was conducted in order to identify research studies exploring coping strategies and their relationship with levels of burden and distress in caregivers of people with a diagnosis of established psychosis or schizophrenia. *PsycINFO* (psychological) was the primary database used. Searches were also conducted within *Cochrane Library* (reviews), *Medline* (biomedical) *ASSIA* (social policy and practice) *CINAHL-EBSCO* (nursing) and *Web of Science*. A final search was also performed in *Google Scholar*. Searches were conducted between July and November 2015. The review followed guidance issued by PRISMA (2009) on how to conduct systematic reviews of health and related research.

### *Search terms*

The following search terms and Boolean operators were employed:

*Psychosis (explode) OR schizophrenia (explode)*

AND

*Caregivers (explode) OR caregiver\* OR carer\* OR famil\* OR parent\* OR partner OR spouse OR sibling OR child*

AND

*Coping strategy (explode) OR cope\* OR coping\**

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\* *Allowing the search term as a root stem of other phrases, thus expanding the search without the need for searching repeated terms)*

### *Additional search strategy*

The reference lists of relevant articles were manually examined and the ‘cited by’ and ‘related articles’ functions on Google Scholar were utilised. These methods identified articles that may have been missed by the database searches for a particular reason, such as using different keywords or being unpublished (grey literature, perhaps in press, or not accepted by peer-reviewed journals due to negative findings). This identified no additional papers, and thus only peer-reviewed journals were included.

### *Article selection*

Dissertations or theses, book chapters or case studies were not included. Only research published in English was included. Due to the aim of the review being to establish links between coping strategies and distress, burden or quality of life in caregivers only articles examining these factors as separate variables were included. Only studies with reporting correlational analyses between these variables were included in the review, in order to clearly explore the relationship between coping and outcomes. As the main aim of this review was to explore and quantify potential relationships and correlations between these factors it was decided to exclude qualitative studies from the review. On examination they would not allow coherent synthesis with the quantitative articles reviewed.

Due to the recent review by Jansen et al. (2015) studies exclusively concerning caregivers of people with early-onset psychosis were also excluded. This allowed the focus to remain on caregivers of people with established psychosis. The full inclusion and exclusion criteria are listed in table 1.

*Table 1: Systematic review inclusion and exclusion criteria.*

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>• Articles meeting PRISMA criteria.</li> <li>• Articles published in peer-reviewed journals.</li> <li>• Research concerning caregivers of people with psychosis</li> <li>• Research examining coping strategies AND burden/distress/quality of life as separate variables (using quantitative/quantifiable methods).</li> </ul>	<ul style="list-style-type: none"> <li>• Articles not published in English</li> <li>• Dissertations/theses, case studies and book chapters</li> <li>• Research exclusively concerning caregivers of people with early-onset psychosis</li> <li>• Intervention studies</li> <li>• Research concerning paid caregivers</li> <li>• Qualitative research</li> </ul>

A diagram detailing the selection process is detailed in figure 1.

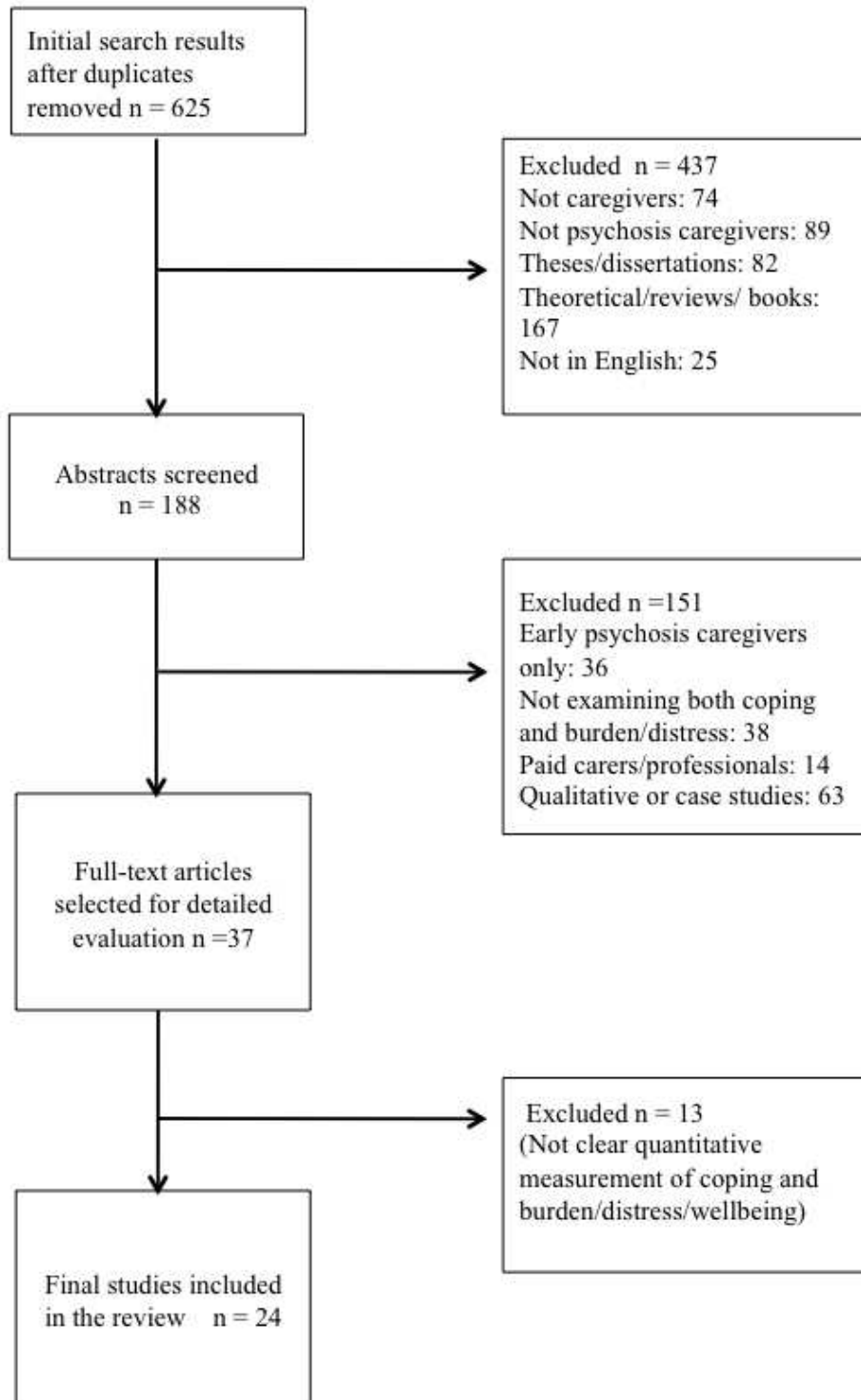


Figure 1: Flow diagram of study selection process



## **Results**

Following the process detailed above, a total of 24 studies were selected for inclusion in this review. Design, sampling and study quality will be considered, before a synthesis of the results is presented. The ‘Strengthening the Reporting of Observational Studies in Epidemiology’ (STROBE) cross-sectional checklist (von Elm et al, 2007) was utilised to rate study quality and guide critique of the studies. See appendix A for a table summarising the reviewed studies.

### *Design characteristics*

The majority of the reviewed studies employed a cross-sectional descriptive design (21 of 24, 87.5%), with data acquired from participating caregivers at one point in time. Cross-sectional studies have the advantage of being able to explore many variables. Roick, Heimer, Toumi and Angermeyer (2006) and Magliano et al. (2000) employed a prospective, longitudinal design. Roick et al. (2006) followed-up caregivers five times over a period of 30 months, while Magliano et al. (2000) followed participants over a period of one year (two time points). Scazufca and Kuipers (1999) assessed caregivers at two points in time; firstly, when their care recipient was admitted to an acute inpatient unit, and then nine months later once the care recipient was in the community, in order to compare coping strategies and other factors over these different periods.

### *Sampling adequacy*

Non-probability sampling methods were most frequently utilised by the reviewed studies. These methods included convenience sampling (in 56.5% of the studies) and consecutive sampling (in 26% of the studies). Probability sampling was

carried out by only a small number of the studies; purposive random sampling was employed by Kate, Grover, Kulhara and Nehra (2013) where 200 caregivers were initially recruited, and then a random sample of 100 of these were further studied. This method of sampling is more robust and less prone to bias, and was also employed by Thunyadee, Sitthimongkol, Sangon, Chai-Aroon and Hegadoren (2015) and Grandón et al. (2008).

Participants were most often recruited from urban hospitals comprising both inpatient and outpatient mental health services, where caregivers were invited to participate as part of caregiver-client dyads once clients had been identified. Four studies (17.3%) exclusively recruited inpatients and their caregivers, whilst seven (30.4%) exclusively explored outpatient dyads. A minority of the studies recruited via caregiver meetings or family support groups (Budd, Oles & Hughes, 1998; Webb et al., 1998; Hanzawa, Tanaka, Inadomi, Urata & Ohta, 2008; Hanzawa et al., 2010; Tan et al., 2012).

### *Sample characteristics*

Almost all (91.3%) of the studies reviewed reported data on both caregivers and the person(s) they cared for (caregiver-client dyads). This allowed additional exploration of factors such as symptoms experienced by the care recipient, which, as discussed above, have been shown to influence levels of caregiver burden and distress.

### *Caregivers*

The studies included data on a total of 2,440 caregivers. Of these, 2,201 (90.2%) were caregivers of people with schizophrenia or established/chronic psychosis-related disorders (for example, schizoaffective disorder). Regarding

demographics of caregiver participants, 17 studies reported age of caregiver, with the overall average age for these studies (n= 1,437) being 48.8 years. Four studies reported age ranges of caregivers, whilst three did not report age. Twenty studies reported gender of caregivers, with 67.3% of the overall sample being female. Hanzawa et al. (2008) explored the experiences of exclusively female caregivers (mothers). Most of the caregivers were parents (68%) or partners (18%) of the care recipients. Three of the studies did not report the relationship between caregiver and care recipient. Seven studies excluded caregivers who were not cohabiting with the care recipient.

### *Service users*

There were a total of 2,144 service users included in the reviewed studies. Their mean age was 35.05 years, based on data from 15 studies. 56.7% of the service users were male (based on data from 20 studies). Twenty of the studies reported on psychiatric diagnosis of service users; which had been made via the ICD-10 (12 studies) or the DSM-III or IV (5 studies) criteria. In three studies, the researchers personally verified diagnosis via standardised assessment tools; the SCID (Spitzer, William, Gibbon & First, 1989), SCAN (Wing et al. 1990) and the Syndrome checklist (Wing, Cooper & Sartorius, 1974) were each used once.

### *Comparison studies*

Four studies compared caregivers of people with schizophrenia or established psychosis with caregivers of people with other diagnoses, in order to explore differences with reference to diagnosis or length of illness. Bibou-Nakou, Dikaiou and Bairactarus (1997) compared 31 caregivers of people with chronic schizophrenia with 21 caregivers of people with 'sub-chronic' or early psychosis (unwell for less than two years). Onwumere et al. (2011) explored the same, with 81 chronic versus 60 early-

psychosis. In terms of differing diagnosis, Webb et al. (1998) compared 59 schizophrenia caregivers with 25 caregivers of people with bipolar affective disorder. Nehra, Chakrabarti, Kulhara and Sharma (2005) explored equally matched groups; 50 each of caregivers of people with schizophrenia and bipolar respectively. Nitsche, Kock and Kallert (2009) compared differences across caregivers of people with schizophrenia (55), bipolar (55) and recurrent depression (53).

### *Ethnicity and cultural breadth*

Studies reviewed were conducted across a wide range of countries. Western countries included England, Wales, Germany, France, Spain, Greece, Portugal and Chile. Eastern countries included India, Korea, Thailand and Japan. The country contributing the most research was India (six studies). Two studies explicitly explored differences between countries; Hanzawa et al. (2010) compared caregivers from Japan with those from South Korea, while Magliano et al. (2000) compared caregivers from five different European countries.

### *Study quality*

There were a number of overall strengths in the reviewed studies, including recruitment from specialist psychiatric services and the use of reliable and valid measures of coping, burden and distress. Thirteen of the reviewed studies focused specifically on coping strategies and their relationship with distress and burden. The remaining ten studies explored wider psychosocial predictors of burden, including coping strategies. In all studies, except two, caregiver involvement was dependent on care recipient interest and consent to the study, thus other populations of caregivers may not have been reached, such as those whose care recipients did not consent to research involvement, or those who have little involvement with mental health services.

Some studies also further limited generalisability by only including a very specific convenience sample, such as Lim and Ahn (2003), who only recruited caregivers visiting their relatives in an inpatient unit. Similarly the studies recruiting from caregiver support groups (four studies) thus limited the generalisability of their findings to caregivers not seeking this type of support.

Of the studies reviewed, sample sizes were varied, ranging from n=31 to n=218, with an overall average sample size of n=102. The aforementioned longitudinal studies were the only studies reporting characteristics of the caregivers who declined to take part or who dropped out during the follow-up process, giving an indication of possible bias.

***Question 1: How are coping strategies elicited and measured in this group of caregivers?***

The reviewed studies utilised a wide variety of measurement scales to explore the range of coping strategies employed by caregivers. Across the 24 studies, 12 different measures of coping were adopted. The majority of these measures were self-report questionnaires, indicating that coping strategies are mainly elicited via self-report in this area of research. The most commonly used self-report measure was the Family Coping Questionnaire (FCQ, Magliano et al, 1996), which was utilised by five studies. The FCQ was specifically designed for assessing coping strategies in relatives of people with schizophrenia, comprising 27 items. The questionnaire has good validity, with Cronbach alphas ranging from 0.68-0.83.

The Coping Checklist (Hindi version, Nehra, Chakrabarti, Sahrma & Raur, 2002) and Ways of Coping Questionnaire (Folkman & Lazarus, 1988) were both used by three studies respectively. The Coping Checklist (Hindi version) is based on the

Coping Checklist devised by Scazufca and Kuipers in their 1999 study, which in turn was based upon the Ways of Coping Checklist (WCCL, Folkman & Lazarus, 1980; 1988). The Revised-Ways of Coping Checklist (R-WCCL, Vitaliano, Russo & Carr, 1985) was used by Dyck, Short and Vitaliano (1999). Therefore, these measures explore very similar domains of coping. Items are rated on a Likert-type scale (for example, 'never used' going to up to 'always used') and items generally form the coping domains of problem-focused coping, seeking social support, avoidance, collusion and coercion. However, the Hindi version is meant for use as a semi-structured interview, rather than a questionnaire. It is not stated if this method was employed in two of the studies utilizing this version, which may indicate a methodological limitation.

Fortune, Smith and Garvey (2005) employed the Brief COPE (Carver, 1997), which has previously been validated in caregiver populations, including psychosis (Meyer, 2001; Cooper, Katona & Livingston, 2008; McClenahan & Weinman, 1998). The 28 items relate to 14 different subscales; nine of negative coping and five of positive coping. Onwumere et al. (2011) collected and examined only the avoidant subscales of the larger COPE measure (Carver, Scheier & Weintraub, 1989). Other forms of coping measurement used by single studies included MacCarthy and colleagues (1986) coping scale (utilised by Bibou-Nakou et al., 1997), which defines coping into five categories; good/warm, critical, over-involved, variable and passive. Rammohan, Rao and Subbakrishna (2002) utilized a different Coping Checklist; devised by Rao, Subbakrishna and Prabhu (1989) and validated on an Indian population. Nitsche et al. (2009) and Roick et al. (2006) explored coping via a limited number of items on the Involvement Evaluation Questionnaire (van Wijngaarden et al.,

2000). This restricted the breadth of coping strategies elicited, but this was acknowledged in their discussion as a limitation.

Budd et al., (1998) utilised their own specifically designed scale – the Carer Coping Style Questionnaire (CCSQ), which was constructed by the authors and refined via factor analysis. However, this scale was not available for examination. Lim & Ahn (2003) also designed their own coping scale, based on research by No and Kak (1996) and Scazufca and Kuipers (1999). Their 22-item scale comprised 12 negative strategies and 10 positive strategies (with high internal consistency of .76 and .80 respectively). Birchwood and Cochrane (1990) devised their own coping behaviour interview. They asked participants about behaviours exhibited by their care recipient, which were presented via a specially designed video of professional actors. The researcher would explore caregiver responses if they indicated that such responses were present in their own care recipient. This provided a thorough exploration of coping strategies in response to particular behaviours and could therefore have provided a more in-depth exploration of coping strategies, as well as the possibility of linking such strategies clearly to certain behaviours and symptoms. However, this method was also time-consuming and potentially more costly, and did not appear to be repeated in any following research.

Overall, a majority of the reviewed studies relied upon self-report of coping strategies in order to elicit and measure this information in caregivers. Self-report measures are subject to bias, particularly in terms of social desirability (for example, a caregiver may hesitate or downplay the use of coercive strategies). Such measures also rely on caregivers remembering if they have used such strategies, introducing recall bias. Self-report measures also limit participant responses to the items present, and do

not provide scope for a greater depth of response, such as in open-ended questions or semi-structured interviews.

***Question two: What types of coping strategies are employed?***

The coping strategies reported in the reviewed studies clearly depend on the measurement of coping, which, as discussed above, is varied. As previously introduced, coping styles have often been defined as either problem- or emotion-focused. Problem-focused coping refers to the ‘development of a plan of action aimed at altering the situation or minimising its effects’ (Webb et al., 1998, p.173). According to the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) planned problem solving, seeking social support, accepting responsibility and positive reappraisal group under problem-focused coping strategies. Escape-avoidance, distancing, ‘confrontive’ coping and self-controlling fall under emotion-focused coping strategies, which serve to change ‘ones emotional response to a problem’ (Webb et al, 1998, p.173). This section will be structured with regards to these identified categories, yet inconsistencies in definition and categorisation will also be addressed.

*Problem-focused coping*

Aggarwal, Avasthi, Kumar and Grover (2009) found that seeking social support and positive communication were the most commonly used problem-focused coping mechanism in their sample. Hanzawa et al. (2010) supported this, and found that seeking information, positive communication and maintaining service users social involvement were strategies used more frequently by Korean caregivers as compared to Japanese caregivers. Goncalves-Pereira et al. (2012) found that coping via one’s own social interests, and via encouraging the service user’s social interests, were amongst the most popular strategies. In Kate et al. (2013) 83% of caregivers reported



that they used problem-focused strategies, and 73% sought social support as a method of coping. This replicated findings by Scazufca and Kuipers (1999) where problem-focused strategies and seeking social support were used by 41% and 32.6% of caregivers respectively.

‘Acceptance’ as a coping strategy is seemingly difficult to define, appearing in varying forms in measures of coping. The Ways of Coping questionnaire included ‘accepting responsibility’ as a problem-focused coping strategy. However, other researchers, such as Fortune et al. (2005), defined acceptance as an emotion-focused coping style, more related to caregiver acceptance and appraisal of illness. They measured acceptance, via the Brief COPE (using the items ‘I’ve been accepting the reality of the fact that it has happened’ and ‘I’ve been learning to live with it’) and found it was one of the most commonly used strategies. Positive reframing and acceptance were successfully used by 24.7% of caregivers in Tan et al. (2012).

### *Emotion-focused coping*

Avoidant coping was the most common form of maladaptive emotion-focused coping identified in the studies reviewed, and can also be characterised as escape behaviour, or wishful thinking. Avoidant coping can be defined as coping via avoiding dealing with or thinking about the stressor at hand (Onwumere et al., 2011). Someone avoiding a stressor may use substances such as alcohol or drugs, may avoid thinking about the problem, or may avoid spending time with the person they are caring for. Birchwood & Cochrane (1990) found that avoidance was the most commonly used strategy (used ‘predominantly or exclusively’ by 24.3% of caregivers) alongside resignation (24.3%) coercion (20.5%) and collusion (17.8%).

Bibou-Nakou et al. (1997) found that caregivers of people with schizophrenia (as compared to caregivers of people with bipolar affective disorder) used more avoidant coping strategies, such as ‘trying to take one’s mind off things by smoking, drinking or taking pills to relax’ or ‘trying not to think about the problem’. Multiple regression analysis found that gender of caregiver explained 14% of the variance in avoidant coping, with females using the strategy less often than males. The study also described avoidant coping as more ‘passive’, with this style of coping relating to a loss of hope, not striving towards goals, and being resigned to the illness. Both Webb et al. (1998) and Nehra et al. (2005) supported this, again finding that caregivers of people with schizophrenia used significantly more avoidant coping strategies than those caring for people with bipolar affective disorder.

‘Confrontive’ coping, including coercion and collusion, is measured by the Ways of Coping Questionnaire and the WCCL (Folkman & Lazarus, 1980; 1988). Coercion refers to behaviours such as acting impulsively, getting angry or losing one’s temper with the person. Nehra et al. (2005) found that caregivers of people with schizophrenia relied on coercion more often than caregivers of people with bipolar affective disorder. Birchwood and Cochrane (1990) found that caregivers adopting coercion as a coping strategy usually did so in response to the service user ‘refusing medication’. Collusion refers to ‘agreeing, giving in or not forcing when the service user does something one does not like’, or actively condoning or supporting maladaptive behaviour displayed by the person in their care. Kate et al. (2013) reported that 79% of caregivers had used collusion as a means of coping. Self-controlling is also classed as an emotion-focused strategy on the Ways of Coping Questionnaire and was highlighted as a strategy used by caregivers in Thunyadee et al. (2012).

*Other forms of coping*

Lim and Ahn (2003) defined coping strategies as either 'positive' or 'negative' in their study, but did not identify the items relating to these categories. Other forms of coping reported include denial, which was explored by Rammohan et al. (2002) and identified via their chosen method, the Coping Checklist (Rao et al. (1989)). However, upon examination it appears that the items pertaining to denial are identical to items pertaining to avoidance in other coping measures. Self-blame was a strategy identified in Dyck et al. (1999) via the R-WCCL (Vitaliano et al. 1985), as was blaming others. Fortune et al. (2005) also highlighted self-blame as a commonly used strategy amongst caregivers (as measured by the Brief COPE, Carver, 1997). Religious coping was also explored by Rammohan et al. (2002) who found that it was predominant in caregivers who rated religious belief as important to them. Although all studies reported correlations between coping styles and burden, some did not give details of the frequencies of coping strategy use (for example, Budd et al. (1998), Tan et al. (2012)). Thus, it was difficult to compare this notion across the reviewed studies.

### **Question three: How do coping strategies relate to outcomes in this population?**

#### *Outcomes investigated in the literature base*

Caregiver outcomes of burden, distress and wellbeing were most frequently explored in the reviewed studies. Regarding caregiver burden, nine different measures of burden were utilised. Most popular were the Involvement Evaluation Questionnaire (IEQ, van Wijngaarden et al., 2000) used in four studies, and the Burden Assessment Schedule (BAS, Thara, Padmavati, Kumar & Srinivasan, 1998) used in three studies. Aggarwal et al. (2009) and Goncalves-Periera et al. (2012) employed the Experiences of Caregiving Inventory (ECI, Szmukler et al., 1996), and praised it as measuring a wide range of caregiving experiences, both positive and negative. Other methods of

measurement included the Japanese and Korean versions of the short Zarit Caregiver Burden Interview (Bédard et al., 2001).

The General Health Questionnaire (GHQ, Goldberg & Hillier, 1979) was the most frequently used measure of distress (employed by eight studies). The GHQ is a questionnaire of mental or psychiatric distress, covering a range of symptoms, with a higher score indicating higher distress. All studies used the revised 12-item version, which has good validity (Goldberg et al., 1997), except for Budd et al. (1998) who utilised the 28-item version. Two studies additionally explored caregiver levels of anxiety and depression, via the CES-D (Radloff, 1977) and the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983). Kate et al. (2013) and Rammohan et al. (2002) explored more positive factors, including quality of life via the World Health Organisation Quality of Life Scale (WHOQOL-Hindi, Saxena, Chandiramani & Bhargava, 1998) and wellbeing via the Psychological Wellbeing Questionnaire (Bhogle & Jaiprakash, 1995).

#### *Correlates of problem-focused coping*

Aggarwal et al. (2009) found that higher use of problem-focused coping correlated with greater positive personal experience and an overall higher positive experience of caregiving on the ECI (Szmuckler et al., 1996). A stepwise linear regression demonstrated that problem-focused coping explained 24.2% of the ECI positive score variance. This strategy, together with seeking social support and education level of the caregiver, explained 30.6% of the positive score variance, indicating lower burden in caregivers. Similarly, Webb et al. (1998) found that problem-focused strategies for coping with positive symptoms was associated with lower subjective burden, but interestingly when used to manage negative symptoms,

problem-focused coping was associated with greater subjective burden. Appraisal of the 'problem' at hand (in this case negative or positive symptoms) and the subsequent appropriateness of the strategy employed, could therefore be key to the outcome for caregivers in terms of burden, which links with the theory proposed in the cognitive model of caregiving (Kuipers et al., 2010).

Bibou-Nakou et al. (1997) found that caregivers who did not utilise social support correlated with higher levels of distress. Aggarwal et al. (2009) found that the seeking of social support correlated with greater positive experience on the ECI, and explained 22.8% of the variance in the ECI positive score, indicating that seeking social support was linked to a more positive experience of caregiving. Hanzawa et al. (2008) found that lower social interests highly correlated with burden, and remained one of the only significant predictors post multiple regression. Similar findings were reported by Magliano et al. (1995) and Tan et al. (2012), who found that coping via acquiring social support was correlated with lower burden, whilst Webb et al. (1998) found that social support correlated significantly with higher wellbeing. Goncalves-Periera et al. (2012) ran a logistic regression where coping via encouraging the patient to be socially involved in life was a significant predictor of burden, supporting findings reported by Grandon et al. (2008). Conversely, Kate et al. (2013) found that seeking more social support correlated negatively with quality of life. This finding was unexpected, though could potentially be explained by caregivers seeking more social support when they are finding things especially difficult, or during a crisis. Therefore this potentially supported earlier findings by Scazufca and Kuipers (1999) who noted that seeking social support was used less by caregivers as a coping strategy during follow-up, once service users were no longer in a period of crisis.

Tan et al. (2012) reported that acceptance (of the illness) appeared amongst the coping strategies they identified as ‘positive’, and correlated with lower levels of burden. This added to findings by Fortune et al. (2005), where the use of acceptance as a coping strategy was protective against distress. Through multiple regression analyses they found that acceptance partially mediated the relationship between distress and illness identity and personal control (appraisals of illness, and perception of how much control the person has over their illness).

Birchwood & Cochrane (1997) found that an ‘ignore/accept’ coping style correlated with lower burden. This seems unclear, given that in later studies ignoring has been linked to avoidance, whereas acceptance is the opposite. In terms of denial, Rammohan et al. (2002) found that this factor, closely linked with avoidance, and the opposite of acceptance, was positively correlated with higher burden and lower wellbeing.

Some of these findings link with the cognitive model of caregiving (Kuipers et al., 2010), in that caregivers who have lessened or reduced social support experienced higher burden. The use of practical problem-solving skills also relates to this model, as these caregivers experienced less burden.

#### *Correlates of emotion-focused coping*

Nehra et al. (2005), Hanzawa et al. (2008) and Onwumere et al. (2011) found that the use of avoidant coping was related to higher levels of burden. Hanzawa et al. (2008) also found that more avoidance correlated significantly with higher burden, and these findings were replicated in their 2010 study (though not in the Japanese sample). Onwumere et al. (2011) supported this, in that avoidant coping correlated positively with a higher GHQ score, for both caregivers of people with chronic

psychosis/schizophrenia and of those with early-onset psychosis. This is contrary to previous research that has suggested that caregivers cope better or suffer less distress the longer they care (Martens & Addington, 2001), and provides evidence for avoidant coping being a problem for caregivers throughout the progression of the illness. Thunyadee et al. (2015) found that less use of escape/avoidance strategies correlated with lower burden. These findings regarding avoidant coping may offer support for the cognitive model of caregiving (Kuipers et al, 2010), in that avoidant coping is linked to higher burden and distress.

Magliano et al. (1995) found that depressed caregivers were more likely to be resigned to the illness. Resignation was significantly correlated with higher burden in findings from Hanzawa et al. (2010), yet only in the caregivers from Japan. Goncalves-Pereira et al. (2012) found that resignation on the FCQ correlated significantly with tension, worrying and overall score on the IEQ. Dyck et al. (1999) found that self-blame as a coping strategy was a significant predictor of burden. The authors describe 'passive' coping strategies as more associated with psychological distress, thus supporting previous research.

Hanzawa and colleagues (2008) found that more coercive coping significantly correlated with higher burden, and replicated this in both Japanese and Korean samples of a later similar study, where coercion was a significant predictor of burden (Hanzawa et al, 2010). Kate et al. (2013) also supported this, in that higher coercion was associated with lower quality of life scores. Goncalves-Pereira et al. (2008) found that coercion correlated significantly with the tension subscale of the IEQ. Nehra et al. (2005) found that in comparison to bipolar caregivers, schizophrenia caregivers used coercion significantly more often. Magliano et al. (1995) identified that coercion significantly correlated with anxiety in caregivers. Budd et al. (1998) found that two coping styles,

criticism and collusion, were significant predictors of burden following regression analyses.

Regarding longitudinal research allows firmer conclusions to be drawn about the direction of causality. Magliano and colleagues' longitudinal study (2000) found that caregivers who reduced their avoidant coping also had reduced levels of both subjective and objective burden. Roick and colleagues' (2006) multi-centre longitudinal study also found that caregivers who improved their coping strategies had reduced levels of burden over a period of time. However, this was based on a simple measure from the IEQ, asking participants to rate how well they could cope on a 5-point scale. More detail regarding the specific coping strategies that led to lower burden was therefore not explored. Lim and Ahn (2003) concluded that negative coping was associated with burden – but again, there was no explanation of what the negative coping strategies were.

Nitsche et al. (2010) and Jagganthan et al. (2015) identified no significant relationships between coping and burden or distress. Birchwood and Cochrane demonstrated that once behavioural disturbance (in service users) was controlled for there were no significant correlations between coping and burden. Magliano et al. (1995) indicated several correlations, such as between resignation and depression, but conceded no clear pattern of coping and distress.

## **Discussion**

This review has aimed to synthesise the literature investigating coping strategies utilised by caregivers of people with psychosis. It extends a recent non-systematic, narrative review (Grover et al., 2015), by selecting studies according to specified search criteria and reporting the methodological detail of the search. This review has focused



on how coping strategies are elicited and measured, what coping strategies are used, and how such strategies relate to outcomes for this population.

In summary, the literature suggests that the use of problem-focused coping, in particular coping via the seeking of social support, is related to lower caregiver burden, a more positive experience of caregiving, and lower distress in caregivers. The caregiver's own social support, and the social support around the service user, both appear to be important. Acceptance was also found by a number of studies to relate to better wellbeing, and to be protective against distress. This could link to other research that has found that appraisal and acceptance of the illness or of one's role can influence and relate to the level of burden and distress experienced by caregivers (Kuipers et al., 2010).

Emotion-focused coping was overall more often related to higher burden and distress in caregivers. The use of avoidant coping was particularly prevalent, and correlated significantly with higher burden in most of the studies reviewed. The longitudinal studies also indicated that a reduction in avoidant coping led to lower burden, thus strengthening the causal link between this type of coping and outcomes. However, it may also be the case that higher burden causes people to engage in avoidant coping strategies, and this may be linked to a myriad of factors, including level of symptoms or previous relationship style (as found by Kuipers et al., 2010 and Tennakoon et al., 2001). Collusion and coercion were also consistently linked with higher burden, as was resignation. Again these strategies could relate to complex factors including client presentation, length of illness and appraisals of the role and diagnosis. There were occasions where emotion-focused coping did not link to burden, therefore it is difficult to draw firm conclusions about its impact. This confirms, using a

systematic methodology, the conclusions of the expert, but non-systematic review of Grover et al. (2015).

### *Limitations of the current literature base*

The majority of the studies utilised convenience sampling, and thus findings are biased towards responders, particularly in the case of participants recruited from caregiver support services. Some studies excluded particular groups of participants, such as inpatients, or caregivers and care recipients not living together, thus further reducing generalisability. Much of the research reviewed here is cross-sectional in nature, which means it is difficult to draw firm conclusions or determine causality. Longitudinal research of this (client) group is few and far between, yet has been accomplished by some researchers, and thus is possible.

The use of many varied measures to determine coping strategies and other outcomes means that it is difficult to fully compare and synthesise, as well as assess if findings are replicated across studies. As discussed, self-report questionnaires are subject to bias, but are also quick and economical, and thus will continue to be utilised for this client group. However, in order to reduce this bias, more objective means of measurement could be considered in order to assess caregiver burden. For example, the amount of contact a caregiver has with a service, or even with their own doctor regarding their stress, could also be considered in measuring burden.

In all studies, only one caregiver was assessed per service user. The Family Coping Questionnaire (Magliano et al., 1996) explores how the family responds, but only one caregiver answered it in most cases, potentially misrepresenting the family view as a whole. How families cope, assessed by responses from all members in contact with the service user, rather than just one caregiver within the family, could be a useful area of research to further explore.

Most studies have aimed to explore strategies used by caregivers in relation to the stress-coping model, yet other models, such as the self-regulation model, have been explored by more recent research (Fortune et al., 2005). Religious coping remains an area that is currently under-researched, and thus could be expanded. Caregiver burden is still the main factor explored in relation to coping in this population. However, a small number of studies have begun exploring other, more positive concepts, such as wellbeing, quality of life, and overall experience of caregiving.

#### *Strengths and limitations of the review*

This review encompassed a wide range of research in terms of culture and ethnicity, which is a strength. However, cultural differences need further consideration within this population in order to help researchers effectively tailor and develop interventions. A limitation of this review is that only studies in English were included. Qualitative studies were also excluded due to complexities in quantifying relationships. A review of the qualitative literature regarding coping strategies in caregivers of people with psychosis could further our understanding of directions of causality, other influencing factors, and how coping strategies relate to a wider breadth of outcomes and experiences.

#### *Future research directions*

The literature base exploring coping strategies and outcomes in caregivers of people with psychosis is large, and findings have often been replicated, despite some limitations in methodology, and difficulties in comparing results.

One of the main limitations of the current literature base is the varied measurement of coping strategies within this population. Specific measures of coping, designed for caregivers of people with psychosis, could be very useful in providing consistency in future research, and thus aiding comparison across populations. This is also the case for measurement of burden in caregivers, of which there are numerous tools. The ECI is a current measure with potential to be used widely, measuring both negative and positive experiences related to caregiving, and is increasing in popularity. A new questionnaire – The Schizophrenia Caregiver Questionnaire (SCQ, Gater et al., 2015), has strong face validity and reliability, and is a promising measure, specific to this population.

Given the findings of this review, it is clear that promoting caregivers' use of problem-focused coping strategies should remain a priority, as these strategies relate to better outcomes. This could be continued via encouraging social support via groups, and increasing knowledge and awareness in order to encourage acceptance and positive reframing. Current NICE (2014) guidance recommends appropriate interventions for caregivers of people with psychosis, particularly in terms of psychoeducation. Increasing caregivers' coping repertoires should continue to help in terms of reducing burden and distress, yet more research could focus on wellbeing and other more positive psychological factors.

More specific interventions could include those aimed at increasing caregivers' own sense of enjoyment and valued living, through the continuation and encouragement of their social interests, which may help in cases of emotional over-involvement. Interventions encouraging values-based activity, such as Acceptance and Commitment Therapy (ACT, Hayes, Strosahl & Wilson, 2011), may be beneficial in this population, and indeed recent research has indicated benefits in terms of improving wellbeing for

caregivers undertaking a brief ACT group intervention (Wutke, Patterson, Kucharska & Barker, 2013; Jolley et al., in prep).

Emotion-focused coping, particularly avoidant coping, has been linked (though somewhat inconsistently) to higher burden and distress in caregivers. Further research into this coping style is warranted, given that it is frequently used and linked with poorer outcomes. The reliance on reducing the emotional burden of caregiving may be linked to the construct of experiential avoidance. Experiential avoidance is described as “the tendency to engage in behaviours that alter the frequency, duration or form of unwanted private events (i.e. thoughts, feelings, physiological events, and memories and the situations that occasion them)” (Karekla & Panayiotou, 2011, p.164). Experiential avoidance is linked with negative outcomes, including increased stress, anxiety and depression (Chawla & Ostafin, 2007).

Kashdan, Barrios, Fortsyth and Steger (2006) explored the parallels between experiential avoidance and avoidant coping, and concluded that there are common elements, when comparing completed measures of the constructs. Exploration of experiential avoidance, or psychological inflexibility (as it is also known, Hayes et al, 2011) has not yet been conducted within caregivers of people with psychosis. Karekla and Panaiyotou (2011) found that experiential avoidance overlaps significantly with coping strategies of avoidance and denial. There is a gap in the literature for exploring this concept within caregivers.

Other emotion-focused strategies, such as self-blame, could also warrant exploration, as the reviewed literature has linked this to increased distress in caregivers. Guilt, self-blame and compassion fatigue in caregivers has received some recent attention, particularly in caregivers of people with dementia (Losada, Marquez-

Gonzalez, Penacoba & Romero-Moreno, 2010; Day & Anderson, 2011), where guilt and fatigue have been linked with depression and distress. Exploring these concepts in caregivers of people with psychosis could also provide researcher and clinicians with a better understand of caregivers' needs and experiences, and could direct the provision of new interventions. Interventions aimed at reducing experiential avoidance, and increasing psychological flexibility may therefore be potentially useful for this client group, particularly ACT, in terms of valued-action and experiential avoidance, but also compassion-focused therapy (CFT, Gilbert, 2009), which has shown promise in reducing self-blame, shame and guilt, and increasing compassion in other populations (Gilbert & Proctor, 2006; Gilbert & Irons, 2005).

## **Conclusion**

In conclusion, the literatures tells us that coping strategies utilised by caregivers of people with established psychosis are varied, widely measured, and do have an impact on outcomes for this population. Emotion-focused coping strategies, such as avoidance, seem to be most consistently related to higher burden and distress. In order to help produce better outcomes for caregivers, and thus hopefully for service users, research and clinical practice should focus on enhancing problem-focused strategies, such as knowledge, social connection and support, as well as aiming to reduce avoidant styles of coping, and those relating to negative appraisal of the role. Further research on wider potentially related factors, such as experiential avoidance, self-blame, guilt and compassion may enhance our understanding of the complex experience of caregiving and coping in this role.

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**Major Research Project**  
**Section B: Empirical paper**

**ACT with Compassion: Exploring third-wave factors and trialling a new group intervention for caregivers of people with psychosis.**

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SALOMONS  
Canterbury Christ Church University

## **Abstract**

**Aims:** The study aimed to examine the relationship between wellbeing, burden, distress and third-wave factors, including self-compassion and psychological flexibility, in caregivers of people with psychosis. The study secondly aimed to trial a new brief group intervention, combining Acceptance and Commitment Therapy (ACT) and Compassion-focused Therapy (CFT) for this population.

**Method:** Twenty-nine participants were assessed at baseline on primary measures of wellbeing, distress, psychological flexibility and self-compassion. Secondary outcomes including burden and mindfulness were also explored. Correlation analyses were used. Fourteen participants completed the group intervention and follow-up measures, and pre-post investigations were employed.

**Results:** Lower levels of psychological flexibility and self-compassion were related to lower levels of wellbeing and higher levels of burden and distress. There was a potential mediating effect of psychological flexibility on the relationship between self-compassion and wellbeing. The group intervention was acceptable to caregivers, and there were significant positive changes in self-compassion, distress, burden and mindfulness.

**Conclusion:** The study adds to the existing data regarding wellbeing and burden in caregivers of people with psychosis. This study provides new insights into the factors of self-compassion and psychological flexibility within this population. The ACT with Compassion intervention is a promising, brief intervention which would benefit from further application and evaluation.

*Key words: Caregivers, psychosis, ACT, compassion, group intervention*



## **Introduction**

### *Informal caregivers of people with psychosis*

Informal caregivers (relatives, or friends, providing unpaid care) are known to play a key role in the lives of people with psychosis and schizophrenia spectrum disorders (National Institute for Health and Care Excellence (NICE), 2014)<sup>2</sup>. Psychosis is a distressing mental health problem, often characterised by hallucinations (such as hearing voices) difficulties in thinking, experiences of delusional beliefs, and issues of low motivation, mood and anhedonia (NHS Choice, 2014). Caregivers of people with psychosis frequently help with day-to-day care, including providing emotional, social and financial support, liaising with a myriad of services and supporting people during crises. Research suggests that service users<sup>3</sup> with caregiver support experience a better quality of life and have fewer and shorter inpatient admissions (Fleury, Grenier, Caron & Lesagel, 2008), demonstrating that caregivers are of critical importance. The Carers Trust ([www.carers.org](http://www.carers.org)) proposes that informal caregivers of people with disability and illness save the economy £87billion per year.

### *Caregiver burden & related models*

Caregivers make substantial sacrifices in order to provide care, and caregiving can provide rewards in terms of self-confidence, maturity and life experience (Bauer, Koepke, Sterzinger & Spiessl, 2012). However, caregiving can also have a negative effect on caregivers themselves. ‘Burden of care’ is a well-documented issue, with caregivers often experiencing clinical levels of stress, depression and anxiety (Scazufca & Kuipers, 1996; Harvey, Burns, Fahy, Manly & Tatten, 2001). Feelings of guilt, self-

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<sup>2</sup> The term ‘psychosis’ will be used throughout this paper to refer to the wider spectrum of disorders.

<sup>3</sup> The term ‘service users’ will be used to refer to people experiencing psychosis who are using services

blame, shame and grief are also common, as is loneliness, with high levels of social isolation, often fuelled by the societal stigma surrounding psychosis (Kuipers & Bebbington, 2005). There is substantial literature indicating that increased burden and poorer caregiver wellbeing often leads to poor relationships, which ultimately impacts negatively on service user outcomes (Sczufca & Kuipers, 1996; Ohaeri, 2003; Kuipers, Onwumere & Bebbington, 2010). Negative appraisals of the service user's illness and maladaptive coping strategies have been demonstrated to be key mechanisms, associated with higher levels of carer distress, poorer relationships and lower levels of functioning, and mediating the effects of stressors on negative carer outcomes (Kuipers et al, 2010; Onwumere et al, 2011; Dyck, Short & Vitaliano, 1999).

Wellbeing amongst caregivers of people with psychosis is correlated with clinical improvements in the people they care for (Pharoah, Mari, Rathbone & Wong, 2010). This suggests that by improving caregiver wellbeing, and reducing burden, that indirectly service users' wellbeing may be also improved. Recent research has started to address this by exploring the specific process and mechanisms contributing to caregiver distress, and developing stand-alone therapeutic interventions for caregivers (Kuipers et al., 2010), in line with NICE guidance (NICE, 2014).

#### *Existing interventions for caregivers*

Family interventions (FI) have been particularly helpful for families affected by psychosis (Pharoah et al., 2010; Okpokoro, Adams & Sampson, 2014). FI is aimed at reducing high levels of expressed emotion (EE). High EE within families, including criticism and emotional over-involvement, has been consistently identified as an indicator for relapse in psychosis (Butzlaff & Hooley, 1998). FI is recommended in the NICE guidance (2014) for all individuals and families in psychosis settings, yet for

several reasons, such as lack of resources, interventions are often not implemented fully within services (Kupiers, 2011; Eassom, Giacco, Dirik & Priebe, 2014; Ince, Haddock & Tai, 2015). Barriers to implementing FI include the fact that the intervention is therapist intensive and requires specialist training. Practical issues, such as timing and caregiver availability, given work and other commitments, can also prevent implementation. FI also depends upon the willingness of both the service user and caregivers to engage, and thus in cases where a service user is unwilling, family members may not receive the input or help they desperately want and need (Kuipers, 2010).

To counter these barriers, caregiver-only interventions have increased over recent years, as recommended by NICE (2014). Interventions most commonly focus on psychoeducation, in order to improve caregiver understanding of psychosis, recovery, medication and relapse. Increasing knowledge and understanding has been shown to influence caregivers' sense of ability to cope, as well as altering appraisals of the illness (Kuipers et al., 2010). Lobban and colleagues (2013) recently reviewed interventions for caregivers of people with psychosis. They found that psychoeducation featured as a component in 43 of the 50 reviewed randomised-controlled trials, with 28 of these finding it an effective intervention. Psychoeducation is a key component of Cognitive-Behavioural Therapy (CBT), and indeed these interventions for caregivers often take a cognitive-behavioural stance, aimed at changing distressing and unhelpful appraisals of the condition, the service user and the caregiving role. Lobban et al., (2013) detailed that a number of the caregiver intervention studies they reviewed included common CBT elements such as goal setting and challenging unhelpful beliefs, which were generally found to be effective for the population.

Other interventions, such as caregiver support groups, are also popular in psychosis services. Chien and Norman (2009) reviewed the literature on mutual support groups for this population, and concluded that many resulted in long-term benefits, such as reduced burden and distress, enhanced coping ability, and social support. Caregivers often experience isolation in their role and this can be countered by meeting with other caregivers, sharing, learning and supporting each other (Chien, Norman & Thompson, 2004). Group interventions are common for this population; they are relatively cost-effective, allowing services to reach a greater number of caregivers, as well as providing a space for connection, openness and acceptance.

*Third-wave approaches for caregivers.*

The ‘third wave’ of cognitive behaviour therapies is a fast-growing area of research, with a focus on process over content, and an emphasis on acceptance of private difficult events, rather than the aim to reduce or eliminate negative content. Such approaches are transdiagnostic, and recent research has shown promise in the use of these interventions for many areas, including depression, anxiety and psychosis (Kahl, Winter & Schweiger, 2012; Jiménez, 2012; Öst, 2014).

Acceptance and Commitment Therapy (ACT, Hayes, Strosahl & Wilson, 1999; 2011), is a third wave, empirically-based cognitive-behavioural psychological therapy involving a combination of acceptance and mindfulness strategies. According to ACT theory, the main underlying problem of psychological disorders is psychological inflexibility (also referred to as experiential avoidance, Hayes et al., 2011), whereby one attempts to exert control over distressing internal experiences with the repeated use of strategies that may not be particularly effective or helpful in the long term (i.e. avoidant coping). Therefore, ACT promotes that higher levels of flexibility in the way

one responds to unpleasant stimuli (including thoughts) is beneficial, and thus values-driven action is increased even in the presence of difficult emotions and stressful circumstances (Hayes, Luoma, Bond, Masuda & Lillis, 2006; Hayes et al., 2011).

Research has identified psychological flexibility as a significant predictor of wellbeing (Mitmansberger, Beck, Höfer & Schüßler, 2009), indicating its usefulness as an intervention target in increasing wellbeing. High psychological inflexibility has been highlighted as present in caregivers of various populations, such as dementia sufferers (Spira et al., 2007). Following exploratory research, a series of studies have demonstrated the effectiveness of ACT interventions across caregiver populations who care for those with severe and enduring disorders, including parents of children with learning disabilities (Eisenhower, Baker & Blacher, 2005) and autism (Blackledge & Hayes, 2006), partners of people with brain injuries (Williams, Vaughan, Huws & Hastings, 2014) and family caregivers of people with dementia (Losada et al, 2015). These studies have found that ACT approaches have helped increase psychological flexibility and wellbeing in these populations.

ACT and mindfulness interventions specifically for caregivers of people with psychosis have also demonstrated promising results in improving wellbeing and reducing levels of distress (Clark, Doyle, Walsh & Robson, 2012; Jolley et al, in prep; Butler et al, 2013; Wutke, Patterson, Kucharska & Barker 2013; Lipkin, 2013).

*Compassion-focused therapy as an additional approach*

Compassion-focused therapy (CFT), another third-wave approach, was developed by Gilbert (2009; 2010a). The approach stemmed from his work with people with high levels of shame and self-blame or criticism, and its' theoretical basis is in evolutionary psychology. CFT aims to develop compassion for the self and others in order to increase wellbeing and aid recovery. The key principles are to motivate the individual to care for their own wellbeing, to become sensitive to their own needs and distress, and to extend warmth and understanding towards themselves and others. Given that caregivers of people with psychosis have demonstrated 'burden of care', including higher levels of guilt and self-blame, it has been suggested that caregivers could benefit from increasing compassion towards themselves (Neff, 2012). Neff also states that caregivers can 'burnout' as they need to develop double the amount of compassion - for both themselves and the people they care for '*in order to remain in the presence of suffering without being overwhelmed*'. (Neff, 2012, para. 4)

Research has shown that mindfulness-based and CFT interventions can increase self-compassion and reduce stress in healthcare professionals (Boellinghaus, Jones & Hutton, 2014; Shapiro, Astin, Bishop & Cordova, 2005), but no study to date has evaluated compassion-focused interventions in caregiving, or investigated the role or levels of compassion (towards the self or others) in caregivers of people with psychosis.

Neff and Tirch (2013) suggest that the combination of ACT and CFT is harmonious considering their similar theoretical underpinnings, with Hayes (2006) noting that self-compassion and compassion are both rooted in ACT processes. Both self-compassion and psychological flexibility are correlated with decreasing depression, anxiety and other psychopathologies (Neff, Kirkpatrick & Rude, 2007; Kashdan & Rottenberg, 2010), and could therefore be helpful for caregivers. Building upon existing ACT protocols with specific CFT techniques would potentially provide

caregivers of people with psychosis with an intervention targeting psychological flexibility, wellbeing and self-compassion, leading ultimately to better outcomes for themselves and for the service users in their care. This is therefore clinically relevant, both for caregivers who are themselves experiencing distress, but also for service users who may indirectly benefit from their caregivers receiving this specialist support.

#### *Aims and rationale for the current study*

Given the highlighted gaps in the current research base of psychological interventions for caregivers of people with psychosis, this study aimed to consider the potential contribution of ACT and CFT approaches to addressing wellbeing in caregivers of people with psychosis. The first part of the study was a baseline examination of the association of psychological flexibility and self-compassion with caregiver wellbeing, alongside other factors including caregiver burden and psychological distress. This is the first study to explore the role of these ‘third-wave’ processes within this population. The second part of this study is a pilot and feasibility study evaluating an ACT and CFT group intervention for caregivers, and exploring the impact of the group intervention on targeted mechanisms and outcomes. In order to explore specific benefits of combining ACT and CFT the results were compared to a previous study evaluating an ACT-only group intervention, compared to a waitlist control group.

#### *Research hypotheses*

The study was designed to investigate the following specific hypotheses in caregivers of people with psychosis:

*Part one.*

1). Caregiver wellbeing will be associated with psychological flexibility and self-compassion, such that higher levels of psychological flexibility and of self-compassion will be independently associated with greater psychological wellbeing (as measured by wellbeing, distress, and caregiver burden scores).

*Part two.*

2a). ACT and CFT delivered in a group format will positively impact on caregivers' levels of psychological flexibility and self-compassion, which in turn will impact on wellbeing.

2b). ACT and CFT delivered in a combined group format will also increase mindfulness and compassion for others, and reduce burden and guilt associated with caregiving.

2c). ACT and CFT delivered in a combined group format will have a greater positive impact on self-compassion, compared to ACT alone for this caregiver population.

2d). ACT and CFT delivered in a combined group format will be feasible and acceptable to this caregiver population.

## **Methodology**

### *Design*

The study comprised two parts. Part one employed a cross-sectional within-group correlational design to examine associations of the key psychological



mechanisms of interest (self-compassion and psychological flexibility) with the key outcomes of interest (primarily carer wellbeing; secondarily, carer distress and burden). Part two employed both a pre-post experimental design, and then a between group comparison, to test the effectiveness of a new, brief (five session) group intervention for caregivers ‘ACT with Compassion’; combining ACT and CFT approaches. Feasibility and acceptability of this novel intervention was also informally assessed through caregiver feedback. The study was conducted over an 11-month period (April 2015 - March 2016). Outcome data from the current study was directly compared with the caregiver outcome data from a recent randomised-controlled trial of an ACT group for caregivers (ACT for Recovery), using between-group analyses of key outcome measures. The methodology for the comparison study is described in appendix B.

#### *Sample size and power calculations*

Regarding sample size and adequate recruitment, power calculations were considered. For the baseline correlational analyses (part one, hypothesis 1), a sample size of 25 was required to detect a large correlation (0.6 and above, Cohen 1988) between the primary measure of wellbeing, and the two candidate psychological mechanisms of self-compassion and psychological flexibility, with 80% power, and alpha adjusted to 0.025 to take account of the two planned tests.

For the pre-post analysis (part two, hypotheses 2a and 2b), a sample size of 15 was required, in order to have 80% power to detect large ( $F \geq 0.4$ ) within-subject effects using repeated measures ANOVA with two measurement points, assuming a correlation between measures of 0.5, with alpha set at 0.05. When comparing change in self-compassion between groups (hypothesis 2c), a sample size of 45 (15 participants in the current study and additional data from 30 recruited in the comparison trial) was

required to detect large ( $F \geq 0.4$ ) between group effect sizes, with 80% power, and alpha set at 0.05. Power calculations were conducted using G-Power version 3.1.5 (Faul, Erdfelder, Lang & Buchner, 2007).

### *Participants*

Twenty-nine caregiver participants were recruited from carer support services within ‘Promoting Recovery’ mental health teams for working age adults with established psychosis. The teams were based within secondary care community psychiatric services, located in two inner city boroughs, and were part of a large National Health Service Mental Health Foundation Trust. The carer support services were specifically funded to provide NICE recommended support for caregivers of people with psychosis. The average age of participants was 53.7 years (standard deviation=16.6 years) and 22 of the participants were female (75.9%). Further demographic details (ethnicity, employment status and relationship to care recipient) are displayed in Table 3 in the results section.

### *Inclusion and exclusion criteria*

Caregivers were invited to participate if they provided informal care for a service user receiving support from one of the Recovery teams. Caregivers had to be aged over 18 and able to provide informed consent. In order to ensure that participants were likely to be able to benefit both from the intervention, and from the group context (sharing similar experiences of caregiving), caregivers who themselves had a known diagnosis of severe mental illness and were currently unwell were excluded, as were those with learning disabilities or any diagnosis of dementia. Caregivers who did not speak English adequately were also excluded, as it was not possible to provide interpreters to aid with research data collection or the group intervention.

### *Ethical considerations*

Ethical approval for the current study was granted as part of a larger series of studies taking place in the carer support services, investigating psychological processes and mechanisms of change in interventions for caregivers. A full IRAS (Integrated Research Application System) application was submitted. The parent study was favourably reviewed by the NHS National Research Ethics Service Committee London – London Bridge (and a full Research Ethics Committee meeting was attended; reference 15/LO/0680, see appendix C for approval letter). The study was also favourably peer reviewed at a university panel and was granted approval from the local Trust’s Research and Development Office (appendix D).

Caregivers’ involvement in the study was recorded by the researcher and by the carer support worker, who added a note to the care recipients’ electronic notes system in the carer/third party section. This was to ensure that services were aware that caregivers were being offered support. Caregiver participants were also asked for their permission for the researcher or carer support worker to inform their own GP of their involvement in the study; however, this was not compulsory, unless issues of risk needed to be communicated. Participants were informed of confidentiality procedures and duty of care to both themselves and the care recipient, should any concerns be raised about themselves or the care recipient during their involvement in the study. Service confidentiality and risk procedures were followed at all times.

### *Procedure*

#### *Part One: Baseline examination*

Potential participants were initially identified via assistant psychologists or support workers based within the carer support teams (caregivers who were either currently involved in the service, or newly referred). Caregivers were sent or given an information sheet (appendix E) before being telephoned by the researcher in order to discuss involvement in the study and potential participation in the groups. A meeting at a mutually convenient time was then arranged. Most participants were seen at the team bases, though some home visits were carried out where necessary (with lone-working policies adhered to at all times).

At the meeting, the researcher answered any questions and gained informed consent (appendix F) from the participant. The baseline measures (described below) were then administered; the researcher either worked through the questionnaires with the participant, or the participant completed them alone (whichever was their preference). It took between approximately 45-75 minutes to complete the questionnaires. In most cases the questionnaires were completed in one meeting. This comprised part one of the study. All participants were offered participation in the ACT with Compassion group intervention.

### *Measures*

In total, eight measures were administered at baseline (see appendices G-N for all measures). Five of these eight measures were specifically included in order to explore the concepts of psychological flexibility, compassion, mindfulness and guilt. Demographic details were also collected from participants.

*1. Psychological flexibility – The Acceptance and Action Questionnaire – Version 2 (AAQ-II, Bond et al., 2011).*

The AAQ-II is a seven-item measure of psychological flexibility, acceptance and experiential avoidance. The second version has high consistency and validity (alpha coefficient .84). Seven items are rated on a seven-point scale (from ‘Never true’ to ‘Always True’), giving a total score ranging from seven to 49. A higher score demonstrates higher psychological inflexibility.

*2. Self-compassion Scale – Short Form (SCS-SF, Raes, Pommier, Neff & Van Gucht, 2011).*

The SCS-SF is a shorter, 12-item version of the original (26-item) self-compassion scale (Neff, 2003), with near-perfect correlation to the longer scale when examining overall score. Items are rated on a five-point scale (‘Almost never’ to ‘Almost always’). A higher overall score (as indicated in the Raes et al., 2011 paper) indicates greater self-compassion.

*3. Compassion for Others Scale (CFOS, Pommier, 2011).*

The CFOS is a recently developed 24-item self-report scale exploring compassion for others. The items contribute to six subscales; kindness, indifference, common humanity, separation, mindfulness and disengagement. Each item is rated on a five-point scale (‘Almost never’ to ‘Almost always’). A higher overall mean score indicates greater compassion.

4. *Five Facets of Mindfulness Questionnaire (FFMQ, Baer, Smith, Hopkins, Krietemeyer & Toney, 2006).*

The FFMQ is a 39-item self-report questionnaire that was developed from a factor analysis study exploring five mindfulness questionnaires, it has high validity and reliability (Baer et al., 2008). The five subscales (facets) are observing, describing, acting with awareness, non-judgment and non-reacting. Items are rated on a five-point scale, with overall scores ranging from 39-195, with a higher score indicating someone is more mindful.

5. *Caregiver Guilt Questionnaire (CGQ, Losada, Marquez-Gonzalez, Penacoba & Romero-Moreno, 2010).*

The caregiver guilt questionnaire is a 22-item self-report scale, exploring the concept of guilt within the caregiver population. It has high validity and reliability, though was originally developed on a population of caregivers of people with dementia. Items are rated on a five-point scale (0='Never' up to 4='Always or almost always') Scores range from 0-88, and internal consistency is acceptable. A score of 22+ is considered the clinical cut-off.

6. *Psychological Distress - Core Outcomes in Routine Evaluation-10 (CORE-10, Barkham et al, 2012).*

The CORE-10 is a brief outcome measure exploring global distress. It is a short form with items taken from the larger CORE-OM, and has high correlation (.94) with the larger scale. Items are rated between 0 (Never) and 4 (Most or all of the time). An overall score of 11 or above is clinically significant in terms of distress.

*7. Warwick Edinburgh Mental Wellbeing Scale (WEMWBS, Tennant et al, 2007).*

The WEMWBS is a 14-item self-report scale comprising only positively worded items related to wellbeing and positive mental health. It was developed by an expert panel and validated on both student and general public representative populations. Cronbach's alphas were high (.89-.91) and the scale correlates highly with other mental health and wellbeing scales. A higher overall score (ranging from 14-70) indicates higher wellbeing. Item eight of the scale ('I feel good about myself') was taken as a measurement of self-compassion for the purpose of examining hypothesis 2c.

*8. Experience of Caregiving inventory (ECI, Szmukler, Burgess, Hermann & Benson, 1996).*

The ECI is a 66-item Likert-scale questionnaire, which explores caregivers' appraisals of the caregiving experience. It measures both negative and positive aspects. The negative aspects are stigma, effects on family, negative symptoms, dependency, difficult behaviours, loss and the need to provide backup. The positive aspects are good aspects of the relationship and positive personal experiences. High reliability and validity has been replicated (Joyce, Leese & Szmuckler, 2000).

*Part Two: 'ACT with Compassion'*

The ACT with Compassion group intervention was based on the ‘ACT for Recovery’ project (O’Donoghue et al., 2015; Jolley et al., in prep), which followed the ACT for Life study (Oliver, Morris, Johns & Byrne, 2011; Johns et al, 2016).

#### *Consultation, development and researcher contribution*

For this study a new group protocol, incorporating aspects of CFT within the ACT approach, was co-written by the researcher and external supervisor, based upon the previous ACT for Recovery manual. Consultation was sought from leading CFT clinicians within the same Trust (with experience of running CFT group interventions for people with psychosis) and CFT exercises and ideas were gleaned from Gilbert’s (2010b) extensive CFT introduction handout. The new manual was distributed within the ACT for Recovery team for advice and feedback. The researcher (who was previously trained in the delivery of ACT group interventions) co-facilitated two sets of groups, one alongside the supervisor, and one alongside a psychologist within the service who had experience of ACT group interventions. Assistant psychologists from the carers’ service also acted as co-facilitators. The other two sets of groups were alternately led by the supervisor and by the additional psychologist, alongside assistant.

#### *The ACT with Compassion group intervention*

Table two outlines the main concepts and exercises within the ACT with Compassion group intervention, session by session. (See appendices P to R for an extract of the group intervention protocol and an example of powerpoint slides and a group worksheet).

#### *Table 2: Session by session summary of the ACT with Compassion group intervention*



Session	Content and concepts
Session 1	<ul style="list-style-type: none"> <li>- Welcome and introduction, establishing group rules</li> <li>- Exploring difficulties associated with coping, using reservoir metaphor</li> <li>- Introduction to theory of compassion; evolution, old/new brain, concept of ‘it’s not our fault’</li> <li>- Introduction to mindfulness and compassionate mind training: soothing rhythm breathing exercise</li> <li>- Introduction to values – identifying values, use of compass metaphor</li> <li>- Setting ‘homework’ – mindfulness practice and committed action for the week, in line with values</li> </ul>
Session 2	<ul style="list-style-type: none"> <li>- Recap of session 1</li> <li>- Mindfulness/ compassionate mind exercises: Body scan</li> <li>- Feedback on committed action and what was noticed</li> <li>- 3 brain systems introduction: threat, drive and soothing</li> <li>- What is compassion – aim to stimulate the soothing system and reduce threat system. Exploring ‘flow’ of compassion</li> <li>- Introduction to ‘Passengers on the Bus’ metaphor</li> <li>- Identifying own passengers and ‘valued direction’</li> <li>- Compassionate colour exercise</li> <li>- Setting ‘homework’ – mindfulness practice and committed action for the week, in line with values</li> </ul>
Session 3	<ul style="list-style-type: none"> <li>- Recap of session 2</li> <li>- Use of imagery in compassionate mind training. Discussion and safe place exercise</li> <li>- Feedback on committed action and committed action – what was noticed.</li> <li>- Exploration of different ways of responding to passengers: struggling, giving in, or willingness. Willingness exercise</li> <li>- Practical exercises: Acting out passengers on the bus metaphor, developing the ‘compassionate driver’</li> <li>- Debrief and feedback</li> </ul>

- 
- Setting 'homework' – mindfulness practice and committed action for the week, in line with values

- Session 4
- Recap of session 3
  - Noticing thoughts exercise: Clouds in the sky / leaves on a stream
  - Discussion of critical self-talk and alternative possibilities
  - Exploring defusing from critical self-talk (labels exercises)
  - Recap of the four sessions
  - Setting 'homework' – mindfulness practice and committed action for the month, in line with values

- Booster
- Recap of whole intervention
  - Repetition of requested mindfulness/ compassionate mind exercises
  - Acting out of passengers on the bus
  - Continuing the work post-group
  - Feedback
- 

### *Group procedure*

The intervention consisted of four, weekly two-hour group sessions (over consecutive weeks), followed by a booster (recap) session four weeks later. The intervention was a closed group, with the same participants attending each week. Due to the brief nature of the groups, participation at all sessions was strongly encouraged, but absence was sometimes unavoidable, due to illness or other commitments.

Over the period of the study, four sets of groups were facilitated, alternating between the team locations and between daytime and evening slots in order to increase accessibility to participants. Overall, 18 participants took part in the group intervention (attending an average of 3.79 sessions each (standard deviation = 1.18), see results section for a flow chart of recruitment and attendance).

During the group intervention, an adequate ratio of facilitator to participants was always maintained (at least 1:3) in order to ensure there was support for participants if any topics or conversations arising should prove upsetting or distressing. Caregivers were advised that they were not obliged to talk about their own difficulties or those of the service user they cared for, but were of course welcome to should they feel comfortable to do so. Post-intervention measures were completed at a convenient time after the fourth session. Participants were offered £10 each as recompense for their travel and time. Participants also completed a feedback form (appendix O). The form consisted of nine questions, four on a Likert-type scale of five options (1= strongly disagree up to 5 = Strongly agree), one on a six-point scale (1= Extremely likely up to 5=extremely unlikely, 6=Don't know), and four open-ended questions with text boxes for free response.

#### *Data Analysis*

Data analysis was conducted using IBM SPSS (version 22). Kurtosis, skewness, Shapiro-Wilks test results were examined to assess normality of the data, as well as visual examination of histograms and box-plots. Z-scores were inspected in order to clarify if the data met parametric assumptions (see appendix S for normality investigations). All data was found to be normal in distribution, thus parametric statistical tests were utilized for the analysis.

For part one of the study Pearson's correlation coefficient was utilised in order to examine the relationships between wellbeing, distress, self-compassion, psychological inflexibility and burden (hypotheses 1) and a multiple regression analysis was employed to determine, post-hoc, the relative contribution of each of the mechanistic variables (self-compassion and psychological inflexibility).

For part two of the study paired samples t-tests were carried out in order to explore the difference between the pre- and post-intervention means (hypotheses 2a & b). Pre-post within-subject effect sizes were also calculated for each outcome. A mixed 3 x 2 level analysis of variance (ANOVA) was carried out in order to test the effect of the ACT with Compassion intervention in comparison the previous ACT-only group intervention (hypothesis 2c). A control group (waitlist) was also available for comparison from the earlier study. Therefore, the between-subjects level was condition (x3) and the within-subjects level was timepoint (x2). Between-group effect sizes were calculated. Content analysis was carried out on caregiver feedback forms in order to explore hypothesis 2d.

#### *Missing data*

Where data was missing (for example, one or two items on a questionnaire) the total score was pro-rated following the guidance of Strube (1985). If more than this number of items had been missed then the data was not included in the final analysis. Due to the large number of measures collected, in some cases a questionnaire was missed. This was more of an issue during follow-up, when a small number of participants declined to complete the entire measures set due to time constraints, resulting in the number of paired measures ranging from nine to 14.

## **Results**

Baseline data analysis will be discussed first (Part 1: hypothesis 1), prior to pre-post intervention analysis (Part 2: hypotheses 2a-c) and finally group feedback analysis (hypothesis 2d).

*Part 1: Characteristics of the sample and baseline analyses of the inter-relationships between self-compassion, psychological flexibility and caregiver wellbeing.*

### *1.1 Sample demographic characteristics*

These are shown in Table three. The majority of the participants were black or minority ethnicity (BME), which is representative of the population in the service borough. The majority of caregivers were parents (34.4% mothers) or partners of service users, which is similar to previous research. Over half (58.6%) of the caregivers and service users lived together. Service users were mainly male (65.5%). No other demographic details were collected regarding service users.

*Table 3: Caregiver demographics (n=29)*

	Frequency (%)
<i>Ethnicity</i>	
White	12 (41.4%)
Black or minority ethnic	17 (58.6%)
<i>Employment Status</i>	
Full-time	7 (24.1%)
Part-time	2 (6.9%)
Unemployed	8 (27.6%)
Housewife/husband	1 (3.4%)
Student	2 (6.9%)

Retired	8 (27.6%)
Other	1 (3.4%)
<i>Relationship*</i>	
Daughter	4 (13.8%)
Son	1 (3.4%)
Sister	1 (3.4%)
Partner/Spouse	8 (27.6%)
Mother	10 (34.5)
Father	2 (6.9%)
Friend	2 (6.9%)
Aunt	1 (3.4%)

\*'Daughter' indicates caregiver is daughter of care recipient (service user)

### 1.2 Sample clinical characteristics

Baseline clinical characteristics are shown in Table four. Average scores were compared (where possible) to norms from similar samples or to the original measure papers. The sample had a significantly lower average level of wellbeing compared to a norm sample. This was also the case for the ECI, where this sample scored significantly more highly on negative experiences of caregiving.

Table 4: Baseline clinical characteristics

Measure	n	Mean ( <i>sd</i> )	Min-max (range)	Mean norms
WEMWBS	29	46.03 ( <i>10.54</i> )	25-67 (42)	51.60*
CORE-10	29	12.34 ( <i>7.14</i> )	0-28 (28)	16.00
AAQ-II	29	23.0 ( <i>9.86</i> )	7-46 (39)	18.53*
Self-compassion Scale	29	36.34 ( <i>7.74</i> )	19-55 (36)	48.12*
Compassion for Others	29	98.62 ( <i>11.56</i> )	74-120 (46)	-
ECI – Negative experience	28	87.21 ( <i>35.97</i> )	14-178 (164)	59.06*
ECI – Positive experience	28	31.94 ( <i>9.57</i> )	14-48 (34)	26.41
FFMQ	28	125.72 ( <i>16.71</i> )	91-155 (64)	116.90
Caregiver Guilt	28	31.86 ( <i>17.31</i> )	69	-

*Key: WEMWBS = Wellbeing, CORE-10 = distress, AAQ-II = Psychological flexibility, ECI = Experience of Caregiving Inventory, FFMQ = Mindfulness. \*= Sample mean statistically different from norm mean.*

Fifty-eight percent (n= 17) of the sample scored above 11 on the CORE-10, indicating clinical levels of distress (Table five). These caregivers were more often female, older and mothers.

Table 5: Levels of psychological distress in the sample (CORE-10)

CORE score range (interpretation)	Frequency (%)
0-4 (Healthy)	6 (20.7%)
5-9 (Low level)	5 (17.2%)
10-14 (Mild distress)	5 (17.3%)
15-19 (Moderate distress)	7 (24.1%)
20-24 (Moderate-Severe distress)	5 (17.3%)
25-40 (Severe distress)	1 (3.4%)

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### 1.3 Association of clinical variables of interest with demographic variables

The relationships of self-compassion, psychological flexibility, wellbeing, caregiver burden and distress with gender and ethnicity (using t-tests) and age (using correlations) were explored in order to identify any potential confounders. T-tests did not indicate any significant differences in scores when exploring differences between gender and ethnicity (defined as white compared to black or minority ethnic). The only significant relationship between the measures of interest and age was a negative correlation with psychological inflexibility (AAQ-II;  $r=-.399$ ,  $p=.032$ ). However, as there was no significant relationship between age and the main outcome variable of wellbeing, or with distress, age was not considered to be a confounding factor (and thus was not included in the later regression model).

### 1.4 Hypothesis testing



Hypothesis 1). Caregiver wellbeing will be associated with psychological flexibility and self-compassion, such that higher levels of psychological flexibility and of self-compassion will be associated with greater wellbeing (as measured by increased wellbeing (primary measure) and lower burden and distress (secondary measures) scores).

Correlations for the variables of interest are displayed in Table six.

Table 6: Baseline correlations

	WEMWBS	CORE-10	AAQ-II	SCS-SF	ECI -ve
CORE-10	$r = -.756^{***}$ $p = .000$				
AAQ-II	$r = -.604^{***}$ $p = .001$	$r = .740^{***}$ $p = .000$			
SCS-SF	$r = .426^*$ $p = .021$	$r = -.462^*$ $p = .012$	$r = -.641^{***}$ $p = .000$		
ECI negative	$r = -.293$ $p = .130$	$r = .513^{***}$ $p = .005$	$r = .498^{***}$ $p = .007$	$r = -.484^{**}$ $p = .009$	
ECI positive	$r = .434^*$ $p = .021$	$r = -.233$ $p = .232$	$r = -.074$ $p = .709$	$r = -.015$ $p = .941$	$r = .020$ $p = .921$

Key: WEMWBS= Wellbeing, CORE-10= Distress, AAQ-II= Psychological Flexibility, ECI= Experience of Caregiving Inventory

\*Significant at .05 level, \*\*significant at 0.01 level \*\*\* significant at Bonferroni corrected level (.008)

### 1.5 Primary outcome: Wellbeing

There was a significant negative correlation, of large size, between psychological flexibility and wellbeing ( $r = -.604, p = .001$ ), indicating that as one increases, the other decreases (a higher score for the AAQ-II indicates higher psychological *inflexibility*). Self-compassion was positively correlated with wellbeing, with a medium effect size, ( $r = .426, p = .021$ ) indicating that as self-compassion increases, wellbeing increases. This association did not remain significant following Bonferroni correction for multiple testing. The primary analyses therefore supported Hypothesis 1.

#### *1.6 Secondary outcomes: Distress and burden*

There was a significant positive correlation, of large size, between psychological inflexibility and psychological distress on the CORE-10 ( $r = .740, p = .000$ ), indicating that as inflexibility increases, distress increases, and vice versa). Self-compassion also negatively correlated with psychological distress ( $r = -.462, p = .012$ ) indicating that as self-compassion increases, psychological distress decreases. This association was of medium size. Caregiver burden, as measured by ECI negative scale score was significantly negatively correlated with self-compassion ( $r = .484, p = .009$ ), again with a medium effect size, and significantly positively correlated with psychological inflexibility ( $r = .498, p = .007$ ), with a medium effect size, indicating that when self-compassion increased or psychological inflexibility decreased, burden also decreased. Secondary analyses therefore also supported hypothesis 1.

#### *1.7 Post-hoc tests: Identifying predictors of wellbeing*

Post-hoc multiple regression testing, with wellbeing as the dependent variable and psychological flexibility and self-compassion as predictor variables showed that the two independent variables together statistically significantly predicted wellbeing;  $R^2 = F(2,26) = 7.545, p = .003$  and explained 36.7% of the variance in wellbeing. Psychological flexibility was a significant predictor of wellbeing when the effects of self-compassion were accounted for;  $\beta = -2.763, p = 0.010$ . However, accounting for the effects of psychological flexibility, self-compassion was not a significant predictor ( $\beta = .326, p = .747$ ). Collinearity statistics indicated acceptable variance inflation factors (1.660) and tolerance (.602) (appendix U).

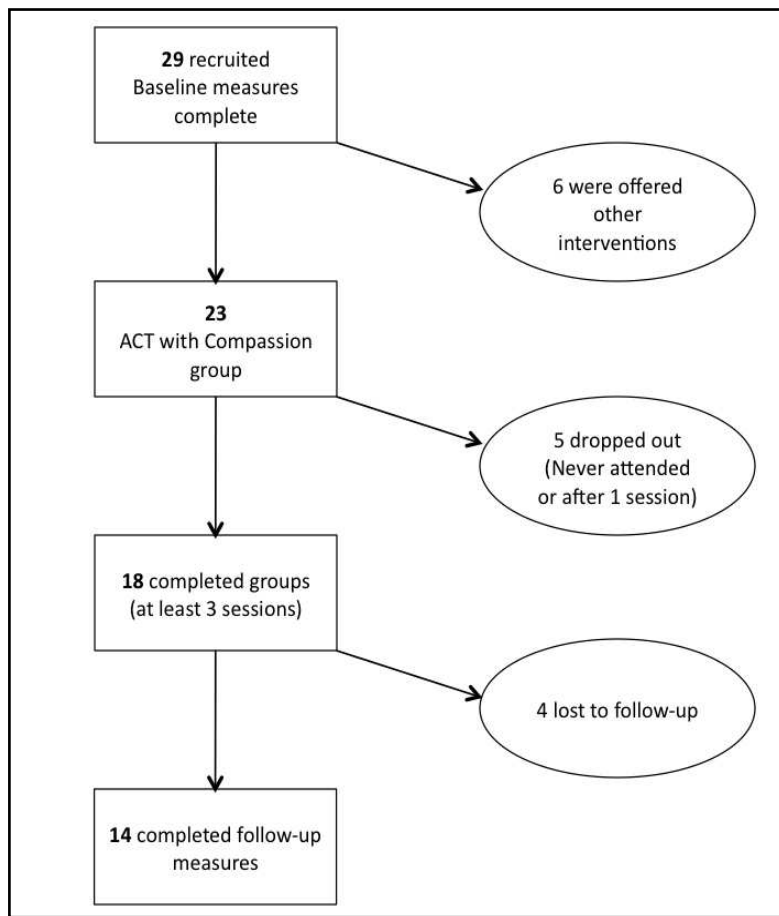
Hypothesis 1 was therefore supported, as caregiver wellbeing (in addition to distress and burden) was significantly correlated with self-compassion and psychological flexibility. However, post-hoc analyses indicated that psychological flexibility and self-compassion did not independently predict wellbeing. Findings are more consistent with a mediating role of psychological flexibility in the relationship between self-compassion and wellbeing, (the association of psychological wellbeing with self-compassion was large and significant,  $r = -.641, p < .001$ ), rather than independent contributions.

## *Part 2: Group intervention results*

### *2.1 Sample and participant flow through the study*

Of the 29 participants included at baseline, 14 completed post-intervention follow-up measures and were included in the pre-post analysis (however, some participants did not complete all measures). The figure below details the flow chart of participants from recruitment to follow-up.

Figure 1. Flow chart of participation



The attrition (drop-out) rate pre-intervention was therefore 21.74%, and the percentage of participants lost to follow-up post-intervention was 22.22%. Overall, 78.2% of participants recruited to the ACT with Compassion group intervention attended at least three sessions and 60.8% completed the follow-up measures.

## 2.2 Changes from baseline to post-intervention

Pre- and post-intervention descriptives are displayed in table seven.

Table 7: Pre- and post intervention clinical characteristics

Measure	Pre		Post	
	n	Mean (sd)	n	Mean (sd)

Primary hypothesised mechanisms of change				
AAQ-II	14	22.57 (10.78)	14	19.73 (10.29)
SCS-SF	14	37.00 (7.73)	14	43.35 (8.39)
Secondary hypothesised mechanisms of change				
CFOS	14	91.29 (12.67)	13	101.46 (13.57)
FFMQ	14	126.15 (16.84)	12	144.41 (20.05)
Primary outcome				
WEMWBS	14	44.71	14	50.62 (11.87)
Secondary outcomes				
CORE-10	13	13.84 (6.28)	13	9.46 (6.21)
ECI -ve	13	92.63 (35.67)	9	82.77 (36.81)
ECI +ve	13	31.90 (9.12)	11	30.45 (7.68)
Guilt	13	29.61 (15.82)	11	22.18 (14.53)

*Key: AAQ-II= Psychological flexibility, SCS-SF= self-compassion, CFOS= compassion for others, FFMQ= mindfulness, WEMWBS= Wellbeing, CORE-10= distress, ECI= Experience of Caregiving*

### 2.3 Hypothesis testing

*Hypothesis 2a). ACT and CFT approaches, delivered in a group format, will positively impact on caregivers' levels of psychological flexibility and self-compassion, which in turn will impact on wellbeing. Secondary outcome and change variables including mindfulness will also improve.*

Pre- and post-intervention means suggest change in the desired direction on all measures. Paired sample t-tests were conducted and effect sizes (Cohen's *d*) were calculated (see appendix V for calculations).

*Table 8: t-, p-values and effect sizes for paired data*

Measure	(df) t value	p value	Effect size
SCS-SF	(13) -3.582	.003	0.87
AAQ-II	(13) 1.492	.159	0.21
WEMWBS	(13) -2.011	.066	0.62
CFOS	(12) -2.730	.018	0.80
FFMQ	(11) -3.333	.007	1.08
CORE-10	(12) 3.527	.004	0.62
ECI negative	(7) 3.367	.012	0.27
ECI positive	(9) -.213	.836	0.15
Guilt	(9) 1.272	.235	0.46

*Key: AAQ-II= Psychological flexibility, SCS-SF= self-compassion, CFOS= compassion for others, FFMQ= mindfulness, WEMWBS= Wellbeing, CORE-10= distress, ECI= Experience of Caregiving*

For the two primary hypothesised mechanisms of change, there was a significant increase in level of self-compassion, with a large effect size. There was an increase in psychological flexibility; this did not reach statistical significance, but showed a medium effect size. For the main outcome variable of wellbeing there was an increase, though this was not statistically significant (again with a medium effect size). The primary analyses therefore partially supported hypothesis 2a.

*Hypothesis 2b). ACT and CFT delivered in a combined group format will also increase mindfulness and compassion for others, and reduce burden and guilt associated with caregiving.*

In the secondary analyses, for the additional measures of mechanistic interest, there was a statistically significant increase in level of compassion for others and in level of mindfulness. In terms of secondary outcomes, there was a significant decrease in psychological distress, and a statistically significant reduction on the negative subscale of the ECI. Effect sizes ranged from small to very large. There was no significant change on the positive subscale of the ECI or in caregiver guilt (though this had reduced to just above the clinical cut-off level of 22). Secondary analyses therefore also partially supported hypothesis 2a.

#### *2.4 Intervention comparison*

*Hypothesis 2c). ACT and CFT delivered in a combined group format will have a greater positive impact on self-compassion and wellbeing compared to ACT alone for this client group.*

Pre-and post intervention scores for self-compassion (as measured by WEMWBS item 8) and wellbeing for the current study and for the intervention and waitlist control group of the previously ACT for Recovery study are shown in Table nine.

*Table 9: Pre- and post-intervention means for the three conditions*

Measure	ACT with Compassion n = 14	ACT only n = 21	Waitlist n = 9

	Pre mean (sd)	Post mean (sd)	Pre mean (sd)	Post mean (sd)	Pre mean (sd)	Post mean (sd)
Self- compassion (WEMWBS-8)	2.667 (0.65)	3.583 (1.24)	3.190 (.51)	3.381 (.80)	3.333 (1.00)	3.111 (.92)
Wellbeing (WEMWBS)	44.71 (9.58)	50.62 (11.87)	46.229 (7.95)	49.143 (8.22)	45.556 (10.88)	44.632 (10.21)
AAQ-II	22.57 (10.78)	19.73 (9.92)	25.048 (7.91)	20.190 (5.81)	20.444 (9.36)	23.333 (10.38)

*Key: WEMWBS = Wellbeing, WEMWBS-8 = self-compassion, AAQ-II = Psychological flexibility*

Baseline means across the three groups were examined. There was no significant difference between means at baseline (all  $f$  values  $< 2.125$ , all  $p$  values  $> .129$ , appendix W).

Mean scores for all measures moved in the desired direction for both the ACT with Compassion and ACT-only groups (i.e. increased wellbeing and decreased psychological inflexibility and distress). Conversely, the waitlist group showed a slight decrease in wellbeing and an increase in psychological inflexibility.

The 3.x2 ANOVA demonstrated that there was a significant main effect of group attended on WEMWBS item 8 (self-compassion item);  $F(2,39) = 5.113, p = .011$ . There was no significant effect of group on overall wellbeing. Post Hoc tests (Tukey's procedure) showed no significant differences in paired group comparisons for WEMWBS-8 ( $p$  values all  $> .05$ ), however, between-group effect sizes (Cohen's  $d$ ) indicated medium to large sized differences in self-compassion change between groups.

*Table 10: Between group effect sizes for WEMWBS-8*



Between group	Effect size
ACT with Compassion v. ACT only	0.73
ACT with Compassion v. Waitlist control	0.84
ACT only v. Waitlist control	0.38

Hypothesis 2c was therefore partially supported, as the ACT with Compassion intervention offered medium improvements over ACT-alone in improving self-compassion, but no significant differences in improvements in overall wellbeing.

### *2.5 Feasibility and acceptability of the ACT with Compassion intervention.*

*Hypothesis 2d): ACT and CFT delivered in a combined group format will be feasible and acceptable to this client group.*

Nine participants completed the post-intervention feedback form. On the quantitative questions, all participants rated positively regarding the intervention (all either agreeing strongly or somewhat) and a high majority said they would recommend it to others. Frequencies are displayed in Table 11.

*Table 11: Frequencies of group feedback responses*

Question	Frequency (%)	
	Somewhat agree	Strongly agree
1. I found the groups useful	2 (22.3%)	7 (77.7%)
2. The groups were easy to understand	4 (45.5%)	5 (55.5%)
3. I learned things that helped me	3 (33.4%)	6 (66.6%)
4. The groups were interesting	1 (11.2%)	8 (88.8%)
	Likely	Extremely likely
5. How likely are you to recommend this course to friends and family if they needed similar care or treatment	1 (11.2%)	8 (88.8%)

## 2.6 Qualitative feedback

Open-ended feedback regarding the intervention was also positive. Participants mainly responded to the questions ‘What parts of the course were helpful?’ (themes and frequencies are shown in Table 12 below) and ‘Any others thoughts’. No participants responded to the question ‘What was unhelpful?’ In terms of things that could be changed, one person mentioned that the intervention could be longer. See appendix X for full feedback data, themes and a thematic diagram.

*Table 12: Frequency of themes in qualitative feedback*

Themes (frequencies)				
ACT (7)	Exercises (5)	CFT (6)	Group process (5)	Other (2)
Passengers on the bus metaphor & exercises (4)	Mindfulness (3)	Evolutionary perspective on thinking - Old/new brain (4)	Meeting others in similar situation, common humanity, sharing, discussion (3)	New ideas (1)
Committed action (2)	Compassionate mind training (2)	Self-compassion (increasing and metaphor of) (2)	Friendly (other participants and facilitators) (2)	Balancing stress (1)
Values (1)				

This content analysis indicates that the ACT with Compassion intervention was acceptable and helpful to the participants who completed the feedback form. Participants particularly highlighted the usefulness of specific ACT and CFT aspects of the intervention, as well as the exercises and practical activities. Group process factors were also indicated as helpful. This, alongside the completion rates, indicates that hypothesis D is supported.

## Discussion

### *Third wave-factors in caregivers of people with psychosis*

Part one of this study primarily aimed to examine the third-wave processes of self-compassion and psychological flexibility in relation to wellbeing in caregivers of people with psychosis. Secondary factors examined were compassion for others, mindfulness, guilt and experience of caregiving. Part two of this study aimed to trial a

brief group intervention combining ACT with CFT in order to explore the feasibility, acceptability and effectiveness of this new intervention.

As predicted, self-compassion and psychological flexibility were both significantly correlated with caregiver wellbeing. These results replicate previous findings by Neff et al. (2007) and Kashdan and Rottenberg (2010), in that higher self-compassion and psychological flexibility are related to greater wellbeing and lower distress. These findings also support previous research linking poorer wellbeing and greater distress to increased burden in this population (Kuipers, 2010). Specifically, it was found that caregiver burden (as measured by the negative subscale of the ECI) was significantly correlated with distress, supporting previous findings by (Harvey et al, 2001). Positive experiences of caregiving correlated positively with wellbeing, which indicates the importance of developing positive appraisals of the caregiving role and relationship. Burden was negatively related to self-compassion, with a large effect. This finding could support ideas proposed by Neff (2012) that caregiving can impact self-compassion, and that increasing this could be helpful in terms of reducing burden. Burden was also positively correlated with higher psychological inflexibility, reflecting findings by Spira et al., (2007) and Losada et al., (2015) in their studies exploring this concept in caregivers of people with chronic conditions.

Self-compassion and psychological flexibility were highly correlated, and further analysis suggested that psychological flexibility might mediate the relationship between self-compassion and wellbeing. This link to Hayes et al. (2011), who found compassion and psychological flexibility to be closely related.

### *A potential new intervention*

In part two, the ACT with Compassion group intervention was effective in that it led to increased self-compassion and decreased distress in caregivers. Wellbeing and psychological flexibility also increased, but not significantly. Secondary findings were also positive in terms of compassion for others, mindfulness and guilt. These results add to the literature around the use of ACT as an effective intervention for this client group, as found by O'Donoghue et al. (2015) and Wutke et al. (2015). This study was the first time CFT has been trialled as an intervention for caregivers, and the results are promising. When compared to the ACT-only intervention, ACT with Compassion showed greater gains in self-compassion.

Regarding feasibility and acceptability, the number of participants completing the intervention was sufficient for the scope of this pilot project. In addition to the encouraging quantitative results, qualitative feedback was also very positive. The arising themes echo qualitative results from the previous ACT for Recovery Project (Amisten, 2014). In summary, the ACT with the Compassion group intervention was acceptable and helpful for the caregivers taking part.

### *Limitations*

The baseline study was powered to detect large associations, but smaller associations with demographic variables, for example, will not have been reliably detected. Further, the sample was drawn from a specific setting, and findings may not generalise beyond the particular participants, or to other contexts, particularly caregivers who do not access the carer support services. The final sample size of 14 for part two of the study was just below the recommended sample size of 15 required to detect large pre-post effects, and also meant the between group comparison was very

slightly underpowered. This may account for the failure to find between group differences in wellbeing, and to identify paired group differences in self-compassion. There is a potential bias in outcome reporting, as a particular pattern of outcome may have predicted those completing the intervention and follow-up. As no measures could be collected for drop-out participants, this cannot be tested, but should be borne in mind when considering the findings.

Part one of this study employed a cross-sectional design, which therefore cannot determine causality (Field, 2009). For part two, in hindsight, it would have been useful to have a current control group in order to validly make comparisons (particularly on the self-compassion scale), which was not utilised in the previous trial. A randomised-control or naturalistic control would have provided more valid comparison group in order to further assess benefits of the intervention.

It is important to take into consideration the potential impact of researcher bias (observer-expectancy effect) as the researcher conducted the pre- and post-group assessments with some participants, as well as co-facilitating the some of the group interventions. This could have been countered by the measures being conducted by another professional, or by the researcher not co-facilitating the group intervention. Due to scope this was not possible in this instance, but would have been preferable, and should be considered in future. ‘Blinding’ the person conducting the measures to the group condition of the participant may also help further reduce the potential for researcher bias.

Although the ACT with Compassion intervention did provide a significant benefit on self-compassion as compared to the previous ACT-only group, the item chosen to indicate this (WEMWBS Item 8: I feel good about myself) was indeed a crude measure of self-compassion, and may not therefore provide valid evidence of the

impact of the group on this concept. It may be that this item more closely correlates to experiences of self-esteem, which is quite separate from self-compassion (Neff & Vonk, 2008).

Self-report measures were relied upon for this study, as has been the case for much of the research exploring burden and other factors in caregivers of people with psychosis. However, such measures are also subject to social desirability and bias. The majority of the measures utilized in this study have good validity and reliability. However, use of the Self-compassion – Short-form (Raes et al, 2011) meant that subscales of self-compassion could not be reliably explored in this study, thus only the overall score was examined. The Compassion for Others Scale (Pommier, 2011) is a relatively new scale that has currently not been validated in any other samples. The fact that compassion is featured heavily in the media recently (for example; The Guardian, 2016) may also impact on social desirability and the way in which caregivers rated their responses. Due to the overall scope of this project it was not possible to examine subscales correlates of the measures (such as the ECI, FFMQ and CFOS).

This study was quantitative in nature, though a brief feedback form was completed by a number of participants. In hindsight, a qualitative interview or focus group, exploring caregivers' experiences of the group intervention would have been very helpful, in order to generate richer data and feedback, which would have benefited future development of this intervention.

### *Strengths*

Despite limitations, this study did have a number of strengths. It is the first study to explore the concepts of psychological flexibility and self-compassion within this population, and adds specifically to the literature regarding correlates of burden. In

addition to these concepts this study explored a number of wider variables, and thus adds to current insight regarding the needs of this population. This study was conducted within a specialist service for caregivers of people with established psychosis, thus despite the non-inclusion of care recipient data, it is likely that the participants do represent a valid sample. This study was the first of its kind to test the feasibility, effectiveness and acceptability of a combined ACT and CFT group intervention for caregivers of people with psychosis. The inclusion of comparison groups from the same service also increases the reliability and validity of the findings regarding the effectiveness of the ACT with Compassion intervention.

### *Clinical Implications*

This study demonstrated that there is a rationale for offering caregivers of people with psychosis interventions that are aimed at increasing psychological flexibility and self-compassion, with the aim of a reduction in burden and distress, and an increase in wellbeing. This study provides evidence for the necessity of assessing additional concepts besides burden and psychological distress in caregivers of people with psychosis. If psychological flexibility and levels of compassion could be considered more frequently, these concepts could be routinely incorporated into formulation of caregiver difficulties, and subsequent interventions.

The ACT with Compassion group was a brief intervention that produced promising results, in just five sessions. The intervention was feasible and acceptable, and thus there are grounds for it to be further developed and potentially routinely offered as an intervention in services for caregivers of people with psychosis. This intervention would fit with NICE guidance (2014) around provision of caregiver support, though ACT nor CFT to not currently feature in NICE guidance.



As with the previous ACT with Recovery study, the ACT with Compassion intervention is protocol-based, thus it would be relatively simple to train others in its' delivery. It could be possible for a wide range of professionals, and even peer-supporters, to become group facilitators. This would enable the intervention to be offered and evaluated more widely. As ACT and CFT are transdiagnostic, this intervention could also be applied within services for caregivers of people with other disorders, and indeed could be employed for service users themselves, as ACT groups and CFT groups have previously shown promise for a range of clients, including those experiencing psychosis and other difficulties (Neff et al, 2007; Bach, Hayes & Gallop, 2011; Braehler et al., 2013).

#### *Future research directions*

Regarding exploration of factors such as psychological flexibility and compassion, there is much scope for larger and more robust studies within this population, and indeed in other groups of caregivers. This was the first study of its kind, and there is a clear need to further investigate the potential mediating relationship between psychological flexibility, compassion and wellbeing. Replication of findings in additional studies, employing larger samples recruited from a range of settings, will increase confidence in the generalisability of the findings and could provide focus in further developing third-wave interventions for this population.

The ACT with Compassion intervention would benefit from comparison with a control group, or with other group interventions, such as ACT-only or CFT-only, preferably in a randomised-controlled format, order to explore the benefit of combining these approaches. Future research could also employ more in depth qualitative

interviews in order to gain a greater understanding of the mechanisms of change and what participants find is useful about the intervention.

## **Conclusion**

In conclusion, this study supports existing research in that burden in caregivers of people with psychosis is related to higher distress and lower wellbeing. This study adds to the literature concerning the factors of psychological flexibility and compassion within this population, and highlights that higher self-compassion is related to lower burden and distress. This study was the first to trial a new intervention combining ACT and CFT in a brief group format for this population, with positive results and high acceptability. As a preliminary study, future research could examine the effectiveness of this intervention in a more robust manner, in order to increase support for effectiveness and identify mechanisms of change.

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Lucy Butler, B.Sc. (Hons). M.Sc.

Major Research Project

Section C: Appendices

May 2016

SALOMONS

Canterbury Christ Church University

## Appendix A: Table of included studies

Author, date, Country	Design	Sample	Measures	Findings: Coping and burden and/or distress	Critique
<i>Aggarwal, Avasthi, Kumar and Grover (2009), India.</i>	- Cross-sectional	- 50 service user-caregiver dyads.	- Coping checklist (Hindi) - ECI (Hindi) - GHQ-12 (Hindi)	- Social support and problem-focused coping led to perceived greater positive experience. - This (+education) explained most variance in positive ECI score. - Negative ECI (especially loss) correlated with lower GHQ scores.	- Non-random sample - Outservice users from one hospital only, thus not generalisable - ECI not validated in Indian samples or in Hindi - Cross-sectional design
<i>Bibou-Nakou, Dikaiou and Bairactaris (1997), England.</i>	- Cross-sectional	- 31 chronic schizophrenia caregivers. - 21 sub-chronic caregivers (unwell for less than 2 years)	- MacCarthy et al. (1986) Coping Scale - Semi-structured interview of burden. - Mastery scale - GHQ-12	Chronic caregivers used more 'passive' ways of coping – ignoring/avoiding. Poor social relationships = distress Mastery and burden significantly associated with burden and mental health functioning.	- No limitations listed in the paper. - All caregivers were living with service users - Not able to distinguish length of illness. - Older scales used - Cross sectional - Sample size
<i>Birchwood and Cochrane (1990), England.</i>	- Cross-sectional - Correlational analyses	- 53 service user-caregiver dyads - Excluded if not living together - Excluded if service user not stable on medication	- Coping behavior interview (-inter-rated) - Symptom Rating Test - Burden interview (inter-rated)	- An Ignore/Accept coping style was associated with lower burden - Disorganised coping correlated with higher stress - Once behavioural disturbance of care recipient was controlled for there was no significant correlation between coping style and burden or stress.	- Cross sectional - Not generalisable to a wider group of caregivers, such as those not living with the care recipient - Sample size is a limitation - Inter-rater reliability described.

<i>Budd, Ines and Hughes (1998), Wales.</i>	- Cross-sectional	- 91 caregivers recruited via convenience sampling from family support groups.	- Carer coping style questionnaire. - GHQ-12 - Cost of care scale - The Symptom-related Behavioural Disturbance Scale	- Emotional over-involvement, criticism/coercion, over-protectiveness and collusion were all meaningfully related to burden. - Resignation correlated with burden but not distress. - 'Warmth' correlated with lower burden.	- Carer coping style is deductive in nature. - Sample not generalisable. - No information about service/ service users.
<i>Dyck, Short and Vitaliano (1999). USA.</i>	- Cross-sectional - Multiple regression analysis used to identify factors predicting burden	- 70 service user-caregiver dyads. - Recruited via a large community mental health centre.	- Revised Ways of Coping Checklist - Family Burden Interview Schedule - Interpersonal Support Evaluation List - Social Supports Questionnaire	- Problem-focused coping was related to greater burden in caregivers - Blaming self and others, avoidance and anger control also correlated significantly with higher burden - Religiosity coping did not correlate	- Not generalisable to a larger sample. - Biased towards responders who volunteered for a 2-year study. - External validity threatened due to lack of male caregivers and minority populations. - Cross-sectional
<i>Fortune, Smith and Garvey (2005), England.</i>	- Cross-sectional	- 42 caregivers	- Brief COPE - Illness Perception Questionnaire-Revised - Family Questionnaire - HADS	- Distress significantly correlated with self-blame and less use of positive re-framing - Coping strategies of self-blame, positive reappraisal and acceptance mediate the relationship between illness identity and treatment control. - Protective factors against distress are acceptance and positive re-framing.	- Small sample - Participants were recruited via a carers support group, thus not generalisable.
<i>Goncalves-Pereira, Xavier, van Wijngaarden, Papoila, Schene and</i>	- Cross-sectional baseline analysis of larger study	- 108 service user-caregiver dyads - Excluded co-existing LD, organic disorder or	- Family Coping Questionnaire - Involvement Evaluation Questionnaire - EU	- Coping styles of avoidance, coercion and resignation correlated significantly with	- Non-randomised sample - Cross sectional - Diagnosis of service user not semi-structured

<i>Caldas-de-Almeida (2012), Portugal.</i>		psychiatric admission within previous 2 months	- ECI - GHQ-12 - Social Network Questionnaire	caregiver tension, and with overall IEQ score. - Logistic regression – only coping by service users social involvement and coercion were significant	
<i>Grandon, Jenaro and Lemos (2008), Chile.</i>	- Cross sectional baseline analysis - Hierarchic regression analysis with blocks, to establish variables that predict burden	- 101 service user-caregiver dyads	- Family Coping Questionnaire - Interview on family burden - Social functioning scale- - Social Network Questionnaire	- Coping was defined via resignation, avoidance, maintaining social interests or positive communication - Coping did predict burden - Maintenance of social interests was significant	- Not generalisable as in a low-status area in Chile - Burden treated as a unidimensional variable. - No mediation analysis - Analysis clearly explained.
<i>Hanzawa, Tanaka, Inadomi, Urata and Ohta (2008), Japan.</i>	- Cross-sectional.	- 57 mothers living with offspring who had a diagnosis of schizophrenia - Recruited from outservice user treatment sites via general meeting for families.	- Family Coping Questionnaire - 8-item Japanese version of Zarit Caregiver Burden Interview - 12-item Oshima scale – degree of difficulty in life - GHQ-12 - Emotional support scale - Mental illness & disorder understanding (MIDUS)	- Social interests, coercion, avoidance, resignation and understanding all correlated with burden. - After multiple regression only significant predictors were social interests and resignation	- No causality possible - Only mothers from one area and in support group involvement – low generalisability, as no male or other relatives. - Small sample
<i>Hanzawa, Bae, Tanaka, Jun Bae, Tanaka, Inadomi, Nakane and Ohta (2010), Japan and South Korea.</i>	- Cross-sectional analysis, comparing across two countries. - t-tests, ANOVA and multiple regression analysis with burden as dependent variable	- 162 caregivers from Japan - 125 caregivers from South Korea - Recruited via general meetings for families.	- Family Coping questionnaire - ZBI-8 (In Japanese and Korean) - Nursing Awareness Among Caregivers Questionnaire	- Significant correlations in both Japan and South Korea samples between burden and all coping styles – social interests, coercion, avoidance and resignation. - Multiple regression analysis found that coercion and	- Non-representative sample as caregivers were recruited via meetings for involved families. - Recruitment only in two cities, thus not inclusive of wider non-urban populations

				resignation were significant predictors of burden in the Japanese sample. - In the Korean sample social interests, coercion and avoidance were significant predictors.	- Studies conducted two years apart - Measures not validated or previously used with Korean participants
<i>Jagannathan, Thirthalli, Hamza, Nagendra and Gangadhar (2014), India.</i>	Cross-sectional baseline analysis, part of trial of yoga for caregivers.	137 caregivers of inpatients with schizophrenia - Recruited if had been ill for at least the last 3 months	- Coping checklist - Burden assessment scale - Knowledge about schizophrenia - Perceived social support	- No correlation between coping style and level of burden	- Trained rater in BAS. - Not generalisable to outservice user samples - Cross-sectional - Unclear if EI or chronic sample. Not examined by duration of illness.
<i>Kate, Grover, Kulhara and Nehra (2013), India.</i>	- Cross-sectional - Purposive random sampling - Exploring the stress-appraisal-coping paradigm	- 100 caregivers	- Coping Checklist (Hindi) - IEQ (Hindi) - Global Assessment of Functioning - Social Support Questionnaire (Hindi) - GHQ-12 (Hindi) - WHO QOL-BREF (Hindi)	- Avoidance, collusion and coercion coping styles correlated with tension on the IEQ. - Coping Checklist total explained 10.1% of the variance of the IEQ total. - There were differences in regards to tension and worrying in regards to 'never used' versus 'ever used' (strategies) by caregivers.	- Mainly families attending an outpatient unit, thus not generalisable to other populations - Predominantly male caregivers. - Hindi versions not validated.
<i>Lim and Ahn, 2003.</i>	Cross-sectional, convenience sample	57 family caregivers 65% female 56.1% parents All living with service user	- Negative coping (12 items) - Positive coping (10 items) - Knowledge scale - Burden scale (Korean) subjective and objective burden	Negative coping, being a parent, and more recent illness was associated with greater burden Negative coping greatest impact on burden Less knowledge- more negative coping	- Difficulty with recruitment due to stigma. - Thus sample biased to responders and not generalisable - Small sample

				Female and older – less positive coping	
<i>Magliano, Fadden, Economou, Held, Xavier, Guarneri, Malangone, Marasco and Maj (2000), Italy, Greece, Portugal, England and Germany.</i>	- Large multi-center longitudinal study. - Participants assessed at one time point, and then again one year later.	- 236 caregiver-service user dyads at baseline - 159 at follow-up (33% attrition rate))	- Family Coping Questionnaire - Social Network Questionnaire - Family Problems Questionnaire	- An increase in resignation and avoidance as coping strategies lead to an increase in objective burden over time. - Subjective burden increased due to resignation as a coping strategy, as well as service user disability and reduction of practical social support.	- The longitudinal design is a strength. -Attrition rate is a potential limitation.
<i>Magliano, Veltro, Guarneri and Marasco (1995), Italy.</i>	- Cross-sectional	- 31 service user-caregiver dyads - Service users had diagnosis of schizophrenia and current exacerbated symptoms - Caregiver must have 25+ hours contact p/wk	- Family Coping Questionnaire - PSE-9 - Family Problems Questionnaire	- Coercion, avoidance and resignation were correlated with symptoms of anxiety and depression in caregivers. - Several correlations between coping styles and distress, but no clear pattern	- Cross-sectional - Small sample size - Service users were at a time of symptom exacerbation. - Not generalisable to others (eg. Caregivers of service users who had not been in hospital. - Excluded drug abuse, thus these caregivers are not represented.
<i>Nehra, Chakrabarti, Kulhara and Sharma (2005), India.</i>	- Cross-sectional	- 50 caregivers of service users with schizophrenia, - 50 caregivers of service users with bipolar affective disorder - Excluded if not living together	- Assessment of caregiver coping - Family Burden Interview - Dysfunction Analysis Questionnaire - Experience of hospitalization - PGI health questionnaire (neuroticism) - Social support	- Schizophrenia caregivers used coercion and avoidant coping more than bipolar caregivers did. - Higher levels of burden correlated with higher neuroticism and lower perceived support.	- No culturally unique coping strategies explored. - Did not assess effectiveness. - Restricted sample to living with. Also relatively small groups thus not generalisable. - Cross sectional.

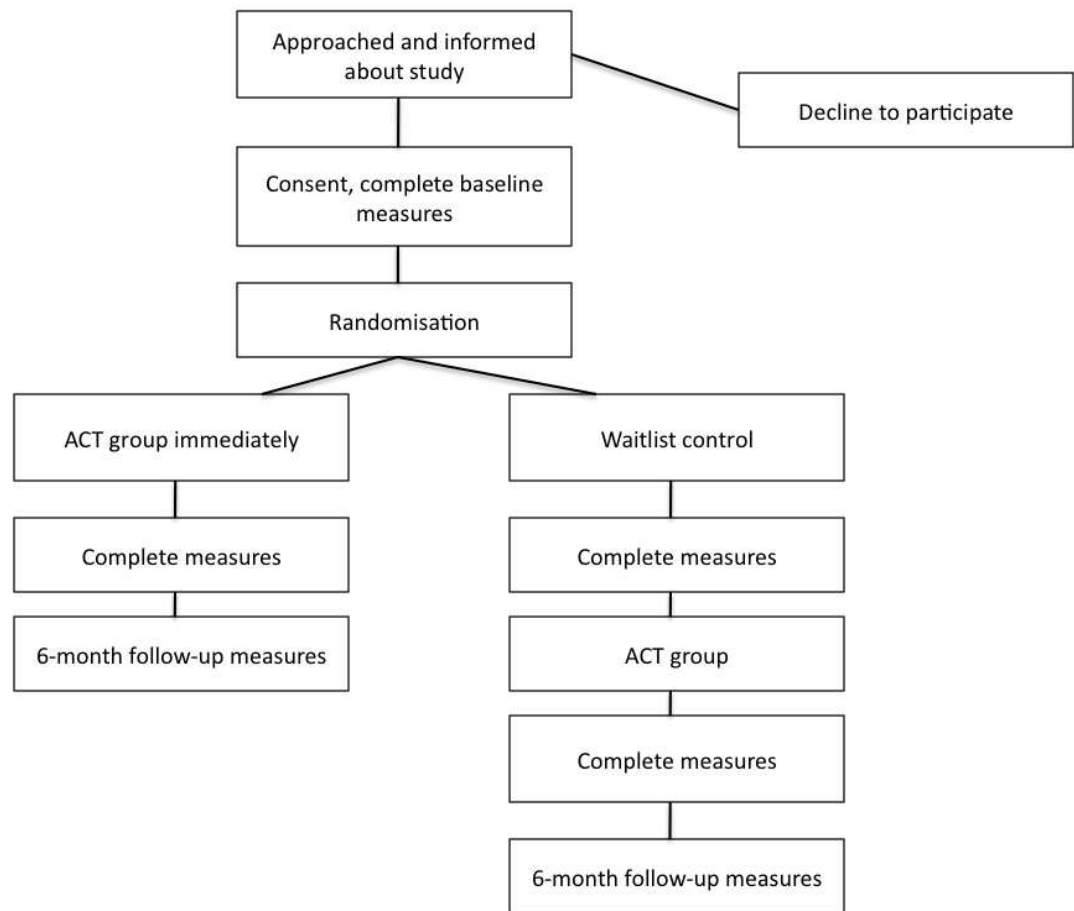


<i>Nitsche, Kock and Kallert (2010), Germany.</i>	<ul style="list-style-type: none"> <li>- Cross-sectional</li> <li>- Exploring the transational stress model.</li> <li>- Bivariate correlation analysis – psychological distress as the dependent variable.</li> <li>- ANOVA</li> <li>- Multiple linear regression</li> </ul>	<p>163 caregivers in total:</p> <ul style="list-style-type: none"> <li>- 55 schizophrenia</li> <li>- 53 recurrent depressive disorder</li> <li>- 55 bipolar affective disorder</li> <li>- Excluded if had a psychiatric admission within past month</li> </ul>	<ul style="list-style-type: none"> <li>- IEQ (worrying, tension and coping subscales)</li> <li>- GHQ-12</li> <li>- Questionnaire on the opinions of the family</li> </ul>	<ul style="list-style-type: none"> <li>- No significant correlation between coping and psychological distress in any of the three groups.</li> </ul>	<ul style="list-style-type: none"> <li>- Cross sectional</li> <li>- No actual coping measure used due to time constraints.</li> <li>- Outservice users only. Not generalisable to other areas.</li> <li>- Good number in each group in terms of effect size detection.</li> <li>- No mention of language</li> <li>- Interesting having psychological distress as DV rather than burden.</li> </ul>
<i>Onwumere, Kuipers, Bebbington, Dunn, Freeman, Fowler and Garety (2011). England.</i>	Cross-sectional. Part of larger study.	<ul style="list-style-type: none"> <li>- 81 schizophrenia caregivers</li> <li>- 60 early psychosis caregivers</li> </ul>	<ul style="list-style-type: none"> <li>- COPE (9 functional and 4 dysfunctional strategies explored)</li> <li>- GHQ-12</li> </ul>	<ul style="list-style-type: none"> <li>- Positive correlation between avoidant coping and GHQ.</li> <li>- Avoidant coping a problem across both early and chronic groups.</li> </ul>	<ul style="list-style-type: none"> <li>- Dependant on service user consent</li> <li>- White mothers heavily represented</li> <li>- Did not report on positive coping (but was a brief report)</li> </ul>
<i>Rammohan, Rao and Subbakrishna (2002), India.</i>	Cross-sectional	<p>60 service user-dyads (no drop outs)</p> <p>Hindus</p> <p>Living with service user</p> <p>97% religious</p> <p>24 parents, 24 spouse, 12 siblings</p>	<ul style="list-style-type: none"> <li>- Carer coping checklist</li> <li>- Semi-structured interview about religious beliefs</li> <li>-Burden assessment schedule of schizophrenia (BASS)</li> <li>-Psychological wellbeing questionnaire</li> </ul>	<p>Denial/ avoidance – greater burden</p> <p>Denial and problem solving significant predictors of burden and wellbeing</p> <ul style="list-style-type: none"> <li>- Religious coping predicted wellbeing.</li> </ul>	<p>Cross-sectional</p> <p>Only hindus (no other religion)</p> <p>Lower SES</p> <p>Retrospective – potentially subject to recall bias about coping strategies used.</p>
<i>Roick, Heider, Toumi and Angermeyer (2006). Germany.)</i>	<ul style="list-style-type: none"> <li>- Longitudinal</li> <li>- Followed up 5 times in 30 months</li> </ul>	<ul style="list-style-type: none"> <li>- 218 service user-caregiver dyads.</li> <li>- Consecutive recruitment.</li> </ul>	<ul style="list-style-type: none"> <li>- Involvement evaluation questionnaire (includes a simple measure of coping)</li> </ul>	<ul style="list-style-type: none"> <li>- Relative coping abilities predicted family burden; where coping ability increased over time, burden decreased.</li> <li>- Coping ability was related to</li> </ul>	<ul style="list-style-type: none"> <li>- Only participants who volunteered were included, therefore not generalisable.</li> <li>- Significant differences</li> </ul>

				intrapersonal changes and reduction in service user symptoms.	in attrition – younger caregiver participants more frequently lost to follow-up (bias). - Only utilised a rudimentary measure of coping.
<i>Sczufca and Kuipers, (1999), England.</i>	- Longitudinal design - Baseline (at service user psychiatric admission) - 9-month follow-up (when in community).	50 caregivers-service user dyads at baseline. - 36 caregivers at follow-up (34% attrition)	- Coping check-list - Camberwell Family Interview (EE) - GHQ-28	- At baseline more avoidance and seeking social support was related to higher burden. - Coping was not significantly associated with distress. - High EE relatives used more avoidance coping than low-EE relatives. - Less strategies were used at follow-up. - At follow-up more use of problem-focused strategies was related to higher burden and distress.	- High probability of Type One error due to number of tests. - Interviewer not blind to service user symptom level at baseline. - Findings specific to admission and discharge. - Small sample size and attrition bias.
<i>Tan, Yeoh, Choo, Huang, Ong, Ismail, Ang and Chan (2012), Singapore.</i>	Cross sectional design, convenience sampling	150 caregivers	-Family crisis oriented personal scales (F-COPES) -Burden Assessment Scale (Reinhard et al, 1994) – exploring objective and subjective burden	- Burden and coping not correlated. - Positive coping strategies present: acquire and mobilizing social support, reframing – accepting, spirituality. - Stigma caused distress	No inpatients considered Very diverse
<i>Thunyadee, Sithimonkol, Sangon, Chai-Aroon and Hegadoren (2015). Thailand.</i>	- Cross-sectional	- 200 caregiver-service user dyads.	- Ways of Coping questionnaire - Centre for Epidemiological Studies Depression Scale (CES-D)	- Regression analysis of the relationship between coping and burden found that self-controlling coping increased burden, and the use of less	- WAYS measure does not employ weighted measurement of strategies (only ever or never).

			<ul style="list-style-type: none"> <li>- Physical Health Scale</li> <li>- Caregiver Reaction Assessment Instrument (Burden)</li> <li>- Social Support Questionnaire</li> </ul>	escape-avoidance reduced burden.	- Not generalisable to non-urban areas, or different groups of caregivers.
<i>Webb, Pfeiffer, Mueser, Gladis, Mensch, DeGirolamo and Levinson (1998), USA.</i>	- Cross-sectional	<ul style="list-style-type: none"> <li>- 59 schizophrenia caregivers</li> <li>- 25 bipolar caregivers</li> </ul> (diagnosis via review or caregiver report of symptoms)	<ul style="list-style-type: none"> <li>-Ways of coping questionnaire (WCQ)</li> <li>-Multi-dimensional scale of perceived social support</li> <li>-Significant other scale (SOS)</li> <li>-Wellbeing schedule</li> </ul>	<ul style="list-style-type: none"> <li>- Problem focused coping = lower subjective burden for positive symptoms</li> <li>- Problem focused coping for negative symptoms was associated with greater burden</li> <li>- Different factors predicted burden versus wellbeing</li> </ul>	<ul style="list-style-type: none"> <li>- Small sample, not matched groups</li> <li>- Validity of route of diagnosis</li> </ul>

## Appendix B: Methodology of ACT for Recovery study



**Appendix C: Ethics approval letter from Research Ethics Committee**

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**Appendix D: R & D approval letter**

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## Appendix E: Information sheet

### Part 1

**What is the purpose of the project?** We want to find out how things change for carers of people in promoting recovery services while they are receiving support from a carer support service. We also want to find out more about the kind of difficulties caregivers have, and what help they might need to deal with them.

**Why have I been asked to take part?** We will ask all caregivers in the services, who are feeling well enough to participate, if they would like to take part.

**What will I be asked to do?** If you would like to take part in the study, you will first need to sign the form at the end of this sheet, to say that you are happy to go ahead.

There are three ways to take part:

**a) firstly**, you can agree for us to use the questionnaires you have already completed routinely in the service (usually when we first meet you, and after three months, when you have completed an ‘intervention’ (a group or individual course of support)) for this research project. You will not need to do anything else.

**b) secondly**, you can agree to up to two extra meetings with a researcher to complete the same questionnaires again, before and after any additional interventions you complete, specifically for this research project. We would ask you to complete the measures again before an intervention (the first extra meeting), if you last completed them more than three months ago. We would ask you to complete the measures again after an intervention (the second extra meeting) if you are going on to complete an additional intervention. We will not ask you to attend any more than two extra meetings as part of the research, and we would expect each meeting to last about an hour. We will try to arrange these meetings at times when you are attending the service anyway. We will also offer you £5 for each extra meeting towards your time and travel. The purpose of the extra meetings and questionnaires is to find out more about how things change, and when, for carers in different circumstances, after different interventions.

**c) thirdly**, you can agree to complete a short (5 minute), audiorecorded interview about your relationship with the person you are caring for. We would ask you to complete this twice, once before and once after an intervention, at the same time as you complete the other questionnaires, so we would not expect you to need to make an extra visit. The interview would be specifically for the research project.

**Will my taking part in the study be kept confidential?** We work closely with the carer support team and the clinical team for the person you are caring for, and the information you give us will usually be shared with these services as it may help them

to provide support for you and care for the person you are caring for. The researcher will note this down on the electronic notes system, where they will also note that you are taking part in the study and when they meet with you. If you tell us anything about someone being hurt or not safe, we will have to tell other people who are there to help with these kinds of situations. More details are included in Part 2.

**How will the information I give you be kept?** All the answers you give to the questionnaires will be kept on paper and as an electronic file. They will only be identifiable by a number. If you complete the audiorecorded interview, we will transcribe this (i.e. write it down, word for word), and keep a paper and electronic copy, from which we will remove personal details like names. Like the questionnaires, this will be identifiable by a number. We will not keep the audiorecording, once we have transcribed it. Your name will be kept separately, with the number, on paper, so that we can identify your questionnaires in the future if we need to (for example, if you decide you no longer want to be part of the study). We will only identify your questionnaires for a reason like this. Your details will be kept for up to 10 years, and then will be confidentially destroyed. We will keep a completely anonymous copy of the electronic file indefinitely, from which you will not be able to be identified at all. At the very end of the study, you will be able to have a summary of the results, if you would like.

**Is there any risk from taking part?** We do not think that this study will be harmful in any way. We want it to be helpful and the questionnaires have all been designed for caregivers in particular, or adults in the general population, and have been approved by researchers who have many years experience of working in this field. However if you feel distressed in any way by taking part, please talk to the researcher, or to one of the carer support workers, who will be able to help you.

**Are there any benefits of taking part?** There is no direct benefit to you from taking part in the study. We hope to find out more about how the difficulties facing carers impact on their day to day lives, so we can provide the most effective support in the future. People also sometimes find completing the questionnaires interesting and helpful.

### **Do I have to take part?**

It is up to you to decide whether or not to take part in this study. If you decide to take part, you are still free to stop at any time and without giving any reasons. This will not affect any other help or support that you, or the person you care for, will be offered.

### **What happens when the project stops?**

We will ask if you would be willing to be contacted regarding future projects, and if you would, we will keep your name and contact details. You will be able to ask us not to contact you at any time, and this will not affect you, or the person you are caring for, in any other way.



**This completes Part 1 of the Information Sheet.**

**If the information in Part 1 has interested you and you are thinking about taking part, please continue to read the additional information in Part 2 before making any decision.**

## **Part 2: What if there is a problem?**

**What if relevant new information becomes available?** Sometimes we get new information during a project. If we find out anything new about any of the questionnaires which means it might be harmful or upsetting for you in any way, we will tell you at once and you can decide whether or not you want to carry on.

**What will happen if I no longer want to carry on with the study?** If you decide you no longer want to take part, you should let us know at once. A member of the research team will talk to you about which parts you no longer want to be involved in (for example, you might not want to do extra questionnaires, but feel OK with us using the questionnaires you have already completed). We would like to still keep the information you have already given us if this is possible, but we will check this with you as well. You can tell us that you would like us not to keep any information at all, and in this case we will destroy all our copies of the information you have given us. This will not affect any other support you might be offered, or your rights in any other way. The only exception to this will be information that is important for your own wellbeing, or the wellbeing of the person you are caring for, care, or that relates to any risk of somebody being hurt or unsafe. We will sometimes have to hand this information over to the clinical team, and will be unable to destroy it because of its importance.

**Complaints:** If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions, or to the staff on the ward. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure – Contact Patient Advice and Liaison Service (PALS) on: 0800 731 2864 or [pals@slam.nhs.uk](mailto:pals@slam.nhs.uk).

**Harm:** In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against your local NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

**Will my taking part in this study be kept confidential?** All information which is collected about you during the course of the research will be kept strictly confidential. All the answers to the questionnaires will be kept on paper and on an electronic database. They will be kept securely and anonymously and will be identifiable only by a number, not by name. Your name will be kept separately, with the number, on a different database and on paper, so that we can identify the questionnaires and recordings in the future if we need to (for example, if you decide you no longer want

to be part of the study). We will only identify your questionnaires for a reason like this. Paper copies of questionnaires will be kept securely by the researchers in a locked filing cabinet in a locked office. Your details will be kept for up to 10 years, and then will be confidentially destroyed. We will keep a completely anonymised copy of the database indefinitely, from which you will not be able to be identified at all.

The information you give will usually be available only to the research team, the carer support team and the clinical team for the person you care for. Information that you provide on the assessment measures, interviews and any support and interventions will not usually be shared with the person you provide care for. We work closely with the clinical services and the information you give us will usually be shared with the clinical team if it will help them to support you and to provide care for the person you care for. The researcher will note this down on the team's notes system, where they will also note that you are taking part in the study and when they meet with you. In addition, should you give any information, such as criminal disclosures, or information relating to anybody's safety, which requires action, we are legally obliged to act on this information, and to pass this information on to others, including services who are able to deal with these concerns, which may include Social Services or the Police.

**What will happen to the results of the research study?** We intend to publish the results of the research. You will not be personally identified in any report/publication. We sometimes use quotes from participants when we write about the research. In this case we will tell you what we want to write and where it will be seen and check that you agree.

**Who is organising and funding the research?** The research is organised by the team, who are members of academic and clinical staff at [service, other university] and Canterbury Christ Church University

**Who has reviewed the study?** The study has been reviewed by the London-London Bridge Research Ethics Committee, of the National Research Ethics Service (reference number 15/LO/0680)

**How can I take part?** If you would like to take part in this project, please complete the attached consent form. If you have any questions or concerns about taking part in this study please contact the researchers below.

**Contact Details:** [team contact details]

## **Appendix F: Consent form**

## CONSENT FORM V1 28/12/14

*Title of project: **Evaluating Interventions for Caregivers***

Names of researchers: *Lucy Butler*

*Please initial boxes:*

1. I have read the information sheet dated 28/12/2014 for the above project,  
and one

of the researchers has talked to me about it. I have had enough time to think  
about it

and ask questions.

2. I understand that taking part is voluntary and that I am free to withdraw at  
any time, without giving any reason, and without my medical care or legal  
rights being affected.

3. I am willing for the researcher to let my GP know that I am taking part in the  
study.

4. I am willing for the researcher to contact other professionals with any  
information relevant to my care, or the care of the person I care for, should  
this become apparent while we are taking part in the study.

5. I am willing for the researchers to pass this information on to the carer  
support team to be recorded in the carer section of the clinical team's  
electronic

notes for the person I care for.

6. I give permission for information from the carer sections of the medical  
notes for

the person I care for to be passed on to the researchers by the carer support  
team,

if it is relevant to taking part in this research

(for example, to get an address, age or confirm clinical information).

7. I am willing for the research interview to be audiorecorded.

8. I understand that information relating to me taking part in this study will be  
stored

in an electronic file for up to 10 years.

9. I agree to take part in the above study.

a) using questionnaires I have already completed within the carer support service.

b) completing the questionnaires at extra time points and the research interview

\_\_\_\_\_

Name of participant

Date

Signature

10. I have explained the study to this participant and answered their questions honestly and fully.

\_\_\_\_\_

Name of researcher

Date

Signature

**Appendix G: Acceptance and Action Questionnaire – II**

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## **Appendix H: Self-compassion Scale – Short form**

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## **Appendix I: Warwick Edinburgh Mental Wellbeing Scale**

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## **Appendix J: Compassion for Others Scale**

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## **Appendix K: Five Facets of Mindfulness Questionnaire**



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**Appendix N: Experience of Caregiving Inventory**

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Thinking about the group session today/the course of groups\*, please grade the following statements by circling a number from 1 to 5 (1=strongly disagree, 5=strongly agree):

	Strongly Disagree				Strongly Agree
I found this session/course* useful	1	2	3	4	5
The session/course* was easy to understand	1	2	3	4	5
I learned things that helped me	1	2	3	4	5
The session/course* was interesting	1	2	3	4	5

How likely are you to recommend the group to friends and family if they needed similar care or treatment?

- 1  Extremely likely
- 2  Likely
- 3  Neither likely nor unlikely
- 4  Unlikely
- 5  Extremely unlikely
- 6  Don't know

If you would recommend the group, please write below any parts of the session/course\* you think are helpful:

If you would NOT recommend the group, please let us know why, especially what parts of the session/course\* you did not find useful:

In the box below, please write what you would have change about this session/the course\*

Do you have any other thoughts about today's group/the course\*?

\*delete as applicable

## **Appendix P: Intervention protocol extract**

### **ACT with Compassion group protocol:**

#### **Session 1.**

##### **Session Aims:**

- *To explore the difficult issues around caregiving and to highlight the importance of caring for oneself.*
- *To introduce concept of compassion and its evolutionary basis – old brain new brain.*
- *Introduction to soothing rhythm breathing*
- *Introduction to values*

##### **Equipment:**

- *Projector*
- *Session 1 powerpoint slides & handouts*
- *Pens / spare paper*
- *Flipchart paper*
- *Sticky labels for names*
- *Compassion/mindfulness CD for each participant*
- *Folder for each participant*
- *Values ripple worksheet*
- *Committed action worksheet*

**Practical:** *The session lasts two hours. We advise taking a 10minute break halfway through (approximately 55 minutes in to the session). Exactly where this falls in terms of the content depends on each individual group and how talkative participants are. A good place may be in between soothing rhythm breathing and introducing values (slide 14/15).*

##### **Slide 1: Title – Welcome to the Act with Compassion group, session 1.**

- Facilitators introduce themselves. Provide participants with name labels for first session.
- Give housekeeping information if required. Explain timings and break.
- Let participants know they will get a folder and set of slides at the end.

### Slide 2: Introduction:

- Discuss what the groups are about: read through the slide and expand in terms of offering specific intervention for carers and why the groups are being offered now.
- Give a bit more information on compassion – when we talk about compassion we are mainly thinking about compassion for the self – being kind to oneself. We will speak a lot more about this in the next session, but for now it is just something to mention.

### Slide 3: Ground rules:

- Read through slide. Invite participants to offer ideas for group rules. Write these on flipchart paper to keep for following sessions.
- Examples could be around confidentiality, what's said within in the group stays within the group, turns to talk, no mobile phones. Emphasise the 'no need to talk if you don't wish to' and 'opting in' to the exercises.
- **Remind participants that this is a skills workshop so there is a certain amount of content to get through each week – we may need to interrupt at some points to keep people on track. (Might be quite different from carer groups where they get a chance to offload – so be mindful of this).**

### Slide 4: Warm up/icebreaker:

- Ask participants to pair up.  
*"With your partner, find out three things the other person really likes doing".* Facilitators give examples to cue people, e.g. *"I like to watch movies"*. Ask people to remember these, as we will ask them to report back to the group afterwards.
- After a minute or so, ask each participant to feedback to the group one thing that their partner likes doing. Ask everyone stand up for this exercise.

### Slide 5: Reservoir metaphor:

*"One way of describing how these groups may be useful to carers is the reservoir metaphor.*

*We all have 'emotional reservoirs' of different types. Some supply energy, others supply calmness, happiness, or wellbeing. When the reservoirs are full, we can*



*maintain our energy, calmness, happiness, or wellbeing, even in times of stress. And we can carry on doing what's important in our lives. If there is a drought (such as a bad day or week, or other forms of stress), we maintain a healthy state, because there is a supply in our reservoir.*

*We know that sometimes being a carer can be difficult and challenging and this can be draining on one's reservoir. If the reservoirs are dry, we can become vulnerable to stresses: there may be some energy or happiness, but only if daily events are going well. The combination of a 'dry reservoir' and a 'bad day' could be problematic and may lead to difficulties such as an emotional crash, lost temper, frustration etc.*

*These workshops aim to teach you some different ways of how to maintain or 'top up' your reservoirs so that you can maintain wellbeing and be able to do more of what's important in life."*

Ask participants if they can relate to this at all? Ask for examples.

#### **Slide 6: Quick chat:**

Ask participants to spend some time thinking about the difficulties that can come up for them as a caregiver. You can get into groups or do this as a bigger group depending on the size of the group. If more than 5 people it is advisable to get into smaller groups, each headed by one facilitator. The facilitator can take notes to feedback.

Focus on:

- What are some of the main difficulties that can come up?
- What stops the reservoir from being replenished?
- What feelings come up?

Write these down on the flipchart (and keep)

Focus on: caregiving as a caring and compassionate role. Guilt and other feelings as normal - coming up and getting in the way for us all at times. Emphasise the shared experience, and the difficulty of admitting to some feelings, such as resentment or anger.

#### **Slide 7: The role of the brain – introducing compassion.**

*We begin with an understanding of what we all share and what we are up against.*

*Our minds and brains are created by evolution. We didn't choose them. We are just one member of the human race, which is just one race. We are all in the flow of life.*

*We did not choose to have a brain that is capable of feeling the powerful emotions and urges that it does. And we didn't choose the environments we were born in to. So a lot that happens to us and goes on in our minds is not our fault, our brains are actually quite tricky.*

**Example given by facilitator: Kidnapped by drugs gang.**

*"If I had been kidnapped as a three-day-old baby and raised by a violent drug gang, what kind of person would I be today? Often, the sons or daughters of drug cartels conduct violent crimes as part of the family business... As much as I don't want to think I could be that sort of person, it is possible that with such a learning history and environment that I would be a very different version of myself.*

*The environments that we grow up in can have a big affect on our brains and how we are in the world in later life.*

**Slide 8: Our brains – old brain, new brain.**

Show slide of old brain and new brain.

We need to think firstly about the evolution of the brain. Firstly the old brain, which evolved a long time, over 2 million years ago.

*Our old brain is very primitive – just like an animals brain. It responds in an emotional way to things and makes us want to run away or fight. It also helps us make social relationships. This is the brain that our ancestors the cavemen had – their priorities were all around survival.*

*Evolution over millions of years has lead to a different type of brain developing. The 'new brain'. Our new brain is amazing at creating, imagining, planning, ruminating, and so on. This is great – it's helped us generate ideas, culture, science and create great inventions.*

*BUT...sometimes the interactions between our 'old brain' and 'new brain' can cause problems (slide 9).*

**Slide 10: Zebra and Lion example:**

- *A zebra has a more of an 'old brain'*
- *Imagine a zebra is chased by a huge, hungry, scary lion.*
- *The zebra luckily manages to get away from the lion – once this happens, it will quickly calm down and return to eating, or other zebra activities.*
- *Whereas the zebra's threat-based emotions may return to baseline calm within minutes, this is unlikely for humans because of our capacity for cognition or though (new brain) - with which we predict events and create internal*

*representations of possibilities. (Ask participants what might happen for a human?)*

- *If a zebra thought as humans do, it might start to ruminate, imagine what might have happened if it had been caught, and worry about what might happen tomorrow.*
- *It might then experience intrusive images, fantasise about being eaten alive, or what might happen if it doesn't spot the lion next time, or if two lions turn up!*
- *Therefore we can see how the human new brain has given rise to science, culture etc, but can also trap us in terrible internal loops, as our thoughts and imaginations allow us to run simulations of numerous possibilities in our minds, stimulating physiological systems involving evolved motives and emotions.*

### **Slide 11: Tricky loops**

- Read through slide – we can often get stuck in a loop where the old and new brain can interact in an unhelpful way
- Ask for examples?
- Problematic loops happen due to the evolution of the brain, it is not our fault. Evolutionary example; it's given us an edge in lots of ways, but unfortunately can cause us more suffering along the way.
- Staying stuck in these loops can keep us in suffering.

### **Slide 12: How can we respond differently to tricky loops**

- Read through the slide
- Importance of noticing as the first step to change
- Can also help us to notice automatic thoughts that might come up.

### **Slide 13: Guilt**

- Guilty thoughts as a normal part of experience (were they raised in the chat earlier?) Normalise for carers especially.
- This is an example of a tricky loop.

### **Slide 14: Exercise: Soothing Rhythm Breathing/Mindful breathing.**

One facilitator reads through the following script.

During these groups we are going to practice a few difference exercises. The first one is called 'soothing rhythm breathing' and involves learning how to pay attention in a gentle and kind way.

The most important thing here is simply to follow my instructions and practice the breathing without worrying if you're doing it correctly. These thoughts are common and understandable, but are distractions. If they arise in your mind, simply notice them, call them your 'judging thoughts', smile kindly to yourself and bring your attention back to the task.

### **Instructions: Soothing rhythm breathing (adapted from Gilbert, 2010)**

- 1. I invite you to get in to a comfortable position in your chair [pause]; sitting upright, with your feet flat on the floor; your arms and legs uncrossed; and your hands resting in your lap [pause]. Let your eyes gently close or fix them on a point in front of you. Allow yourself to have a gentle facial expression, maybe a slight smile [pause 5 seconds].*
- 2. Gently bring your attention to your breathing [pause 5 seconds]. See if you can notice the sensation of breathing in [pause] and out [pause 5 seconds], allowing your stomach to expand, and your chest to gently rise and fall [pause 5 seconds]. Notice your diaphragm, the area under your ribs, and see how it expands with each in-breath.*
- 3. Kind a breathing pattern that, for you, seems to be your own soothing, comforting rhythm. It is like you are checking in, linking up, with the rhythm within your body that is soothing and calming to you.*
- 4. What you will usually find is that your breathing is slightly slower and deeper than normal. Try breathing in for about 3 seconds ... hold ... then breathe out for 3 seconds. Repeat in this manner. Ensure that the breaths in and out are smooth and even. [pause for 10 seconds].*
- 5. Now spend a little while just focusing on the breath coming down into the diaphragm, your stomach lifting and then the air moving out, through your nose. Focus on the point just inside the nose where the air leaves. Try breathing in through your mouth and out through your nose, in through your mouth and out through your nose. Just focus on that for a while [pause 10 seconds].*
- 6. From time to time, your attention will wander as you get caught up in your thoughts. This is quite normal; it happens to everyone; and it may happen*

*repeatedly. Each time you notice your mind wandering; take a split second to notice where your mind took you and gently and kindly bring it back to your breathing [pause 5 seconds].*

7. *Next, gently bring your attention to sitting in the chair [pause]. Observe the sensation of sitting in the chair, and see if you can notice the sense of your weight on the chair [pause 5 seconds]. Allow yourself to feel held and supported. Maybe notice where parts of your body contact the chair [pause]. Notice where your body doesn't contact the chair [pause 5 seconds]. Notice the parts of your feet that touch the ground [pause 5 seconds]. Notice where parts of your feet don't touch the ground [pause 5 seconds]. If you drift off in to your thoughts, simply acknowledge where your mind went and bring it back to focus on the sensation of sitting in the chair [pause 5 seconds].*
8. *As you do this exercise, the feelings and sensations in your body may change. There may be pleasant feelings and sensations, such as relaxation, calmness or peacefulness [pause]. There may be unpleasant feelings like boredom, frustration and anxiety [pause]. Whatever feelings, urges, or sensations arise, whether pleasant or unpleasant, gently acknowledge their presence and let them be. Allow them to come and go as they please, and keep your attention on the soothing rhythm of your breathing [pause 5 seconds] and the sensation of sitting in the chair.*
9. *Lastly, bring your attention back to your breathing [pause 5-10 seconds]. Notice again the steady soothing rhythm of your breathing that is with you all the time [pause 5-10 seconds]. When you are ready, bring your attention back to the room. Open your eyes if they are closed. Notice what you can see [pause], notice what you can hear [pause]. Push your feet into the ground, have a stretch and notice yourself stretching. Welcome back.*

### **Invite observations from this exercise (debrief)**

Reinforce anything people noticed.

- If feedback is ACT consistent, reinforce and take further. Reinforce any noticing.
- If feedback is not ACT consistent, just notice it and put back to the group e.g. *“what else did you notice? The same as other people or something different perhaps?”*
- Give opportunity for lots of feedback before responding in detail to any one client.
- If clients report that they found the exercise relaxing, suggest that this is what they noticed on this occasion. Highlight that this is an added bonus of doing the exercises but that the main aim is about noticing.

- If no feedback is given, share your own experience rather than suggesting feedback (modelling rather than prompting).
- The most important action is to draw on group experiences/process.

Explore compassionate aspects of the exercise – noticing kindly, rather than the ‘oh I’m doing it wrong!!’

Discuss briefly other ways of doing this exercise – e.g. on the bus, waiting, holding a comforting object such as a smooth stone or a ball.

### **Slide 15 & 16: Values:**

What are the important things in life?

- *Part of these workshops is about focusing on what is important to you. Values are our heart’s deepest desires for the way we want to interact with the world, other people and ourselves. They’re what we want to stand for in life, how we want to behave, what sort of person we want to be, what sort of qualities we want to develop.*
- *Here are some broad examples of important areas in life. Highlight that this is not an exhaustive list, merely some suggestions:*

### **Important things in life:**

- Provide some broad examples as prompt:
  - Relationships:** e.g. your partner, children, parents, relatives, friends, co-workers, and other social contacts
  - Personal growth/Health:** e.g. nutrition, physical health. May also include religion, spirituality, creativity, life skills, exercise, nutrition, physical health etc.
  - Work/Education:** Includes, education, skills development, careers, etc.
  - Leisure:** e.g. how you play, relax, or enjoy yourself; activities for rest, recreation, fun and creativity
  - Other:** Ask for any other ideas

## Slide 17: Values Exercise – Ripple worksheet

*“If these group could really be about doing something important, if magic could happen, and you leave the group and just do this thing... what would it be?”*

Give out a ripple worksheet to each participant. Explain worksheet. Ask participants to get into small groups and fill in. Facilitators take a group each.

Facilitators to assist participants to identify values and where they are currently with their value – stuck in the middle or moving away from middle towards value.

NB. Be mindful of the tendency to identify goals. If this does happen, try to help them identify the value behind the goal. Discuss the compass metaphor on the next page.

## Slide 18: Compass Metaphor

- *‘One way to think about your values is the **Compass Metaphor** Values are like a compass. A compass gives you direction and keeps you on track when you’re travelling. And our values do the same for the journey of life. We use them to choose the direction in which we want to move and to keep us on track as we go’.*

*‘So when you act on a value, it’s like heading west. No matter how far west you travel, you never get there; there’s always further to go. But goals are like the things you try to achieve on your journey; they’re like the sights you want to see or the mountains you want to climb while you keep travelling west’.*

- **Highlight difference between goals and values**  
Participants often identify goals rather than values, so it is important to clarify the difference. Explain that values are like direction in which we want to move throughout our lives (*link back to the compass metaphor*), whereas goals are things that we want to achieve or complete.
- **Examples to help clarify the difference:**  
The difference between ‘getting married’ and ‘being loving’. If you want to be loving and caring, that’s a value- it’s on going; you want to behave in that way for the rest of your life. And in any moment you have a choice: you can act on your value or neglect it. But if you want to get married, that’s a goal. It is something that can be achieved and you can achieve the goal of marriage even if you neglect the values around being loving and caring.

**Slide 19: Homework for next session: Committed action**

**Read through slide.** Give out the committed action sheet to each participant.

**Slide 20: SMART Goals:** read through slide. Break into small groups, one facilitator per group. Help participants fill in committed action worksheet, keeping actions SMART.

Also: Give out folders, slides and CDs to each participant. Ask them to practice the soothing rhythm breathing track, noticing what comes up. Also to notice if they start getting stuck in any loops.

**Slide 21: Feedback:**

- How did people find the group today?
- Any questions?



## Appendix Q: Intervention powerpoint slides extract

### (Session 1)

**ACT with Compassion**  
Workshops for caregivers  
Session 1



### What these groups are about

- Identifying what is important for **you**...
- ...And how our **minds** can sometimes cause us to **struggle** when trying to do things we care about.
- Practicing different ways of being with our **minds**
- Learning new skills to increase compassion.
- And also about having some fun with some new people!

### Group rules

- We want this to be a safe space for everyone.
- Keep what's said in the group within the group.
- No pressure to talk if you don't want to.
- Any other rules?

### Warm up...

- Turn to the person next to you and ask them:  
*"What are three things you like to do?"*
- Try and remember what they say as we will feedback about each other to the group.



### Quick chat:

- What are some of the main difficulties around caregiving?
- What stops your reservoir from being replenished?
- What are some of the feelings that come up for you as a caregiver?

## The role of the brain

- Our minds and brains have been created by evolution. We didn't choose them.
- We did not choose to have a brain that is capable of feeling the powerful emotions and urges that it does. And we didn't choose the environments we were born in to. So a lot that happens to us and goes on in our minds is not our fault.



## Old brain, new brain

- Our 'old brain' is very primitive – just like animals. It responds in an emotional way to things and makes us want to run away or fight. This is brain our cave-men ancestors had.
- Evolution over millions of years has lead to a different type of brain developing. The 'new brain': Our new brain is amazing at creating, imagining, planning, ruminating, and so on. This is great – it's helped us generate ideas, culture, science.



*BUT...sometimes the interactions between our 'old brain' and 'new brain' can cause problems.*



## The zebra and the lion...

- A zebra has more of an 'old brain'.



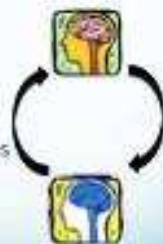
It uses it's old brain to get into flight flight mode when chased by a hungry lion!



A zebra who escapes a lion can quickly down... the same cannot be said for humans! What might a human think?

## Tricky loops

- We can often get stuck in a loop – where the old brain and new brain interact in an unhelpful way
- Problematic loops arise because the brain is not perfectly designed, it's an evolutionary trade-off (like the giraffe's long neck). **It's not our fault!**
- But not being able to get out of these loops keeps us in suffering.



## How can we respond differently to tricky loops?

- Firstly we can begin to notice what is going on in our minds by observing it in action.
- This can help us become more familiar with what's going on in our minds.
- We can then learn to understand our minds and make choices to move forward.
- We can also try and increase compassion for ourselves (and our minds!) and others.



## Guilt?

- Does your mind ever bring up guilty thoughts?
- This is an example of a tricky loop that is often common to carers!

"Guilt isn't always a rational thing –  
Guilt is a weight that  
will crush you  
whether you deserve  
it or not."

*© M. J. Johnson*

## Soothing rhythm breathing



## Values

- What are the important things in life?



- What do you want your life to be about?

## Common Values

Relationships  
e.g. to be  
more loving to  
my partner

Leisure  
e.g. activities  
I enjoy with  
my family

Work/  
Education  
e.g. a job that  
gives me a  
sense of  
satisfaction

Personal  
Goals/  
Health e.g.  
maintaining  
good physical  
health

## Ripple worksheet



## Compass metaphor

- The difference between values and goals



## For next week: Committed action

- Think back to the values sheet we filled in earlier
- What is one thing you can do in the next week that will help you move closer one of your values?
- Keep your action S M A R T
- Practice the soothing breathing rhythm exercise



## SMART Goals

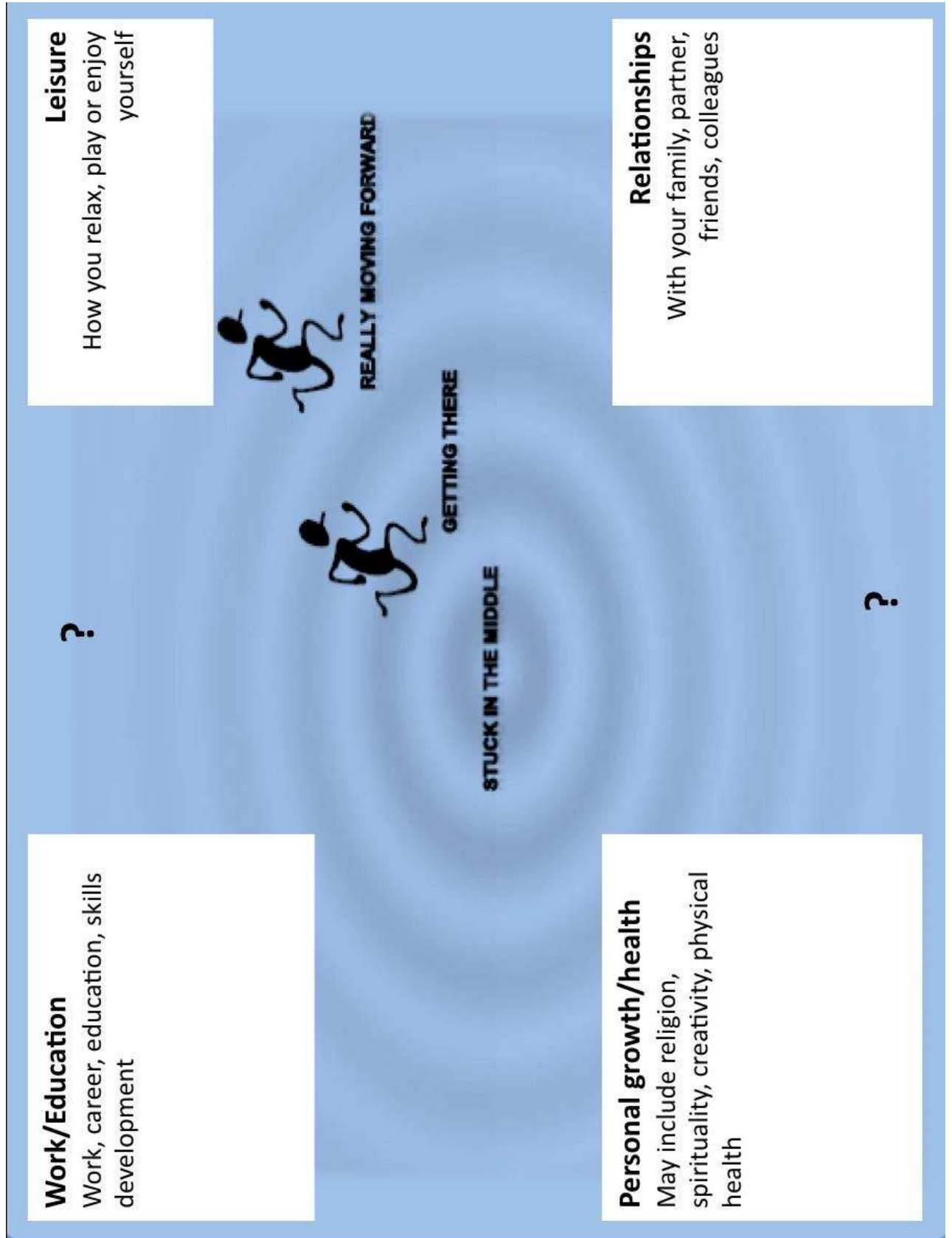
- **Specific** – Specify the actions you will take
- **Meaningful** – Make it personally meaningful to you
- **Adaptive** – Does it help you to take you forward?
- **Realistic** – Is it realistically achievable?
- **Time-framed** – Set a day, date and time

## Feedback

- How was the group today?
- What did you notice?
- What did you find most helpful/unhelpful?
- Please take a moment to fill in the feedback forms, thanks!

## Appendix R: Intervention group worksheet example

### Values worksheet



## Appendix S: Parametric data assumptions

Timepoint	Variable	Skewness z-value (statistic / std error)	Kurtosis z-value (statistic / std error)	Shapiro- Wilk statistic	Shapiro- Wilk p- value (normality assumed if >0.05)
Baseline	WEMWBS	-0.355	-0.815	0.982	0.880
	AAQ-II	1.477	0.092	0.932	0.063
	Self-Compassion Scale	-0.907	0.841	0.964	0.405
	CORE-10	0.213	1.346	0.965	0.488
	Compassion for others scale	0.513	-0.898		
	COPE	0.277	0.802	0.961	0.391
	FFMS	0.318	0.623	0.980	0.872
	Caregiver Guilt	0.656	0.487	0.973	0.684
	ECI Negative score	0.025	0.635	0.967	0.537
ECI Positive score	-1.162	-0.321	0.964	0.459	

## Appendix T: Internal consistency

### Cronbach Alphas

Measure	Alpha level
WEMWBS (Wellbeing)	.934
AAQ-II (psychological flexibility)	.897
CORE-10 (distress)	.770
SCS-SF (Self-compassion)	.715
CFOS (Compassion for others)	.855
FFMQ (Mindfulness)	.838
CGQ (Guilt)	.918
ECI Negative (Caregiver burden)	.927
ECI Positive	.783

## Appendix U: SPSS sample: Multiple regression

**Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.604 <sup>a</sup>	.365	.316	9.232

a. Predictors: (Constant), Self-compassion Scale Total, AAQ\_II Total Score

**ANOVA<sup>a</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1274.269	2	637.134	7.476	.003 <sup>b</sup>
	Residual	2215.832	26	85.224		
	Total	3490.101	28			

a. Dependent Variable: WEMWBS Total Score

b. Predictors: (Constant), Self-compassion Scale Total, AAQ\_II Total Score

**Coefficients<sup>a</sup>**

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	57.934	14.555		3.980	.000		
	AAQ_II Total Score	-.647	.222	-.586	-2.912	.007	.602	1.660
	Self-compassion Scale Total	.040	.294	.028	.138	.891	.602	1.660

a. Dependent Variable: WEMWBS Total Score

**Collinearity Diagnostics<sup>a</sup>**

Model	Dimension	Eigenvalue	Condition Index	Variance Proportions		
				(Constant)	AAQ_II Total Score	Self-compassion Scale Total
1	1	2.827	1.000	.00	.01	.00
	2	.165	4.144	.00	.38	.05
	3	.009	18.185	1.00	.61	.95

a. Dependent Variable: WEMWBS Total Score

## Appendix V: Effect size equations and calculations

Equation for effect size (paired data)  $d = \frac{Time1\bar{x} - Time2\bar{x}}{SDTime1}$

(Field, 2013 p.80).

*Hypothesis 2b: Effect sizes for pre-post data ACT with Compassion intervention*

Measure	Construct	Calculation	Effect size interpretation
CORE-10	Psychological distress	$d = \frac{(13.143 - 9.071)}{6.5850} = \mathbf{0.62}$	Medium effect
SCS-SF	Self-compassion	$d = \frac{35.933 - 43.357}{8.5228} = -\mathbf{0.87}$	Large effect
WEMWBS	Wellbeing	$d = \frac{44.714 - 50.620}{9.5871} = -\mathbf{0.61}$	Medium effect
AAQ-II	Psychological flexibility	$d = \frac{22.571 - 19.733}{10.78} = \mathbf{0.26}$	Small effect
CFOS	Compassion for others	$d = \frac{91.20 - 101.46}{12.67} = -\mathbf{0.80}$	Large effect
FFMQ	Mindfulness	$d = \frac{126.15 - 144.41}{16.84} = -\mathbf{1.08}$	Very large effect
CGQ	Guilt	$d = \frac{29.61 - 22.18}{15.82} = \mathbf{0.46}$	Small effect
ECI Negative	Burden	$d = \frac{92.63 - 82.77}{35.67} = \mathbf{0.27}$	Small effect
ECI Positive	Positive aspects	$d = \frac{31.90 - 30.45}{9.12} = \mathbf{0.15}$	Small effect



**Appendix W: SPSS output baseline means across condition**

ANOVA						
		Sum of Squares	df	Mean Square	F	Sig.
t0_I've been feeling good about myself	Between Groups	3.264	2	1.632	2.125	.129
	Within Groups	42.253	55	.768		
	Total	45.517	57			
t0_CORE_10 Total Score	Between Groups	3.304	2	1.652	.038	.963
	Within Groups	2377.597	55	43.229		
	Total	2380.901	57			
t0_AAQ_II Total Score	Between Groups	203.304	2	101.652	1.403	.255
	Within Groups	3912.625	54	72.456		
	Total	4115.930	56			
t0_WEMWBS Total Score	Between Groups	118.903	2	59.451	.700	.501
	Within Groups	4672.717	55	84.958		
	Total	4791.620	57			

Appendix X: Qualitative feedback, themes and frequencies.

